



Centre for  
Palliative Care  
Informing Choice. Enabling Care.



International Palliative Care Family-carer Research Collaboration

# Newsletter

May 2020

## EAPC Blog on IPCFRC

Read the blog [\[here\]](#).

## EAPC Taskforce on Costs of Family Caregiving in Palliative Care

We are pleased to announce that the IPCFRC EAPC Reference Group is now formally linked with the EAPC Task Force on Costs of Family Caregiving in Palliative Care. The task force 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 task force [\[here\]](#).

## Published 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 2020 version is available as a downloadable resource on the [\[IPCFRC website\]](#).

## Membership

The IPCFRC has 305 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 IPCFRC include: International Observatory on End of Life Care (IOELC), Lancaster University, UK and St Christopher's Hospice, UK.

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.

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 members

**Please note:** due to COVID-19 some planned conferences listed for 2020 would have been postponed/ cancelled/ conducted as a virtual online interactive meeting – please check the relevant conference websites for most recent updates/ info on conference status and dates.

9<sup>th</sup> International Conference of Patient and Family Centred Care

Dates: August 18-20, 2020

Location: Nashville TN, USA

Website: [[ICPFCC 2000](#)]

24<sup>th</sup> International Philosophy of Nursing Conference IPONS. Personhood: philosophies, applications and critiques in healthcare (IPONS 2020)

Dates: August 26-28, 2020

Location: Gothenburg, Sweden

Website: [[IPONS 2000](#)]

2020 Australian and New Zealand Society of Palliative Medicine (ANZSPM) Biennial Conference

Dates: September 17-20, 2020

Location: Auckland, New Zealand

Website: [[ANZSPM 2000](#)]

11<sup>th</sup> World Research Congress of the European Association of Palliative Care (EAPC 2020)

Dates: October 8-9, 2020

Location: interactive online/virtual

Website: [[EAPC 2020](#)]

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

Dates: October 13-16, 2020

Location: Montreal, Canada

Website: [[ICPC 2000](#)]

22<sup>nd</sup> IPOS World Congress of Psycho-Oncology and Psychosocial Academy

Dates: New dates to be scheduled

Location: Kyoto, Japan

Website: [[IPOS 2000](#)]

## 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.

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Bovero A, Gottardo F, Botto R, Tosi C, Selvatico M, Torta R. (2020). Definition of a Good Death, Attitudes Toward Death, and Feelings of Interconnectedness Among People Taking Care of Terminally ill Patients With Cancer: An Exploratory Study. *Am J Hosp Palliat Care* 37(5):343-349.

Choo PY, Tan-Ho G, Dutta O, Patinadan PV, Ho AHY. (2020). Reciprocal Dynamics of Dignity in End-of-Life Care: A Multiperspective Systematic Review of Qualitative and Mixed Methods Research. *Am J Hosp Palliat Care* 37(5):385-398.

Hudson P, Morrison RS, Schulz R, Brody AA, Dahlin C, Kelly K, Meier DE. (2020). Improving Support for Family Caregivers of People with a Serious Illness in the United States: Strategic Agenda and Call to Action. *Palliative Medicine Reports* 1(1): 6-17.

Patel P, Lyons L. (2020). Examining the Knowledge, Awareness, and Perceptions of Palliative Care in the General Public Over Time: A Scoping Literature Review. *Am J Hosp Palliat Care* 37(6):481-487.

*Continued...*

## Recent articles relevant to IPCFRC members *continued...*

Sedig LK, Spruit JL, Paul TK, Cousino MK, Pituch K, Hutchinson R. (2020). Experiences at the End of Life From the Perspective of Bereaved Parents: Results of a Qualitative Focus Group Study. *Am J Hosp Palliat Care* 37(6):424-432.

Valero-Cantero I, Martínez-Valero FJ, Espinar-Toledo M, Casals C, Barón-López FJ, Vázquez-Sánchez M.Á. (2020). Complementary music therapy for cancer patients in at-home palliative care and their caregivers: protocol for a multicentre randomised controlled trial. *BMC Palliat Care* 19(1):61.

Yoo SH, Lee J, Kang JH, Maeng CH, Kim YJ, Song EK, Koh Y, Yun HJ, Shim HJ, Kwon JH, Nam EM, Kang E, Choo J, Yun YH. (2020). Association of illness understanding with advance care planning and end-of-life care preferences for advanced cancer patients and their family members. *Support Care Cancer* 28(6):2959-2967.



### Featured Member

Professor Joakim Öhlén, *PHD, RN*  
Advocate Member - IPCFRC EAPC Reference Group  
*Professor of Nursing and Centre Director*  
*Sahlgrenska Academy and Centre for Person-Centred Care,*  
*Department of Palliative Care, Sahlgrenska University Hospital*  
*University of Gothenburg*  
*Sweden*

**Joakim Öhlén, PhD, RN**, is a professor of nursing at the Sahlgrenska Academy, University of Gothenburg in Sweden, and has a clinical appointment at the Department of Palliative Care at Sahlgrenska University Hospital in Gothenburg. He is also the Centre Director at the University of Gothenburg Centre for Person-Centred Care, and leads a research programme focusing on person-centeredness in palliative care. His areas of interest include research on how to put person-centeredness in action including a practice model for communication in the context of palliative care, patients' preparedness for recovery, and support to family members in palliative care. Joakim has extensive teaching experience in palliative care, nursing and research methods, and is the recipient of the Excellent Teacher award at the University of Gothenburg.

#### ***What is your specific area of interest in family caregiver research?***

*I'm interested in support for family caregivers in bereavement, especially in grief and suffering as part of life, as it's something that's unavoidable.*

#### ***What are you currently researching?***

*My ongoing research is related to theoretical development of person-centred care, grief during bereavement and implementation of a palliative approach. I'm also part of a multidisciplinary group developing a narrative approach in engaging care with older people and some other exciting projects.*

#### ***What inspires your research?***

*From the beginning the centre for person-centred care, of which I am the director currently, has been innovative in testing person-centred care practices with philosophy and ethics of the person as a foundation. I've actually been involved in quite a few studies that tried to intertwine empirical and philosophical knowledge. Ethics is present in care issues whether we make it explicit or not. Questions related to the unknown is fascinating and we should perhaps, to some degree, not take for granted that empirical investigation is the first choice. Philosophical and theoretical inquiry has its place especially in a field like palliative care.*

*Continued...*

## Featured Member

*continued...*

### **What is it that you enjoy most about your research?**

*Exploring and learning new things; including the process of inquiry as well as giving and receiving support from colleagues and other people interested in the work. Having “outsiders” recognizing and acknowledging the relevance and significance of the research is wonderful.*

### **Tell us something that people might be interested to know about you?**

*Well, it certainly depends on what you're interested in ... I started my research career with a narrative study into alleviation of suffering thanks to colleagues at a hospice who confirmed some questions I pondered upon, and through that I've learned a lot over the years from patients in palliative care services. Now, here on this part of the globe I'm living in, we're approaching summer and I'm longing for gardening and swimming. I love to cook and bake in my spare time, and hope for not being too restricted from having fun with my family and friends – including my grandchild.*

### **How is being a member of IPCFRC relevant to your work?**

*Being part of a community to tune up with – to seek and receive valuable support from. I believe we could plan to do more of multicenter research, and maybe it is already happening but that's something I think everyone would benefit from.*

**If you would like to know more about Prof Öhlén and his work, you can contact him directly at [joakim.ohlen@fhs.gu.se](mailto:joakim.ohlen@fhs.gu.se)**

## 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).

### 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)