



Centre for
Palliative Care
Informing Choice. Enabling Care.



StChristopher's

Lancaster
University

International Observatory on
End of Life Care (IOELC)

International Palliative Care Family-carer Research Collaboration

Newsletter

December 2020

Aims of the IPCFRC

The IPCFRC is a reference group of the EAPC, it aims to:

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

Membership

The IPCFRC has 306 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.

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 (*1 Jan 2019 – 22 Apr 2020*) is available as a downloadable resource on the [\[IPCFRC website\]](#).

Please find below a link to the USA's Palliative Care Research Cooperative Group's 'Caregiver Core' group. This initiative is led by Betty Ferrell and J. Nicholas Dionne-Odom. The roles & responsibilities of the Caregiver Core:

- Discuss opportunities to include caregivers in palliative care studies involving patients
- Explore areas of science needed to advance understanding of caregiving in palliative care
- Assist investigators in the selection of conceptual models, study designs, outcome variables and measurement tools for use in caregiver research
- Discuss opportunities for inclusion of qualitative data in caregiver research

<https://palliativecareresearch.org/corescenters/caregiver-core>

Conferences relevant to IPCFRC Members

22nd Annual Congress of the
International Psycho-Oncology
Society

Dates: May 26th – 29th, 2021

Location: online
interactive

<https://ipos2020.com/ipos2021/>

Oceanic Palliative Care Conference

Dates: September 7th – 10th, 2021

Location: Sydney, Australia

<https://oceanicpallcare.com/>

17th World Research Congress of the
European Association of Palliative
Care (EAPC 2021)

Dates: October 6th – 8th, 2021

Location: online interactive

<https://www.eapc-2021.org>

23rd International Congress on
Palliative Care

Dates: October 18th – 21st, 2022

Location: Montreal, Canada

<https://www.palliativecare.ca>

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 with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

Davies, N., Iliffe, S., Hopwood, J. et al. (2020). The key aspects of online support that older family carers of people with dementia want at the end of life: A qualitative study. *Aging & Mental Health*, 24(10), 1654–1661.

<https://doi.org/10.1080/13607863.2019.1642299>

Tanghe, M., Van Den Noortgate, N., Deliens, L. et al. (2020). Comparing Symptom Ratings by Staff and Family Carers in Residents Dying in Long-Term Care Facilities in Three European Countries, Results From a PACE Survey. *Journal of Pain and Symptom Management*, 60(2), 362–371.

<https://doi.org/10.1016/j.jpainsymman.2020.03.002>

Moeke-Maxwell, T., Collier, A., Wiles, J. et al. (2020). Bereaved Families' Perspectives of End-of-Life Care. Towards a Bicultural Whare Tapa Whā Older person's Palliative Care Model. *Journal of Cross-Cultural Gerontology*, 35(2), 177.

<https://doi.org/10.1007/s10823-020-09397-6>

Vermorgen, M., Vandenbogaerde, I., Van Audenhove, C. et al. (2020). Are family carers part of the care team providing end-of-life care? A qualitative interview study on the collaboration between family and professional carers. *Palliative Medicine*.

<https://doi.org/10.1177/0269216320954342>

Cruz-Oliver, D. M., Pacheco Rueda, A., Viera-Ortiz, L. et al. (2020). The evidence supporting educational videos for patients and caregivers receiving hospice and palliative care: A systematic review. *Patient Education and Counseling*, 103(9), 1677–1691.

<https://doi.org/10.1016/j.pec.2020.03.014>

Krakowiak, P. (2020). Gaps in end-of-life care and lack of support for family carers in Poland and Central Eastern Europe. *Palliative Care & Social Practice*, 1–10.

<https://doi.org/10.1177/2632352420958001>

Friedel, M., Brichard, B., Boonen, S. et al. (2020). Face and Content Validity, Acceptability, and Feasibility of the Adapted Version of the Children's Palliative Outcome Scale: A Qualitative Pilot Study. *Journal of Palliative Medicine*.

<https://doi.org/10.1089/jpm.2019.0646>

Higginson, I. J., Yi, D., Johnston, et al. (2020). Associations between informal care costs, care quality, carer rewards, burden and subsequent grief: the international, access, rights and empowerment mortality follow-back study of the last 3 months of life (IARE I study). *BMC Medicine*, 18(1).

<https://doi.org/10.1186/s12916-020-01768-7>

Hudson, P., Girgis, A., Thomas, K. et al. (2020). Do family meetings for hospitalised palliative care patients improve outcomes and reduce health care costs? A cluster randomised trial. *Palliative Medicine*.

<https://doi.org/10.1177/0269216320967282>

McKibben, L., Brazil, K., McLaughlin, D. et al. (2020). Determining the informational needs of family caregivers of people with intellectual disability who require palliative care: A qualitative study. *Palliative & Supportive Care*, 1–10.

<https://doi.org/10.1017/S1478951520001157>

Salifu, Y., Almack, K., & Caswell, G. (2020). ‘My wife is my doctor at home’: A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliative Medicine*.

<https://doi.org/10.1177/0269216320951107>

Featured Member

Dr Clare Gardiner, PhD, Senior Research Fellow, Palliative and End of Life Care Research Group, Health Sciences School, The University of Sheffield, UK.

Clare Gardiner, PhD, is a senior research fellow in the Division of Nursing & Midwifery, Health Sciences School at The University of Sheffield in the UK. She is the lead for the Palliative and End of Life Care Research Group and co-director of the Mesothelioma UK Research Centre – Sheffield.

Her areas of interest broadly comprise research on equitable approaches to palliative care, including financial support, benefits and economic aspects of palliative care, palliative care for older people, palliative care in non-cancer and support for family caregivers. Clare has over 10 years experience in palliative care research and in 2015 was awarded a Vice Chancellor’s Fellowship to explore economic aspects of palliative care, particularly in relation to family caregivers.

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What is your specific area of interest in family caregiver research? I'm interested in financial support for family caregivers, as we know that financial burden can be a serious problem for carers from across the world. Related to this I'm interested in researching working or employed end of life caregivers, and exploring how we can better support caregivers in employment. This work has led to the EAPC Taskforce on Costs of Family Caregiving in Palliative Care, which was established in 2019 and which you read about on the EAPC website.

What are you currently researching? My ongoing research is related to financial support for carers, and comparing support across different countries. I'm also involved in some work with Marie Curie exploring policy on financial support for patients at the end of life in the UK, and the impact of improved financial support on carers (in terms of ability to work, bereavement outcomes etc). I was recently awarded a Fellowship from the Winston Churchill Memorial Trust to undertake research on supporting working end of life carers, and I hope to travel to Canada to learn from some of their policies on this. I'm also co-director for the recently launched Mesothelioma Research Centre – Sheffield which will undertake research on patient and caregiver experience of mesothelioma, including palliative care.

What inspires your research? I've always been very passionate about health inequalities and equity in healthcare, and much of my research stems from trying to achieve equitable access to palliative care. Early on in my career I was a researcher on studies about palliative care in COPD, and palliative care in hospitals and it was apparent that the role of the family carer was pivotal in delivering high quality palliative care in these settings. This really inspired my interest in family carer research.

What is it that you enjoy most about your research? For me the most important aspect of research is delivering impact, and ensuring that change occurs as a result of our work. When I am able to see a change in practice or policy that has been directly informed by my research I get a huge sense of satisfaction. I also enjoy the variation that you experience in the constantly evolving world of research, and the chance to work alongside a range of dedicated and inspirational colleagues from across the globe.

Tell us something that people might be interested to know about you? I started my academic career with a PhD in sleep, and changed direction as a post-doc after being offered an amazing opportunity to run a palliative care study. When I'm not working on research I'm a mum to two young girls, who keep me busy in my spare time. Here in the UK we are lucky to live in the beautiful Peak District National Park, where I'm able to indulge my two passions for rock climbing and fell running.

How is being a member of IPCFRC relevant to your work? It's hugely helpful to be able to access so much international expertise in the area of family caregiver research in palliative care. I really enjoy reading about the work of others and being inspired by new and innovative research from around the world. Being part of this community offers endless opportunities for collaboration – I just need to find the time to write that next grant application!

You can follow Clare Gardiner on Twitter @claregardiner8, or if you would like to know more about her work, you can contact her directly at c.gardiner@sheffield.ac.uk

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 with the subject 'IPCFRC member profile'.

Forward IPCFRC to a friend!

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

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