



International Palliative Care Family-carer Research Collaboration

Newsletter

June 2015

Featured Member of the Month

Prof Gunn Grande - IPCFRC Executive Committee member

Gunn Grande is Professor of Palliative Care at the School of Nursing, Midwifery & Social Work at the University of Manchester, United Kingdom. Her background is in psychology and health services research and she has an MPhil in Psychology, MSc in Health Psychology and a PhD in Health and Social Welfare.

Gunn began her career working on driver errors at the Medical Research Council Applied Psychology Unit in Cambridge, UK. However, she became involved in cancer and palliative care research in 1992 when she became the RA on a study into domiciliary palliative care, investigating patients' and carers' experiences of the health and social care support they received. Based at the General Practice & Primary Care Unit, University of Cambridge, she also ran a large scale evaluation of Hospital at Home for Palliative Care, including an RCT, mapping of referrals and health care services use in the last year of life, and exploration of bereaved relatives views of end of life care.

Gunn moved to the University of Manchester in 2002, where her work has mainly focused on support for family carers in end of life home care, particularly the development and trialling of a Carer Support Needs Assessment Tool intervention in collaboration Gail Ewing at the University of Cambridge, with further trialling of the CSNAT taking place at Curtin University, Australia and University of Victoria, Canada. Gunn's further interests include general factors that enable patients' to remain at home at end of life, and socioeconomic and age related differences in patients' access to palliative care.

Promoting collaboration amongst members

In order to promote collaboration amongst IPCFRC members, we have attached a membership listing (detailing all of IPCFRC members' affiliations, email address, and areas of research interest) with this edition of the IPCFRC e-newsletter. We encourage you to contact other IPCFRC members with similar interests in order to promote collaboration.

Please note that this membership listing is intended for IPCFRC members' information only and is not for re-distribution. If you would like to become a member, please refer to the 'Membership' section of this newsletter.

Online Forum

The IPCFRC online forum provides a web based communication system for IPCFRC members. It is a resource that aims to foster discussion about family caregiver research in palliative care across the IPCFRC membership database. IPCFRC members can use the forum to ask questions to the IPCFRC community, establish networks, discuss their research, enquire about previous research or existing instruments, or to notify others in the membership about upcoming events and grant opportunities that are of relevance to family caregiver research in palliative care. The focus of the content of the correspondence should always be relevant to family caregiver research in palliative care.

The way the forum operates is as follows:

- To post a message, click the 'Post to the Forum' link on the [IPCFRC website] or type the following email address into a new email: ipcfrc@medstv.unimelb.edu.au
- When you post to the forum, your message is sent directly to all IPCFRC members. Everyone who receives an email has the opportunity to reply to the group by pressing the 'reply' button. You can unsubscribe from this list at any time by pressing the 'unsubscribe' button at the bottom of each post.

When you post to this forum, always remember to adhere to the following:

- Write only public (never private) messages. Lists are a public forum; personal comments should be sent directly to the person, not the entire list.
- Stick to the purpose of the list; the more topic-specific the contributions are, the more useful the list is for everyone.
- Make the subject line descriptive of your topic.
- Sign your posting by listing your contact information or auto-signature.
- When you are replying to a list message please be aware that this list is set up to automatically reply-all. If your reply is not of interest to everyone on the list, change the address to the person to whom your reply is directed.
- Be mindful of what you write; never write anything you would not say to someone directly. Never use the Forum for personal attacks or profanity.
- Avoid using humour or making political or religious comments.
- Do not send chain letters, spam, flames, or solicitations.
- Avoid posting attachments.
- To report errors, please contact centreforallcare@svhm.org.au

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 reviewed and updated annually, and serves as a basic resource to aid those who are looking for publications related to family caregiver research in palliative care. It is available as a downloadable resource on the [IPCFRC website].

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 centreforallcare@svhm.org.au with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

Aoun S, Grande G, Howting D, Deas K, Toye C, Troeung L, Stajduhar K, Ewing G. (2015). "The impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial." *PLOS ONE* 10(4). doi:10.1371/journal.pone.0123012.

Daveson BA, de Wolf-Linder S, Witt J, Newson K, Morris C, Higginson IJ and Evans CJ; on behalf of BuildCARE. (2015). "Results of a transparent expert consultation on patient and public involvement in palliative care research." *Palliative Medicine*, 2015 Apr 30. pii: 0269216315584875. [Epub ahead of print] PubMed PMID: 25931336.

F. E. Witkamp, L. van Zuylen, Y. Vergouwe, C. C. D. van der Rijt, and A. van der Heide. (2015). "Concordance between Experiences of Bereaved Relatives, Physicians, and Nurses with Hospital End-of-Life Care: Everyone Has Their "Own Truth"." *International Journal of Palliative Care*. doi:10.1155/2015/623890.

Harding R, Gao W, Jackson D, Pearson C, Murray J, Higginson IJ. (2015). "Comparative Analysis of Informal Caregiver Burden in Advanced Cancer, Dementia and Acquired Brain Injury." *Journal of Pain and Symptom Management*, 2015 Apr 22. pii: S0885-3924(15)00184-0. doi: 10.1016/j.jpainsymman.2015.04.005. [Epub ahead of print] PubMed PMID: 25912274.

Henriksson A, Hudson P, Ohlen J, Thomas K, Holm M, Carlander I, et al. (2015). "Use of the Preparedness for Caregiving Scale in Palliative Care: A Rasch Evaluation Study." *Journal of Pain and Symptom Management*. doi: 10.1016/j.jpainsymman.2015.04.012. [Epub ahead of print] PubMed PMID: 26004399.

Holm M, Carlander I, Fürst CJ, Wengström Y, Årestedt K, Ohlen J, Henriksson A. (2015). "Delivering and participating in a psycho-educational intervention for family caregivers during palliative home care: a qualitative study from the perspectives of health professionals and family caregivers." *BMC Palliative Care* 14:16. doi: 10.1186/s12904-015-0015-1.

Reigada C, Pais-Ribeiro JL, Novellas A. (2014). "Educational programs for family caregivers in palliative care: A literature review." *Journal of Palliative Care & Medicine* 4:195. doi:10.4172/2165-7386.1000195.

Thomas K, Moore G. (2015). "The development and evaluation of a multimedia resource for family carers of patients receiving palliative care: A consumer-led project." *Palliative & Supportive Care* 13(3):417-23. doi: 10.1017/S1478951513001090.

Recent IPCFRC Events

Two of the IPCFRC Executive committee members; Professor Peter Hudson and Professor Gunn Grande facilitated a well-attended Meet the Experts Session titled: "Family carers: evidence based practice" at the recent EAPC Conference in Copenhagen on 9 May 2015.

The session's main theme was on providing support for family carers and focused on:

1. Why more needs to be done to improve family carer support;
2. Challenges faced by health professionals associated with supporting family carers;
3. Examples of evidence based interventions to assist family carers.

Upcoming Meeting

An open meeting for current and prospective IPCFRC members will be held at the [\[2016 European Association of Palliative Care Research Congress in Dublin\]](#).

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.

Update your details!

We are now collecting information on member research interests and expertise.

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

Conferences relevant to IPCFRC members

APOS 12th Annual Conference and IPOS 17th World Congress of Psycho-Oncology and Psychosocial Academy

Dates: July 29-August 1, 2015

Location: Washington DC, USA

Website: [\[APOS Conference\]](#)

13th Australian Palliative Care Conference

Dates: September 1-4, 2015

Location: Melbourne, Australia

Website: [\[13th Australian Palliative Care Conference\]](#)

Palliative Care in Oncology Symposium

Dates: October 9-10, 2015

Location: Boston MA, USA

Website: [\[Palliative Care in Oncology Symposium\]](#)

5th International Seminar of the European Palliative Care Research Centre (PRC) and European Palliative Care Research Network (EAPC RN)

Dates: October 15-16, 2015

Location: Leeds, UK

Website: [\[PRC & EAPC RN Seminar\]](#)

3rd Australian Palliative Care Research Colloquium

Dates: October 22-23, 2015

Location: Melbourne, Australia

Website: [\[3rd Australian Palliative Care Research Colloquium\]](#)

Membership

The IPCFRC now has 192 registered members from many countries of the world, including; Australia, Bulgaria, Cameroon, Canada, Denmark, France, Germany, Ireland, Japan, New Zealand, Nigeria, Norway, Spain, Sweden, Thailand, UK & 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.