



International Palliative Care Family-carer Research Collaboration

Newsletter

March 2015

Featured Member of the Month

Dr Richard Harding – IPCFRC Advocate member

Richard Harding is Reader in Palliative care and Director of Global Programmes and Partnerships at the Cicely Saunders Institute, King's College London. He is also Director of African Programmes for Cicely Saunders International, and Professor of Palliative Care at the University of Cape Town.

What lead you to a career in research and how did you get into the palliative care field?

One of my principal interests is the promotion of palliative care as a discipline within the global health agenda, and this is increasingly possible as our Institute is a WHO (World Health Organisation) collaborating centre and I sit on the Palliative Care Technical Working Group for the WHO. My research has focused on the measurement of self-reported outcomes, and also on the wellbeing of patients and families facing non-cancer diagnoses.

For the past 12 years I have had a large programme of research in sub-Saharan Africa (and additional studies in Latin America and across Europe). Having originally studied social anthropology and then social work, I am interested in cross-cultural study of family caregiver wellbeing. International studies have revealed the differing family structures and responsibilities including the phenomenon of child-headed households, and how context influence decision making such as preferred place of death and advance care planning.

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

I see the IPCFRC as providing a unique opportunity to address the current gap in evidence on effective interventions for family caregivers in palliative and end-of-life care. The specific challenges of the patient population, the time-limited window of opportunity to intervene for family caregivers, the issues of feasibility and acceptability of intervention models, and the challenges of outcome measurement create a particularly challenging context for our research. International collaboration offers us the chance to develop and test interventions by advancing methods in response to these challenges.

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.

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

Upcoming IPCFRC Events

Two of the IPCFRC Executive committee members - Professor Peter Hudson and Professor Gunn Grande - will be facilitating a Meet the Experts Session, entitled: "Family carers: Evidence based practice" at the EAPC Conference in Copenhagen, Denmark.

Details:

Session title: Family carers: Evidence based practice

Date: 9th May 2015

Time: 8:00 am to 8:45 am

Location: EAPC Conference
Auditorium 15 of Bella Center
Copenhagen Congress Center,
Center Boulevard, 2300
Copenhagen, Denmark

Further information on the conference is available on the [\[EAPC website\]](#).

Membership

The IPCFRC now has 176 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.

Promoting collaboration amongst members

In order to promote collaboration amongst IPCFRC members, with 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 were not included for circulation, please inform us as soon as possible via email to: centreforallcare@svhm.org.au. If we do not hear back from you by 30 March 2015, we will presume that you give consent for your details to be published and shared with other members.

Please note that the list will only be circulated to IPCFRC members. If you would like to become a member, please see the directions under the [\[Membership\]](#) section of this newsletter.

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, Deas K, Toye C, Ewing G, Grande G, Stajduhar K. "Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial." *Palliat Med.* 2015 Feb 2. pii:0269216314566061. [Epub ahead of print] PubMed PMID: 25645667.

Low J, Myers J, Smith G, Higgs P, Burns A, Hopkins K, Jones L. "The experiences of close persons caring for people with chronic kidney disease stage 5 on conservative kidney management: contested discourses of ageing." *Health (London).* 2014 Nov;18(6):613-30. doi: 10.1177/1363459314524805. Epub 2014 Apr 1. PubMed PMID: 24695386.

Dosser I, Kennedy C. "Family carers' experiences of support at the end of life: carers' and health professionals' views." *Int J Palliat Nurs.* 2012 Oct;18(10):491-7. doi: 10.12968/ijpn.2012.18.10.491. PubMed PMID: 23123952.

Totman J, Pistrang N, Smith S, Hennessey S, Martin J. 'You only have one chance to get it right': A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer. *Palliat Med.* 2015 Jan 29. pii: 0269216314566840. [Epub ahead of print] PubMed PMID: 25634637.

Remedios C, Willenberg L, Zordan R, Murphy A, Hessel G, Philip J. A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions. *Palliat Med.* 2015 Jan 29. pii: 0269216314560008. [Epub ahead of print] PubMed PMID: 25634634.

Conferences relevant to IPCFRC members

2015 Marie Curie Annual Palliative Care Research Conference

Dates: March 27, 2015

Location: London, UK

[\[Website\]](#)

11th Asia Pacific Hospice Conference (APHC 2015)

Dates: April 30-May 3, 2015

Location: Taipei, Taiwan

[\[Website\]](#)

14th World Congress of the European Association for Palliative Care (EAPC 2015)

Dates: May 8-10, 2015

Location: Copenhagen, Denmark

[\[Website\]](#)

2015 Multinational Association of Supportive Care in Cancer (MASCC)

Dates: June 25-27, 2015

Location: Copenhagen, Denmark

[\[Website\]](#)

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

[\[Website\]](#)

Forward e-news 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: centreforallcare@svhm.org.au