



International Palliative Care Family-carer Research Collaboration

Newsletter

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Featured Member



Associate Professor Anette Alvariza (Henriksson)

IPCFCRC Executive Committee member

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Anette Alvariza is a researcher and lecturer at the Department of Health Care Sciences, Palliative Research Centre, Ersta Sköndal University College in Stockholm, Sweden. She is also a Care Development Manager at a specialist palliative inpatient and outpatient care unit that provides care for 270 patients. She is actively involved in palliative care education and supervision, mainly in the Master courses, and continues to provide clinical care at Dalens Hospital.

As a specialist nurse in cancer care, Anette has an extensive clinical experience in specialist palliative inpatient and outpatient care. Her research focuses mainly on interventions aiming to support family caregivers during palliative homecare. Anette was the primary investigator in a randomized controlled trial study in which a group-based intervention is tested at ten palliative homecare units in Sweden. The intervention proved to be effective with caregivers reporting increased feelings of preparedness and competence for caregiving. The study also examined the experiences of patients after their family members' participation and it was found that these patients experienced safe care and support at home, as well as more open and facilitated communication. A further research study will look at the long term effects and influences of family caregivers' experiences on grief. Currently, Anette is also working on interventions targeting families with children where one parent receives specialized palliative homecare, as well as interventions to support families after the death of a parent. Anette has great interest in concepts such as preparedness for caregiving and preparedness for death, and is continuously involved in projects that translate and validate scales to facilitate research concerning family caregivers' experiences. She has also undertaken numerous qualitative studies to explore deeper understandings about family caregiver experiences. Another of Anette's interests is in studying how palliative care is provided and at what quality, and consequently several of her studies are based on a Palliative Care Register in Sweden.

What lead you to a career in research?

My great interest and fascination in palliative care. I have been working in specialist palliative care since 1994 and I have brought many of the questions and discussions that have been raised in my clinical work into my research.

Continued...

Featured Member *continued...*

What inspires your research?

I am also inspired by the leading Professors in the field as well as by theoretical assumptions and frameworks. I think it is very interesting to work on how we can use our theoretical knowledge in interventions and implementations to improve our clinical work in palliative care. I believe that I have a great advantage in being able to combine clinical work and research. My research is very much inspired by patients, family caregivers and colleagues at the palliative care unit.

In what way does your work benefit the community?

My research might benefit the community since it highlights the situation and the need for support in family caregivers. It may also contribute to new ways of working and meeting family caregivers in health care. I also do my best to educate the community by making my research public, using all available media.

How did you get into the palliative care field?

I was working extra hours as a nurse in a geriatric clinic and on one occasion I had to help out at the palliative care unit. The way the palliative care approach guided my work made me feel that this was something I wanted to do. It was a feeling of coming home.

What do you think makes you a good researcher?

My curiosity and my great interest in palliative care. I am also eager to learn more. It is easy for me to advocate and highlight the need of palliative care. I think that health care science has a lot to benefit from the experiences of patients and family caregivers.

What is it that you enjoy most about your research?

To learn more and having the possibility to work together with clinicians in interventions and implementations. To know that my work can also be implemented in clinic really gives me strength.

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

It is relevant because it has connected me with great researchers in the field and it gives me an opportunity to discuss important matters with others. It has also resulted in great research collaborations.

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 basic resource to aid those who are looking for peer-reviewed publications related to family caregiver research in palliative care. The 2016 version 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 centre.palliativecare@svha.org.au with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

Hagell P, Alvariza A, Westergren A, Årestedt K. (2016). "Assessment of burden among family caregivers of people with Parkinson's disease using the Zarit Burden Interview." *J Pain Symptom Manage*. doi: 10.1016/j.jpainsymman.2016.09.007. [Epub ahead of print]

Kim JY, Sun V, Raz DJ, Williams AC, Fujinami R, Reckamp K, Koczywas M, Cristea M, Hurria A & Ferrell B. (2016). "The impact of lung cancer surgery on quality of life trajectories in patients and family caregivers." *Lung Cancer* 101:35-39.

Leroy T, Fournier E, Penel N & Christophe V. (2016). "Crossed views of burden and emotional distress of cancer patients and family caregivers during palliative care." *Psychooncology* 25(11):1278-1285.

Long AC, Kross EK & Curtis JR. (2016). "Family-centered outcomes during and after critical illness: current outcomes and opportunities for future investigation." *Curr Opin Crit Care* 22(6):613-620.

Saini G, Sampson EL, Davis S, Kupeli N, Harrington J, Leavey G, Nazareth I, Jones L & Moore K. (2016). "An ethnographic study of strategies to support discussions with family members on end-of-life care for people with advanced dementia in nursing homes." *BMC Palliat Care* 15:55.

Veloso VI & Tripodoro VA. (2016). "Caregivers burden in palliative care patients: a problem to tackle." *Curr Opin Support Palliat Care* 10(4):330-335.

Recent IPCFRC Event

An open meeting for current and prospective IPCFRC members was held at the [21st International Congress on Palliative Care] in Montreal, Canada on Thursday 20th Oct 2016. The meeting was chaired by Professor Peter Hudson (Australia) and Professor Kelli Stajduhar (Canada).

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.

Conferences relevant to IPCFRC members

6th International Seminar of the European Palliative Care Research Centre (PRC) and European Palliative Care Research Network (EAPC RN)

Dates: December 1-3, 2016

Location: Banff, Canada

Website: [\[6th International Seminar of the PRC and EAPC RN\]](#)

24th International Conference of the Indian Association of Palliative Care (IAPCON)

Dates: February 10-12, 2017

Location: Coimbatore, Tamil Nadu, India

Website: [\[IAPCON 2017\]](#)

2017 Annual Assembly - American Academy of Hospice and Palliative Medicine (AAHPM) & Hospice and Palliative Nurses Association (HPNA)

Dates: February 22-25, 2017

Location: Phoenix, Arizona, USA

Website: [\[AAHPM & HPNA 2017\]](#)

15th World Congress of the European Association for Palliative Care

Dates: May 18-20, 2017

Location: Madrid, Spain

Website: [\[EAPC 2017\]](#)

21st IAGG World Congress of Gerontology and Geriatrics

Dates: July 23-27, 2017

Location: San Francisco, California, USA

Website: [\[IAGG 2017\]](#)

19th World Congress of Psycho-oncology and Psychosocial Academy

Dates: August 14-18, 2017

Location: Berlin, Germany

Website: [\[IPOS 2017\]](#)

Membership

The IPCFRC has over 210 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.

Forward IPCFRC to a friend!

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

Update your details!

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

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