IPC FRC

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Centre for Palliative Care
Informing Choice. Enabling Care.

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International Palliative Care Family-carer Research Collaboration

Newsletter

October 2019

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 redistribution.

If you would like to become a member, please refer to the 'Membership' section of this newsletter.

Membership

The IPCFRC has 296 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.

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.

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 key resource to aid those who are looking for peer-reviewed publications related to family caregivers. The 2019 version is available as a downloadable resource on the [IPCFRC website].

Conferences relevant to IPCFRC members

27th International Conference of Indian Association of Palliative Care (IAPCON 2020)

Dates: February 14-16, 2020
Location: Guwahati, India
Website: [IAPCON 2020]

The Annual Assembly of the American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA)

Dates: March 18-21, 2020
Location: San Diego CA, USA
Website: [AAHPM/HPNA 2020]

Palliative Care Congress 2020

Dates: March 19-20, 2020
Location: Telford, UK
Website: [PCC 2020]

State of the Science in Hospice and Palliative Care

Dates: March 20-22, 2020
Location: San Diego, CA, USA
Website: [State of the Science 2020]

11th World Research Congress of the European Association of Palliative Care (EAPC 2020)

Dates: May 14-16, 2020
Location: Palermo, Italy
Website: [EAPC 2020]

2020 International Death, Grief and Bereavement Conference

Dates: June 1-3, 2020
Location: La Crosse WI, USA
Website: [IDGBC 2020]

22nd International Psycho-oncology Society (IPOS) World Congress of Psycho-Oncology

Dates: June 16-19, 2020
Location: Kyoto, Japan
Website: [IPOS 2020]

Annual Meeting on Supportive Care in Cancer (MASCC/ISOO 2020)

Dates: June 25-27, 2020
Location: Seville, Spain
Website: [MASCC/ISOO 2020]

24th 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 2020]

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.

Breen LJ, Aoun SM, O'Connor M, Howting D, Halkett GKB. (2018). Family caregivers' perspectives on preparing for bereavement: A qualitative analysis. *J Pain Sympt Manage.* 55: 1473-1479.

Gardiner C, McDermott C, Hulme C. (2019). Costs of Family Caregiving in Palliative Care (COFAC) questionnaire: development and piloting of a new survey tool. *BMJ Support Palliat Care.* 9(3):300-306.

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Recent articles relevant to IPCFRC members

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Kreyer C, Bükki J, Pleschberger S. (2019). Development of a German version of the Carer Support Needs Assessment Tool (CSNAT): The process of translation and cultural adaptation. *Palliat Support Care.* doi: 10.1017/S1478951519000671. [Epub ahead of print]

Lalani N, Duggleby W, Olson J. (2019). Rise Above: Experiences of Spirituality Among Family Caregivers Caring for Their Dying Family Member in a Hospice Setting in Pakistan. *J Hosp Palliat Nurs.* 21(5):422-429.

O'Callaghan C, Brooker J, de Silva W, Glenister D, Melia Cert A, Symons X, Kissane D, Michael N. (2019). Patients' and Caregivers' Contested Perspectives on Spiritual Care for Those Affected by Advanced Illnesses: A Qualitative Descriptive Study. *J Pain Symptom Manage.* doi: 10.1016/j.jpainsymman.2019.08.004. [Epub ahead of print]

O'Callaghan C, Seah D, Clayton JM, Welz M, Kissane D, Georgousopoulou EN, Michael N. (2019). Palliative Caregivers' Spirituality, Views About Spiritual Care, and Associations With Spiritual Well-Being: A Mixed Methods Study. *Am J Hosp Palliat Care.* doi: 10.1177/1049909119877351. [Epub ahead of print]

Richards CA, Liu C-F, Hebert PL, Ersek M, Wachterman MW, et al. (2019). Family Perceptions of Quality of End-of-Life Care for Veterans with Advanced CKD. *CJASN* 14(9): 1324-1335.

Scott D, Hudson P, Charnley K, Payne C, Westcott G. (2019). Development of an eHealth information resource for family carers supporting a person receiving palliative care on the island of Ireland. *BMC Palliative Care* 18: 74.

Virdun C, Lucketta T, Gilmore I, Brassil M, Liliand R, Lorenze K, Phillips J. (2019). Involving consumers with palliative care needs and their families in research: A case study. *Collegian.* doi: 10.1016/j.colegn.2019.08.002. [Epub ahead of print]

Featured Member

A/Prof Martin Loučka, *PhD, MSc*

Advocate Member - IPCFRC EAPC Reference Group

Director, Center for Palliative Care

Assistant Professor, Third Faculty of Medicine,

Charles University

Prague, Czech Republic

Martin Loučka is a psychologist, director of Center for Palliative Care in Prague and Assistant Professor at the 3rd Medical Faculty at Charles University. He got his PhD in Health Research at Lancaster University, UK, where he focused on methodological aspects of international comparisons of the development of palliative care. He was a Visiting Scholar at VU Medical Center in Amsterdam and Fulbright Schuman Visiting Scholar at the Icahn School of Medicine at Mount Sinai in New York. Dr Loučka was awarded the Early Researcher Award by European Association for Palliative Care (EAPC) in 2016 and in 2019 was elected to the Board of Directors of the EAPC. With his team at the Center for Palliative Care he runs a number of research and educational projects for both clinicians and the general public.

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Featured Member

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What are you currently researching?

Our largest current project is focused on prognostic awareness of advanced cancer patients and their families. We are following a cohort of patients and their caregivers, looking into which factors influence their understanding of what is the likely prognosis and how serious is their current situation. We have not concluded the data collection yet, but preliminary results confirm that both patients and families are more optimistic than their physicians and also that it is difficult for the family to speak with their ill loved one about poor prognosis. We have also recently started an international project, which is a effectiveness-implementation study of the Family Caregivers Decision Support Tool for family caregivers of people with advanced dementia in nursing homes. The intervention has been previously proved effective in the UK and we are excited to be part of the transnational effort to scale up this brief and effective tool to support those families.

What inspires your research?

When we started the work of our Center, there was basically non-existent research (and also very limited clinical service provision) in palliative care in my country. I believe that successful implementation of palliative care into health care system requires not only open hearts and good intentions but also robust evidence and data about what we do. Otherwise palliative care will always struggle to establish working collaborations with other fields of medicine.

In what way does your work benefit the community?

Apart from research, we run a number of educational projects, e.g. ELNEC for nurses, communication skills course ESPERO for physicians or a popular monthly webinar series which is available for free. We also serve as expert consultants for the government and local councils and for example recently conducted a conceptual analysis for the development of palliative care in the capital city of Prague. Together with the Avast foundation we developed a programme for hospital palliative care, which helped to start "revolution" in our health care system, leading to establishment of first palliative care consult teams in the country.

How did you get into the palliative care field?

When I was a psychology student at the university, I was inspired by the work of Rollo May, Irvin Yalom and other existential psychologists who consider death to be one of the key issues in life. I was looking around whether anybody uses this approach in clinical work and discovered hospice movement. Around the time when I was choosing the topic for my bachelor thesis, I was accepted to a 2 year long training in paediatric palliative care in one Slovakian hospice called the Flicker. This was a fundamental experience for me and as I sometimes say, the Flicker set a fire in my heart that is still there.

What is it that you enjoy most about your research?

The best part of research for me is when we can present the results to our colleagues in clinical practices with some clear message about what helps or what is important to keep in mind when treating patients and their families. I try to keep this moment in my mind always when we think about any new project, that there will come the day when a doctor from local hospice might come and ask us "What is this all about?" and that we will need to have an answer for them. This is my motivation and also the source of feeling that it makes sense to do what I do.

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

I have amazing wife and three beautiful daughters who are reminding me every day that I am very lucky man. I love jazz music and used to be a keen rock climber.

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

I believe that we can learn so much from each other internationally. I had a chance to live in several countries and to work with people from many more and despite the differences in our health care systems, when people face serious illness, there are so many things that we share in common – the burden and experience of families and caregivers is a great example. I am grateful for the work of the IPCFRC, which enables us to learn from the work of colleagues from all around the world as we can look for the best way to support families.

If you would like to know more about Prof Loučka and his work, you can contact him directly at
m.loucka@paliativnicentrum.cz

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’.

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