



International Palliative Care Family-carer Research Collaboration

# Newsletter

June 2018

## International Psycho-Oncology Society (IPOS) Survivorship Online Survey

If you have not already, please complete the IPOS Survivorship Online Survey. Your effort will help IPOS better understand the current involvement in clinical services and research with cancer patients/survivors in various age groups and their family caregivers worldwide.

**Who should complete this survey?** This survey is for any healthcare professional, researchers, and teachers/educators whose work involves cancer patients/survivors in any ages or in any illness trajectories, and their family members. IPOS encourage each of you to participate in the survey and to forward this invitation to your colleagues and your regional Psycho-Oncology members.

**How to complete the survey?** This survey may take 15 to 50 minutes depending on the type of your work or patient age groups you work with. This online survey uses REDCap, which does not currently have a mobile mode for completing the survey. So the IPOS team suggest you complete the survey using a desktop computer or tablet. The IPOS team also understand you may not have a block of time to complete the survey, so they suggest you return to it later using the return code provided, or simply continue later if you did not close the web browser.

**Which languages are available?** The survey is available in 15 languages: Catalan, Chinese (Simplified and Traditional), English, French, German, Hindi, Hungarian, Italian, Japanese, Korean, Portuguese, Romanian, Spanish and Turkish. You choose the language you will complete the survey in. The full list of survey links in 15 languages can be found at: <https://ipos-society.org/ipos-survivorship-online-survey/>

**Who to contact with questions?** If you have any questions or concerns, please feel free to contact either your local IPOS representative listed below or Youngmee Kim, PhD ([ykim@miami.edu](mailto:ykim@miami.edu)).

Sincerely,

*IPOS Survivorship Online Survey Team*

*Agustina Sirgo, Amanda Ting, Andrada Parvu, Andy Roth, Ashley Wang, Cherry Lam, Christina Drace, Cris Bergerot, Csaba Degi, Daisuke Fuiisawa, Emi Takeuchi, Eunjung Shim, Gokce Sokmen, Hande Okan, Hyerim Noh, Isadora Azevedo, Jayita Doedhar, Jelana Stanic, Juliane Lessing, Karin Ribic, Lilla Gerlinger, Manuela Eicher, Marcella May, Maria Die Trill, Martine Hoffman, Ozan Bahcivan, Samantha Serpentine, Savita Goswami, Sylvie Lambert, Talia Zaidler, Tania Estape, Tim Hartung, Sara Colomer, Seyma Aydogan, Wendy Lam, Yanan Song, Yesne Alici, and Youngmee Kim.*

## 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 2018 version is available as a downloadable resource on the [\[IPCFRC website\]](#).

## Recent IPCFRC Event

An open meeting for current and prospective IPCFRC members was held at the [10<sup>th</sup> World Research Congress of the European Association for Palliative Care (EAPC)] in Bern, Switzerland on Friday 25<sup>th</sup> May 2018. The meeting was chaired by Professor Peter Hudson (Australia). Some suggestions arising from the meeting will be considered by the IPCFRC Executive Committee.

## Upcoming IPCFRC Event

An open meeting for current and prospective IPCFRC members will be held at the [22<sup>nd</sup> International Congress on Palliative Care in Montreal], on Wednesday 3<sup>rd</sup> October at 1.15-1.45pm (Location: Palais de congrès – Actual room location TBC on the on-site Congress Programme). Meeting Co-Chairs: Professor Peter Hudson (Australia) and Professor Kelli Stajduhar (Canada). All Congress delegates are welcome to attend (free of charge).

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

22<sup>nd</sup> International Congress on Palliative Care

Dates: October 2-5, 2018

Location: Montreal, Canada

Website: [ICPC 2018]

6<sup>th</sup> Australian Palliative Care Research Colloquium

Dates: October 25-26, 2018

Location: Melbourne VIC, Australia

Website: [APCRC 2018]

20<sup>th</sup> International Psycho-Oncology Society (IPOS)

World Congress of Psycho-Oncology and Psychosocial Academy

Dates: October 31- November 2, 2018

Location: Hong Kong

Website: [IPOS 2018]

45<sup>th</sup> Clinical Oncology Society of Australia (COSA)  
Annual Scientific Meeting

Dates: November 13-15, 2018

Location: Perth WA, Australia

Website: [COSA 2018]

## Membership

The IPCFRC has 246 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.



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## 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](mailto:centre.palliativecare@svha.org.au) with the subject 'IPCFRC Newsletter' and we will feature your publication in an upcoming edition.

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Abreu W, Rodrigues T, Sequeira C, Pires R, Sanhudo A. (2018). The experience of psychological distress in family caregivers of people with dementia: A cross-sectional study. *Perspect Psychiatr Care* 54(2):317-323.

Aoun SM, Toye C, Slatyer S, Robinson A, Beattie E.(2018). A person-centred approach to family carer needs assessment and support in dementia community care in Western Australia. *Health Soc Care Community*. doi: 10.1111/hsc.12575. [Epub ahead of print]

Baillie J, Anagnostou D, Sivell S, Van Godwin J, Byrne A, Nelson A. (2018). Symptom management, nutrition and hydration at end-of-life: a qualitative exploration of patients', carers' and health professionals' experiences and further research questions. *BMC Palliat Care* 17(1): 60.

Carter G, McLaughlin D, Kernohan G, Hudson P, Clarke M, Froggatt K, et al. (2018). The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study. *J Adv Nurs*. doi: 10.1111/jan.13576. [Epub ahead of print]

Collins A, McLachlan SA, Philip J. (2018). How should we talk about palliative care, death and dying? A qualitative study exploring perspectives from caregivers of people with advanced cancer. *Palliat Med* 32(4): 861-869.

Ewing G, Austin L, Jones D, Grande G. (2018). Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach. *Palliat Med*. 32(5):939-949.

Gamondi C, Pott M, Preston N, Payne S. (2018). Family Caregivers' Reflections on Experiences of Assisted Suicide in Switzerland: A Qualitative Interview Study. *J Pain Symptom Manage*. 55(4):1085-1094.

Green E, Knight S, Gott M, Barclay S, White P. (2018). Patients' and carers' perspectives of palliative care in general practice: A systematic review with narrative synthesis. *Palliat Med*. 32(4):838-850.

Harris M, Thomas G, Thomas M, Cafarella P, Stocks A, Greig J, McEvoy RD. (2018). Supporting wellbeing in motor neurone disease for patients, carers, social networks, and health professionals: A scoping review and synthesis. *Palliat Support Care* 16(2):228-237.

Heath A, Carey LB, Chong S. (2018). Helping Carers Care: An Exploratory Study of Factors Impacting Informal Family Carers and Their Use of Aged Care Services. *J Relig Health* 57(3):1146-1167.

Hwang IC, Kim YS, Lee YJ, Choi YS, Hwang SW, Kim HM, Koh SJ. (2018). Factors Associated With Caregivers' Resilience in a Terminal Cancer Care Setting. *Am J Hosp Palliat Care* 35(4):677-683.

Mi E, Mi E, Ewing G, White P, Mahadeva R, Gardener C, Farquhar M. (2018). Do patients and carers agree on symptom burden in advanced COPD? *Int J COPD* 13:969-977.

Mi E, Mi E, Ewing G, Mahadeva R, Gardener C, Holt Butcher H, Booth S, Farquhar M. (2017). Associations between the psychological health of patients and carers in advanced chronic obstructive pulmonary disease. *Int J COPD* 12: 2813-2821.

Mohammed S, Swami N, Pope A, Rodin G, Hannon B, Nissim R, Hales S, Zimmermann C. (2018). "I didn't want to be in charge and yet I was": Bereaved caregivers' accounts of providing home care for family members with advanced cancer. *Psychooncology* 27(4):1229-1236.

Philip J, Remedios C, Breen S, Weiland T, Willenberg L, Boughey M, Jelinek G, Lane H, Marck C, Weil J. (2018). "The experiences of patients with advanced cancer and caregivers presenting to Emergency Departments: A qualitative study". *Palliat Med*. 32(2):439-446.

Pidgeon TM, Johnson CE, Lester L, Currow D, Yates P, Allingham SF, Bird S, Eagar K. (2018). Perceptions of the care received from Australian palliative care services: A caregiver perspective. *Palliat Support Care* 16(2):198-208.

## Featured Member



J. Nicholas Dionne-Odom, *PhD, RN, ACHPN*  
IPCFCRC Member

*Assistant Professor, School of Nursing*  
*Co-Director, Caregiver and Bereavement Support Services*  
*Center for Palliative and Supportive Care*  
*University of Alabama at Birmingham*  
*Birmingham, Alabama, USA*

**J. Nicholas Dionne-Odom, PhD, RN, ACHPN** is an Assistant Professor in the School of Nursing at the University of Alabama at Birmingham (UAB) and Founding Co-Director of Caregiver and Bereavement Support Services in the Center for Palliative and Supportive Care in the UAB Health System. He is board certified in hospice and palliative care advanced practice nursing with over 10 years clinical experience in critical care and 7 years of experience in telehealth palliative care coaching. Dr. Dionne-Odom's program of research has focused on developing and testing telebehavioral early palliative care coaching interventions to enhance support of family caregivers of persons with advanced cancer and heart failure. He has been involved in a number of federally- and foundationally-funded grants as a PI, co-investigator and pre- and post-doctoral fellow that have involved intervention development and clinical trials testing and implementation of models of early concurrent palliative care for family caregiving. He is currently PI of a 5-year National Institutes of Health/National Institute of Nursing Research K99/R00 entitled *An Upstream Palliative Care Intervention for Rural and African-American Family Caregivers* (1K99NR015903) where he is developing and pilot testing a palliative care health coaching intervention for family caregivers of persons newly-diagnosed with advanced cancer.

### **What are you currently researching?**

*Myself and my team are preparing to conduct a small-scale pilot randomized controlled trial of a lay navigator-led early palliative care telehealth intervention for rural and African-American family caregivers of individuals newly-diagnosed with advanced solid tumor cancers, based a stress-appraisal model of family caregiving. Intervention group family caregiver participants will receive a series of brief psychoeducational sessions in addition to long-term follow up that includes distress screening and problem solving support and health coaching. Therapeutic techniques of the intervention are based conceptually on therapeutic alliance building, goal pursuance, social cognitive theory, and andragogy.*

### **What inspires your research?**

*I was an intensive care unit (ICU) nurse for 10 years and was briefly doing clinical ethics consultations as part of my Masters practicum where I witnessed many families having traumatic experiences as surrogate decision-makers and watching their loved ones receive very aggressive treatments at end of life. Their experiences capped what was the end of an oftentimes very long road of providing daily support to someone who'd been struggling with serious illness. Many were unprepared for this role and what would happen at the end and nearly all had no support along the way.*

### **In what way does your work benefit the community?**

*Inherent to the design of our interventions is the principle that it be composed of elements that are scalable beyond the confines of a clinical trial context and replicable in a "real world" setting. As a Co-Director of UAB's Caregiver and Bereavement Support Service that is newly established this year, we hope to take what we learn from our clinical trials and immediately package and integrate them into our live clinical service that directly serves the Birmingham community and the wider catchment area it serves in Alabama and other surrounding states in the U.S. Deep South.*

### **How did you get into the palliative care field?**

*In 2011 as I was getting my PhD at Boston College, I began doing outpatient palliative care coaching for patients with newly-diagnosed advanced cancer and their family caregivers as part of a randomized controlled trial of an early concurrent oncology palliative care intervention called ENABLE (Educate, Nurture Advise Before Life Ends), originally developed by Dr. Marie Bakitas. In this capacity, I coached advanced cancer patients and their family caregivers in decision support, advance care planning, problem solving, positive coping, symptom management, communication, self-care, and care coordination. I began to see how promoting the early adoption of this education and skills training better prepared caregivers for supporting someone with serious illness through the end-of-life and bereavement.*

### **What is it that you enjoy most about your research?**

*What I enjoy most about my research is the larger cause to which I hope it is contributing, namely the support and validation of the work, love, and experiences that families and close friends are giving to those with serious illness. It is the feeling that what I do every day and the people I get to work with are contributing to something immensely bigger than ourselves.*

*Continued ...*

## Featured Member *continued...*

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

*From 2007-2008, my family and I lived for a year in Lusaka, Zambia and Kigali, Rwanda. My wife was conducting a study on HIV and syphilis and I was completing my master's thesis in philosophy on 20th century phenomenology.*

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

*The cadre of scientists in family caregiving is proportionally small and yet the task of supporting caregivers worldwide is fantastically enormous. Because of this, I think it's critical that the work I do and the work of all IPCFRC community members be shared, talked about, and disseminated. It's also critical that we find opportunities to collaborate and I think the IPCFRC represents just the hub that is needed to make this happen.*

***If you would like to know more about Dr Dionne Odom and his work, you can contact him directly at [dionneod@uab.edu](mailto:dionneod@uab.edu)***

## 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](mailto: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 [\[free membership\]](#)!

### **Update your details!**

We are now collecting information on member research interests and expertise. [\[Update your details now\]](#)

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