



StChristopher's

International Palliative Care Family-carer Research Collaboration

Newsletter

December 2018

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](#).

The IPCFRC is auspiced by the European Association for Palliative Care and is administered by the Centre for Palliative Care (St. Vincent's Hospital and a Collaborative Centre of the University of Melbourne, Australia)
Email: centre.palliativecare@svha.org.au or Telephone: +61 3 9416 0000

Conferences relevant to IPCFRC Members

[IPOS: 21st World Congress of Psycho-Oncology,](#)
[Banff, Alberta, Canada, September 23 – 26, 2019](#)

[EAPC: 16th World Congress of the European Association for Palliative Care,](#)
[Berlin, Germany,](#)
[May 23 – 25, 2019](#)

[19OPCC: Oceanic Palliative Care Conference,](#)
[Perth, Australia, September 10 – 13, 2019](#)

Membership

The IPCFRC has 258 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.

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.

Hoare S, Kelly M P, Prothero L, Barclay S. (2018). Ambulance staff and end-of-life hospital admissions: A qualitative interview study. *Palliat Medicine* 32(9):1465-1473

Shulman-Green D, Feder S. (2018). Integrating Family Caregivers into Palliative Oncology Care Using the Self- and Family Management Approach. *Semin Oncol Nurs.* 34(3):252-263

Tucker A. (2018). Palliative Care — Online Resources for Patients, Families, and Caregivers. *J Hosp Librariansh.* 18(4):331-336

Kuo S, Chou W, Hou M, Wu C, Shen W, Wen F, Tang S. (2018) Changes in and modifiable patient- and family caregiver-related factors associated with cancer patients' high self-perceived burden to others at the end of life: A longitudinal study. *Eur J Cancer Care.* 27(6)

Weekly T, Riley B, Wichman C, Tibbits M, Weaver M. (2018) Impact of a Massage Therapy Intervention for Pediatric Palliative Care Patients and Their Family Caregivers. *J Palliat Care.* doi: 10.1177/0825859718810727. [Epub ahead of print]

Gayoso M V, Avila M A G, Silva T A D, Alencar R A. (2018). Comfort level of caregivers of cancer patients receiving palliative care. *Rev Lat Am Enfermagem.* 9(26) doi: 10.1590/1518-8345.2521.3029. [Epub ahead of print]

Kirby E, Kenny K, Broom A, MacArtney J, Good P. (2018). The meaning and experience of bereavement support: A qualitative interview study of bereaved family caregivers. *Palliat Support Care.* 16(4):396-405

Silvera A, Amaral S, Castro A R, Monteiro E, Oimental F, Sequiera T. (2018). Cancer Palliative Care: Technology Support for Quality of Life Assessment of Family Caregivers. *Procedia Comput Sci.* 138:294-302

Sawatsky R, Laforest E, Schick-Makaroff, Stajduhar K, Reimer-Kirkham S, Krawczyk, Öhlén J, McLeod B, Hilliarn N, Tayler C, Cohen R. (2018) Design and introduction of a quality of life assessment and practice support system: perspectives from palliative care settings. *J Patient Rep Outcomes.* 2:36

Ullgren H, Tsitsi T, Papastavrou E, Charalambous A. (2018) How family caregivers of cancer patients manage symptoms at home: A systematic review. *Int J Nurs Stud.* 85:68-79

Vitorino L M, Lopes-Júnior L C, de Oliveira G H, Tenaglia M, Brunheroto A, Cortez P J O, Lucchetti G. (2018) Spiritual and religious coping and depression among family caregivers of pediatric cancer patients in Latin America. *Psychooncology.* 27(8):1900-1907

Rainsford S, Phillips C B, Glasgow N J, MacLeod R D, Wiles R B. (2018). The 'safe death': An ethnographic study exploring the perspectives of rural palliative care patients and family caregivers. *Palliat Med.* 32(10):1575-1583

Washington K T, Demiris G, Parker Oliver D, Albright D L, Craig K W, Tatum P. (2018). Delivering problem-solving therapy to family caregivers of people with cancer: A feasibility study in outpatient palliative care. *Psychooncology.* 27(10):2494-2499

Soto-Rubio A, Perez-Marin M, Tomas Miguel J, Barreto Martin P. (2018) Emotional Distress of Patients at End-of-Life and Their Caregivers: Interrelation and Predictors. *Front Psychol.* 6(9):2199

Strang S, Osmanovic M, Hallberg C, Strang P. (2018) Family Caregivers' Heavy and Overloaded Burden in Advanced Chronic Obstructive Pulmonary Disease. *J Palliat Med.* doi: 10.1089/jpm.2018.0010. [Epub ahead of print]

Kerr A M, Biechler M, Kachmar U, Palocko B, Shaub T. (2018). Confessions of a Reluctant Caregiver Palliative Educational Program: Using Readers' Theater to Teach End-of-Life Communication in Undergraduate Medical Education. *Health Commun.* doi: 10.1080/10410236.2018.1550471. [Epub ahead of print]

Krug K, Ballhausen R A, Bölter R, Engeser P, Wensing M, Szecsenyi J, Peters-Klimm F. (2018). Challenges in supporting lay carers of patients at the end of life: results from focus group discussions with primary healthcare providers. *BMC Fam Pract.* 19(1):112

Featured Member



Katharine Whittingham, PhD, RN, BSc (Hons)

MPH Senior Fellow of Higher Education Academy

Assistant Professor in the School of Nursing at the University of Nottingham, United Kingdom

Brief Bio

Katharine Whittingham PhD RN BSc (Hons) MPH Senior Fellow of Higher Education Academy is an Assistant Professor in the School of Nursing at the University of Nottingham, United Kingdom. Katharine has worked as a RN in various specialist areas of nursing including oncology, haematology, acute medicine and palliative care. Katharine's most recent clinical role was as a community based Specialist Heart Failure Nurse. It was this clinical experience that inspired Katharine's research interest in the role of carers supporting people with advanced heart failure and she has continued to pursue this research area in her academic role.

What are you currently researching?

In 2018, I was awarded a PhD from the School of Health and Associated Research, University of Sheffield. My PhD study used a mixed methods approach to explore factors influential to carers' perceptions of caring and examined how caring affects QOL in carers supporting a patient with advanced heart failure. The study measured positive and negative aspects of caring (physical, social, psychological and spiritual wellbeing) using a structured survey, explored carers' experiences of supporting a patient with advanced heart failure and elicited the views of carers in relation to positive and negative aspects of being a carer.

What inspires your research?

My personal aim when undertaking the research was driven by my clinical experiences working as a community based heart failure nurse. As a nurse I visited patients with advanced heart failure in their own homes to optimise the management of their condition with the aim of improving their quality of life. Many patients were living with family members or had friends and neighbours who were providing supportive care on a daily basis. I was mindful that the main focus of demonstrating the effectiveness of the heart failure nurse service was a reduction in unplanned patient admissions to secondary care. However, during the time I spent working as a heart failure nurse I had an increasing awareness that the role additionally offered support to carers that was not captured. I was also interested to note some carers appeared to be able to deal with their circumstances with positivity and enduring resilience, rather than viewing their situation as a negative experience.

In what ways does your work benefit the community?

The findings of my PhD demonstrated key issues relating to the carer experience. Living arrangements and how long the person had been caring were statistically significant on overall QOL, physical wellbeing and psychological wellbeing. Working status showed statistical significance; carers who had previously worked reported better QOL, physical health and social wellbeing. Carers were mainly spouses and had significant lower social wellbeing scores than non-spousal carers. Qualitative data demonstrated carers encounter fragmentation accessing information and support, experience feelings of uncertainty and social isolation. However importantly 40% of carers reported caring added purpose to their lives.

Heart failure nurses were valued in offering support, information, and validating the role carers provided. Accessibility, continuity and community based attributes of heart failure nurses were seen as integral and the carer experience was positively influenced by close social networks, proactive support and strong partnerships between patient and carer.

Findings point to a need for further exploration of new initiatives, for example a carer support worker, to complement the role of specialist heart failure nurse as part of future community based mainstream services.

How did you get into the palliative care field?

Between June 2003 and June 2005 I worked as a Cancer Support Nurse in a palliative care project in a deprived area of Nottingham. The role required the case management of patients with non-curative cancer to develop programmes of care to support patients from point of diagnosis to end of life. The post utilised a multi professional approach to patient care and worked in partnership with patients, carers, GPs, district nursing teams, Macmillan nurses, specialist nurses, secondary care teams, social services and a range of voluntary organisations.

Following this I worked as a Community Matron working with patients living with complex long - term conditions. The role involved proactive case management utilising advanced nurse practitioner skills to support patient choice and reduce the rate of unplanned hospital admissions. The majority of patients in the case - load had heart failure and through the management of these patients I gained an in depth knowledge into the complex clinical and psychosocial issues facing this client group. In April 2006 I was appointed as a Specialist heart failure nurse funded by the British Heart Foundation working within Nottingham City. Key responsibilities of the role included: support and education of patients/carers in recognising clinical symptoms that indicated decompensation; monitoring of clinical and psychosocial needs throughout disease trajectory; prescribing evidence based medication in accordance with the Extended and Supplementary Nurse Prescribing guidance; development of clinical management plans in conjunction with primary and secondary care to optimise treatment in partnership with patient/carers; care of patients with end stage heart disease.

What is it that you enjoy most about your research?

Many carers I encountered during my time spent working as a heart failure nurse had great responsibility for the day to day care and used opportunities during home visits to gain reassurance and information in order to effectively and safely support the patient. I felt compelled to raise the profile of this carer population as an important and worthy topic of investigation. During my PhD study, I was privileged to hear the experiences of the carers who gave their time and spoke freely about their own lives as a carer.

I therefore think it is important that these voices are heard to raise both positive aspects and challenges carers may encounter and to advocate for further research to explore the effectiveness of roles dedicated to carer support.

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

I am about to embark on a paddle boarding course. I hope to complete the couch to 10k programme and to progress to international waters!

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

Expectations of our carer population are increasing; it is therefore timely and necessary in the current health and social care climate to explore new and innovative ways of working with this population in order to provide personalised, proactive supportive initiatives. Networks such as the IPCFRC provides the opportunity for the creation of alliances to develop research initiatives to meet the challenge of developing services that acknowledge the uniqueness of each carer's circumstances.

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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!](#)

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