Palliative Care
Research Network
CAPACITY . COLLABORATION . CONNECTION

e-News

June 2018

About the PCRN

The purpose of the Palliative Care Research Network (PCRN) is to develop a platform for sustainable research collaboration. The PCRN is currently funded by the Victorian Cancer Agency and the Department of Health and Human Services, Victoria, Australia. The Centre for Palliative Care (a Collaborative Centre of St Vincent's Hospital and The University of Melbourne) is the administering organisation.

PCRN Report

The end is just the beginning – a PhD journey

by Dr Lucy Forrest, RMT PhD – PCRN PhD Scholarship recipient

It is a great privilege to be a music therapist in palliative care, to walk with people on their journey, share their stories and music, and be witness to the moments that define life and death, living and dying.

It is also a great privilege to be a clinician-researcher in palliative care, to seek answers to clinical questions, and to broaden and deepen understanding so that we can provide the best possible care for patients and families.

It was a desire to better understand what was important for the patients and families with whom I work that led to my undertaking my PhD. For more than 20 years, I have worked with people across the lifespan who come from diverse cultural backgrounds and who are living with life-limiting illness. I have observed people engage with palliative care, music, and music therapy in differing ways, and wanted to know what factors impacted this, particularly for families caring for a child in home-based palliative care, an area about which there is little written.

Informed by grounded theory, my research examined the experience of music and home-based music therapy for paediatric palliative care (PPC) patients and their families, who come from diverse cultural backgrounds. Three studies were undertaken to capture the perspectives of 1) parents of children in PPC, 2) music therapists working with children in home-based palliative are; and 3) my own experiences of working with children and families from diverse cultural backgrounds in PPC. A fourth study was then undertaken to collectively examine the findings of studies one to three using meta-synthesis. The synthesis provided deeper understanding of findings across the three studies, and allowed the findings to be looked at in different ways to offer new insights and understandings.

Continued...

Victorian Cancer Agency
Linking research and patient care
VICTORIA State Government

The end is just the beginning – a PhD journey *continued...*

Findings showed that cultural factors play a significant role in families' experiences of and engagement with PPC, music and music therapy. PPC was found to be an inherently stressful experience for families, regardless of culture; whilst factors such as migration and cultural beliefs impacted family experiences of caring for a child in PPC; and family use of and engagement with music at home and in daily life. Cultural factors also shaped the design and implementation of, and participation in music therapy programs; although music therapy was found to be an overwhelmingly positive part of the palliative care journey for families regardless of culture, helping to ameliorate stress and enhance wellbeing, support the cultural life of the family, and transform family experiences of palliative care.

It has been an immense privilege to undertake my PhD, and to have the opportunity to think about research questions whilst I work in a clinical context. I wish to extend my sincere thanks to my supervisors, Assoc Prof Clare O'Callaghan and Emeritus Prof Denise Grocke, AO, for so generously sharing their wisdom and expertise with me, and for their guidance and support throughout. I also wish to acknowledge my fellow researchers at the National Music Therapy Research Unit at the University of Melbourne; colleagues in palliative care, particularly those working in community palliative care, with the Victorian Paediatric Palliative Care Program, with the PCRN, with the Palliverse Researchers' Hub and with the Centre for Palliative Care; and most especially the participants in my research, who welcomed me into their homes and shared their stories and insights with me, in order to help me better understand what families need and want when caring for a child at home in palliative care.

Finally, I would like to thank the PCRNV for their financial support of my PhD through their inaugural PhD Scholarship. The funding provided me with that most precious of commodities – time - to focus on my research, and for that I am extraordinarily grateful. It was certainly a most precious and privileged time, a time of learning and growing, a time of exploring, a time to reflect, think more deeply about my work, and to apply what I have learned back in the clinical sphere. Undertaking my PhD has helped me to answer some of my questions, whilst also raising many more, and I realise that although I have reached the end, I am of course just at the beginning!

Useful Resources in Palliative Care Research

Please find below a sample list of useful resources which you can subscribe to in order to keep up with the latest palliative care news and publications on evidence-based palliative care research.

Media Watch, created and distributed by Barry R. Ashpole – to subscribe email: barryashpole@bell.net

E-Hospice – to subscribe to e-newsletter go to the website.

Briefings in Palliative, Hospice, and Pain Medicine & Management – to subscribe to table of contents go to the website.

CareSearch palliative care knowledge network – to subscribe to e-newsletter go to the website.

All Ireland Institute of Hospice and Palliative Care (AIIHPC) – to subscribe to mailing list go to the website.

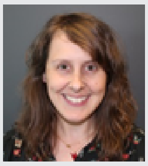
Upcoming PCRN Events

PCRN Forum – Tuesday 28th August 2018

"A Little Bit of Money Goes A Long Way"
Research updates from our PCRN Small Project Grants recipients

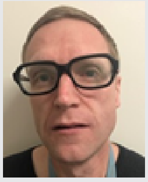
Please join us for presentations by our 2017 PCRN Small Project Grants recipients. The forum will focus on the background and rationale for their research, methodologies employed, results and implications for clinical practice as well how they have responded to the research challenges which they have encountered.

Presentations



'Mapping patterns of care for people with pancreatic cancer: how close are we to the optimal care pathway recommendations?' *by Ms Allison Drosdowsky (Researcher, Statistics and Research Methodology, Department of Cancer Experiences Research, Peter MacCallum Cancer Centre, VIC)*

Pancreatic cancer has one of the lowest survival rates of all cancer types, and people with pancreatic cancer can experience a range of symptoms including pain, weight loss and high rates of anxiety and depression. In order to determine where improvements can be made to patient outcomes, the pathways of a cohort of Victorian pancreatic cancer patients will be mapped and compared to the consensus-based optimal care pathways developed by the Victorian Department of Health and Human Services and Cancer Council Victoria. Timely referral to palliative care services is a key component of the optimal care pathway, and has the potential to deliver a range of beneficial patient outcomes.



'Understanding patients' and family members' clinical trial experiences and perspectives about palliative care's relevance' *by Dr Justin Dwyer (Medical Director, Department of Psychosocial Cancer Care, St Vincent's Hospital Melbourne, VIC)*

It can be difficult for cancer patients and their doctors to strike the right balance between realistic expectations and wishful thinking. As clinical trials become more accessible, managing this tension has become increasingly important and there is evidence that those patients who are taken off the investigational product struggle, both psychologically and physically. Our project seeks to understand the experience of patients and their care-givers after the trial treatment has been withdrawn with regards to their initial consent, their interpretation of events as they entered then left the trial, and their experiences around palliative care. The results may be helpful in future trial design, and in planning palliative care service provision.

'Understanding spiritual views and requirements of caregivers of people living with serious illnesses' *by Dr Clare O'Callaghan (Research Associate, Department of Palliative and Supportive Care, Cabrini Health, VIC)*

Palliative care providers need to explore spiritual requirements of those affected by serious illnesses to address existential concerns and spiritual pain. There remains, however, limited Australian related data. Findings from mixed methods, multi-site research involving 100 informal palliative caregivers will be presented. Survey data will elucidate understanding of associations between caregivers' spiritual well-being, levels of spirituality, spiritual concerns and support received. Opt-in interview data will highlight what enables caregivers to connect with that deemed sacred/important. Findings will extend understanding of how health services can offer spiritual care aligned with caregivers' requirements and promote development of innovative spiritual palliative care approaches.

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PCRN Forum – Tuesday 28th August 2018 *continued...*

Event Details

Date: Tuesday, 28th August 2018

Time: 5:00 pm - 6:05 pm followed by networking drinks

Venue: Level 2, Clinical Sciences Building, St. Vincent's Hospital Melbourne,
29 Regent St, Fitzroy VIC 3065

RSVP: This is a free event.
*Please register online by COB Monday 20th August 2018 to secure your place here.

*This forum will be available online via a webinar and in person (please select your preference when registering).

PCRN Breakfast Forum – Thursday 25th October 2018

"Cannabis Research in Palliative Care – The Highs and Lows"

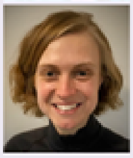
Would you like to know how to build a cannabis research program in palliative care?

The Palliative Care Research Network (PCRN) is hosting a Breakfast Forum entitled 'Cannabis Research in Palliative Care – The Highs and Lows' at the *6th Australian Palliative Care Research Colloquium*. This forum will provide an overview on the current situation of cannabis research in palliative care and also provide general guidance on how to build a cannabis research program, using examples of current cannabis research studies. Additional issues with cannabis research that can become barriers to progress and possible solutions will also be discussed. A discussion panel will follow the forum presentations.

Presentations

What we know about cannabis research in palliative care
by Professor Jennifer Philip (University of Melbourne & St Vincent's Hospital Melbourne, Victorian Comprehensive Cancer Centre, VIC)

An overview on how to build a cannabis research program and current cannabis research study in NSW
by Professor Jennifer Martin (University of Newcastle, NSW)



Current cannabis research study at Monash Health
by Dr Grace Walpole (Monash Health, VIC)

Continued...

PCRN Breakfast Forum – Thursday 25th October 2018 *continued...*

Event Details

Date:	Thursday, 25th October 2018
Time:	8:45 am - 10:35 am
Venue:	Rendezvous Hotel 328 Flinders Street, Melbourne, VIC 3000 Australia
Cost (incl. GST):	AUD $10.00 (light breakfast included)
Registration:	Please register online here.

For additional information, please go to the Colloquium website www.apcrc.net.au or contact the PCRN Program Manager, Soula Ganiatsas, on +61 (3) 9416 0000 or by email at pcrnv@svha.org.au

Upcoming Funding Opportunities 2018

Bethlehem Griffiths Research Foundation
For more information visit the website
Closing Date: 20 July 2018

Jack Brockhoff Foundation – Early Career Research Grants
For more information visit the website
Closing Date: 31 July 2018
(applications open 4 June 2018)

MS Research Australia
(various grant opportunities)
For more information visit the website
Closing Date: various

National Breast Cancer Foundation
(various grant opportunities)
For more information visit the website
Closing Date: various

Upcoming Conferences

International

Multinational Association of Supportive Care in Cancer (MASCC)/ International Society of Oral Oncology (ISOO) Annual Meeting on Supportive Care in Cancer 2018
Dates: June 28-30, 2018
Location: Vienna, Austria
[Website]

22nd International Congress on Palliative Care
Dates: October 2-5, 2018
Location: Montreal, Canada
[Website]

20th IPOS World Congress of Psycho-Oncology
Dates: October 31-November 2, 2018 Location: Hong Kong
[Website]

Upcoming Conferences

National

21st Cancer Nurses Society of Australia (CNSA) Annual Congress
Dates: June 21-23, 2018
Location: Brisbane, Australia
[Website]

Australian Grief and Bereavement Conference 2018
Dates: August 6-10 2018
Location: Sydney NSW, Australia
[Website]

Australian and New Zealand Society of Palliative Medicine (ANZSPM) Annual Conference 2018
Dates: September 6-9 2018
Location: Sydney NSW, Australia
[Website]

6th Australian Palliative Care Research Colloquium
Dates: October 25-26, 2018
Location: Melbourne, VIC
[Website]

45th Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting
Dates: November 13-15, 2018
Location: Perth WA, Australia
[Website]

Recent Publications Relevant to PCRN Members

In each edition we will feature some recently published articles relevant to PCRN members. If you have published in a peer reviewed journal recently and the subject matter is relevant to the PCRN community, or if you come across key publications that foster evidence based palliative care, please email pcrnv@svha.org.au *with the subject 'PCRN Newsletter' and we will feature the publications in an upcoming edition.*

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.* doi:10.1186/s12904-018-0314-4. [Epub ahead of print]

Carter G, McLaughlin D, Kernohan G, Hudson P, Clarke M, Froggatt K, Passmore P, Brazil K. (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.

Collins A, Sundararajan V, Burchell J, Millar J, McLachlan SA, Krishnasamy M, Le BH, Mileshkin L, Hudson P, Philip J. (2018). Transition Points for the Routine Integration of Palliative Care in Patients with Advanced Cancer. J Pain *Symp Manage.* doi: 10.1016/j.jpainsymman.2018.03.022. [Epub ahead of print]

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Recent Publications Relevant to PCRN Members

Continued...

Hardy J, Skerman H, Glare P, Philip J, Hudson P, Mitchell G, Martin P, Spruyt O, Currow D, Yates P. (2018). A randomized open-label study of guideline-driven antiemetic therapy versus single agent antiemetic therapy in patients with advanced cancer and nausea not related to anticancer treatment. *BMC Cancer* 18(1):510.

Healy S, Israel F, Charles M, Reymond L. (2018). Laycarers can confidently prepare and administer subcutaneous injections for palliative care patients at home: A randomized controlled trial. *Palliat Med.* doi: 10.1177/02692163187738. [Epub ahead of print]

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.

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.

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.

Smallwood N, Gaffney N, Gorelik A, Irving L, Le B, Philip J. (2018). Breathlessness and palliative oxygen therapy in advanced chronic obstructive pulmonary disease. *Int Med J.* doi: 10.1111/imj.13748. [Epub ahead of print]

Smallwood N, Gaffney N, Gorelik A, Irving L, Le B, Philip J. (2018). Doctors' attitudes to palliation and palliative care in patients with advanced chronic obstructive pulmonary disease. *J Pain Symptom Manage.* 55(5):e9-e11.

Smallwood N, Gaffney N, Gorelik A, Irving L, Le B, Philip J. (2017). Junior doctors' attitudes to opioids for the management of refractory breathlessness in patients with advanced chronic obstructive pulmonary disease. *Int Med J.* 47(9):1050-1056.

Smallwood N, Thompson M, Warrender-Sparkes M, Eastman P, Le B, Irving L, et al. (2018). Integrated respiratory and palliative care may improve outcomes in advanced lung disease. *ERJ Open Res.* 4(1):00102-2017.

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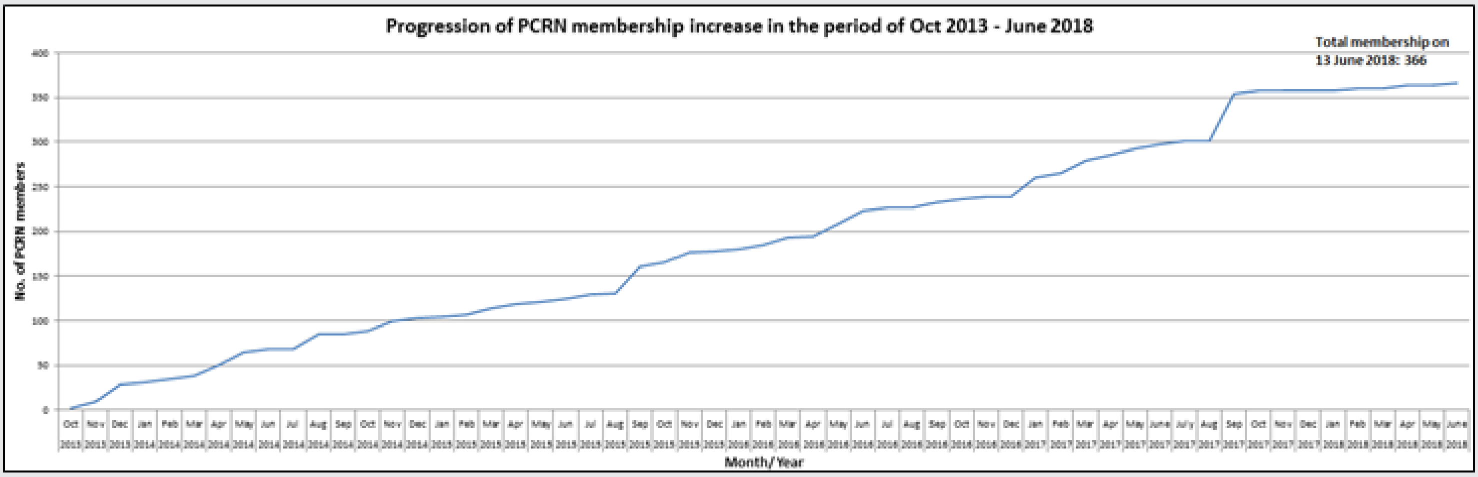
Membership

The PCRN now has 366 registered members from around Australia and other countries such as Hong Kong, India, Malawi, Norway, the UK and USA. Individuals with a genuine interest in palliative care research may become individual members of the PCRN. Membership is free and some of the *key benefits* of membership include:

- An opportunity to network and collaborate with other palliative care researchers through PCRN seminars and forums;
- Apply for a range of PCRN funding including: PhD scholarship, proect and travel grants;
- Assistance in developing your research;
- Opportunities to provide mentorship to junior researchers.

**Please note that even though membership is open to everyone, some resources and funding may be restricted to Victorian residents only.*

To formalise your membership, please complete the online form on the PCRN website.



Progression of PCRN membership increase in the period of Oct 2013 - June 2018

Total membership on 13 June 2018: 366

Forward e-news to a friend!

Please forward this newsletter to friends or colleagues interested in palliative care research.
They can also sign up for free membership

Contribute to the PCRN e-News

If your work is relevant to the PCRN community, please email pcrnv@svha.org.au with the subect 'PCRN e-News ubmission'` and we will feature your article or publication in an upcoming edition.

Unsubscribe

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