

e-News

July 2021

About the PCRN

The purpose of the Palliative Care Research Network (PCRN) is to foster the evolution of collaborative scholarly inquiry in palliative care in Australia.

Objectives:

1. Influence the development of a critical mass of palliative care scholars in Australia.
2. Develop programs of research that focus on improving the quality of palliative care.
3. Facilitate opportunities to build relationships for collaboration and mentorship.
4. Raise awareness of grant opportunities, research training and research findings.

The PCRN is supported by the Department of Health, Victoria, Australia and administered by The Centre for Palliative Care (a Collaborative Centre of St Vincent's Hospital and The University of Melbourne).

Update on PCRN consumer & community involvement program

We are glad to share that Avi Paluch and Christine Hofmeyer have agreed to partner with us as consumer representatives for the ***“Program to enhance consumer and community involvement in palliative care in Australia”***. We are excited to be working together with Avi and Christine in our Project Management Team and wanted to take a moment to introduce you to them both.



Christine Hofmeyer has worked as a palliative care nurse consultant for 27 years. She has been involved in providing palliative care for patients and their caregivers and family, together with informing service and policy development in her local work setting and at a statewide level. Christine has experienced being a carer for several family members with life limiting illness and palliative care needs.

Christine sees her role as a consumer representative as providing her with the opportunity to act as an advocate for patients and carers, to promote person-centred care and programs that seek to improve health literacy in death and dying. She believes it is essential to ensure consumers' and carers' views and experiences are heard and integrated into research, policy development and service improvements.

Christine is a representative of the National Register of Palliative Care Consumers and Carers. Learn more about Christine's story at [Palliative Care Australia](#).

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Update on PCRN consumer & community involvement program

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Avi Paluch cared for his wife Gita who lived with cancer for 12 years. When Avi became a carer, this presented a whole new set of challenges as he worked to navigate and juggle so many different roles. Yet while he faced challenges, Avi believes there were also incredible rewards in being a carer for his wife. In caring for Gita, Avi was able to witness the beauty of how our human spirits rally - both hers and those doing their bit to provide support for Gita, Avi and their family.

Following his wife's death, Avi felt compelled to help others and has trained as a grief counsellor to listen to, empathize with, and support other carers. As a consumer representative in palliative care, Avi believes it is important for patients, carers and people in the community to learn about and seek out palliative care as it can enable a person to be more comfortable physically, emotionally and in other various ways.

Read more about Avi's story on the [Carer Help](#) website and in the [Canberra Times](#).

For more information on the PCRN consumer & community involvement program, please contact Dr Stacey Panozzo at stacey.panozzo@svha.org.au

Surveying members' interest for a PCRN journal club

Journal clubs can be very useful not only as an opportunity to highlight the latest evidence on a particular topic but also as a means for exploring a variety of methods of inquiry. We seek your feedback as to whether or not you would be interested in trialling a PCRN journal club. If supported, the plan is that it would be held every 6 weeks or so for a maximum duration of 45 minutes via a virtual platform (e.g. zoom).

In order for us to gauge potential support for this initiative, if you are interested in participating in a journal club can you please email pcrnv@svha.org.au with the following subject line and statement and your name:

Subject "PCRN journal club",

Statement : "Yes I am interested in being involved in this initiative"

Name: _____

Promoting collaboration amongst members

In order to promote collaboration amongst PCRN members, in the next edition of our e-newsletter we will be sending out a list detailing *PCRN members' affiliations, email address, and areas of research interest. This list (which will be circulated to PCRN members only) will make it easier for members to contact other members directly about potential research collaborations.

If you are a PCRN member and you would like for your details to be included on the list for circulation, please inform us by 20 August 2021 via email to: pcrnv@svha.org.au.

**Note: Only PCRN members who provided consent for their details to be published will be included on the list.*

Please note that the list will only be circulated to PCRN members. If you would like to become a member, please see the directions under the 'Membership' section of this newsletter.

Would you like to be profiled in the PCRN e-News?

One of the key objectives of the PCRN is to facilitate opportunities to build relationships for collaboration in palliative care research. To help enable this we would like to offer members the opportunity to be profiled in the PCRN e-News. One member will be profiled within each edition.

If you are interested in being considered, please provide the details below to pcrnv@svha.org.au with the subject 'PCRN member profile'.

Please provide the following details: Your Name, Professional Role/Title, Discipline, Institution, City/Country, Specific area of interest in palliative care research and your Email address (so that other members can contact you directly).

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 Medicine – 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 (AIHPC) – to subscribe to mailing list go to the [website](#).

Upcoming Funding Opportunities 2021

Bethlehem Griffiths Research Foundation

For more information visit the [website](#)
Closing date: 15 August 2021

Cancer Australia – Priority-driven Collaborative Cancer Research Scheme (PdCCRS): Clinical Trials and Cohort Studies Scheme

For more information visit the [website](#)
Closing date: 25 August 2021

Ian Potter Foundation

(various grant opportunities)
For more information visit the [website](#)
Closing date: various

Jack Brockhoff Foundation – Early Career Medical Research Grants Program

For more information visit the [website](#)
Closing date: 27 July 2021

Lung Foundation Australia

(various grant opportunities)
For more information visit the [website](#)
Closing date: TBC
(applications open in July 2021)

MS Research Australia

(various grant opportunities)
For more information visit the [website](#)
Closing date: various

Upcoming Conferences

Please note: due to COVID-19, please check the relevant conference websites for the most recent updates/ information on conference status and dates.

International

17th World Congress of the European Association for Palliative Care (EAPC 2021)

Dates: October 6-8, 2021
Location: Virtual
[\[Website\]](#)

14th Asia Pacific Hospice Conference

Dates: November 13-14, 2021
Location: Virtual
[\[Website\]](#)

3rd and 4th Sapporo Conference for Palliative and Supportive Care in Cancer

Dates: July 21-23, 2022
Location: Sapporo, Japan
[\[Website\]](#)

23rd International Congress on Palliative Care

Dates: October 18-21, 2022
Location: Montréal, Canada
[\[Website\]](#)

National

Oceanic Palliative Care Conference 2021 (PCA 2021)

Dates: September 7-10, 2021
Location: virtual
[\[Website\]](#)

48th Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting

Dates: November 16-18, 2021
Location: Melbourne, VIC
[\[Website\]](#)

Recent articles published by PCRN members

In each edition we aim to feature recently published articles by PCRN members. If you have published in a peer reviewed journal recently and the subject matter is relevant to the PCRN objectives and community (for example articles that relate to enhancing evidence-based palliative care) then please email pcrnv@svha.org.au with the subject 'PCRN Newsletter - article to share' and we will feature the publication in an upcoming edition.

Everitt R, Robinson N, Marco D, Weil J, Bryan T. (E-Pub 23 June 2021). "Increased number of deaths within 24 h of admission during a period of social restriction related to the COVID-19 pandemic: A retrospective service evaluation in a metropolitan palliative care unit". *Palliative Medicine*. doi: 10.1177/02692163211026518. Epub ahead of print.

What is already known about the topic?

- COVID-19 has resulted in over three million deaths worldwide, with many countries around the world consequently enforcing strict social restriction measures to limit viral transmission.
- Fear of viral disease transmission has previously been shown to result in reductions in healthcare utilisation, for example during the SARS outbreak in 2003.
- Within inpatient palliative care environments rapid deaths are associated with increase distress amongst patients, caregivers and staff.

What does this paper add?

- This study describes a previously unreported increase in number of deaths within 24 h of admission to an inpatient palliative care unit during the COVID-19 pandemic, in patients not infected with coronavirus.
- Patients with non-malignant illnesses accounted for a significantly greater number of deaths within 24 h.

Implications for practice, theory or policy:

- Palliative care units should prepare for an increase in non-malignant rapid deaths during, and after, the COVID-19 pandemic in patients not infected with coronavirus.
- The impact on access to healthcare services, including specialist palliative care, is an essential consideration when planning pandemic control measures.
- Further research is required to map the impact of COVID-19, and associated wide-ranging social restriction measures on access to, and utilisation of, specialist palliative care services, and the subsequent impact on the patient and caregiver experience of death.

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Recent articles published by PCRN members

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Mitchell I, Lacey J, Anstey M, Corbett C, Douglas C, Drummond C, Hensley M, Mills A, Scott C, Slee JA, Weil J, Scholz B, Burke B, D'Este C. (E-Pub 2 June 2021). "Understanding end-of-life care in Australian hospitals". *Australian Health Review*. doi: 10.1071/AH20223. Epub ahead of print.

What is already known about the topic?

The majority of Australian patient deaths occur in hospitals whose care needs to align to the Australian Commission on Safety and Quality in Health Care's National Consensus Statement, essential elements of safe and high-quality end-of-life care.

What does this paper add?

The largest Australian study of hospital deaths reveals only 12% of patients have existing advance care plans, recognition of death is predominantly within the last 48 h of life, with 60% receiving investigations and interventions during this time with late symptom relief.

What are the implications for practitioners?

Given the poor alignment with the National Consensus Statement, a nationally coordinated approach would improve the patient experience of end-of-life care.

PCRN output

The following publication is an output from the research project on "*Family meetings for hospitalized palliative care patients: Benefits and resource implications*", which was conducted under the auspices of PCRN.

Hudson P, Girgis A, Thomas K, Philip J, Currow DC, Mitchell G, Parker D, Liew D, Brand C, Le B, Moran J. (2021). "Do family meetings for hospitalised palliative care patients improve outcomes and reduce health care costs? A cluster randomised trial". *Palliative Medicine* 35(1):188-199. doi: 10.1177/0269216320967282. PMID: 33135552.

Background: Family meetings facilitate the exploration of issues and goals of care however, there has been minimal research to determine the benefits and cost implications.

Aims: To determine: (1) if family caregivers of hospitalised patients referred to palliative care who receive a structured family meeting report lower psychological distress (primary outcome), fewer unmet needs, improved quality of life; feel more prepared for the caregiving role; and receive better quality of end-of-life care; (2) if outcomes vary dependant upon site of care and; (3) the cost-benefit of implementing meetings into routine practice.

Design: Pragmatic cluster randomised trial involving palliative care patients and their primary family caregivers at three Australian hospitals. Participants completed measures upon admission (Time 1); 10 days later (Time 2) and two months after the patient died (Time 3). Regression analyses, health utilisation and process evaluation were conducted.

Results: 297 dyads recruited; control (n = 153) and intervention (n = 144). The intervention group demonstrated significantly lower psychological distress (Diff: -1.68, p < 0.01) and higher preparedness (Diff: 3.48, p = 0.001) at Time 2. No differences were identified based on quality of end of life care or health utilisation measures.

Conclusions: Family meetings may be helpful in reducing family caregiver distress and enhancing their preparedness for the caregiving role and it appears they may be conducted without increased hospital health utilisation impacts; although opportunity costs need to be considered in order to routinely offer these as a standardised intervention. Additional health economic examination is also advocated to comprehensively understand the cost-benefit implications.

Membership

The PCRN now has 422 registered members. Individuals with a genuine interest in enhancing the development of collaborative scholarly inquiry in palliative care in Australia are encouraged to join.

Membership is free.

To formalise your membership, please complete the [online form](#) on the PCRN website.

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, or if you would like to share news relevant to palliative care research to the membership (i.e. call for participation in research study), please email pcrnv@svha.org.au with the subject 'PCRN e-News submission' and we will feature your article or publication in an upcoming edition.

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