

SUMMER 2021 | ISSUE 2

PALLIATIVE NEXUS NEWSLETTER

Palliative Care Research



Jennifer Philip



Welcome to the Summer Edition

It is a great joy to see the days getting longer and summer finally arriving in Melbourne. For many people, myself included, the year has been long, but the prospect of summer seems to put a spring in our step.

Yet despite the ongoing challenges that COVID-19 has, and no doubt will continue, to put our way, I think there is much to be proud of, even celebrate, as we reflect on the year.

First and foremost, palliative care is helping people. Still pulling out all stops to deliver great patient care, often under difficult circumstances, often in changed settings and in unfamiliar ways. Yet the care continues. And patients and families have the benefit of this care and these efforts. (cont'd page 2)

UPDATE

RESEARCH IN FOCUS THIS EDITION

- Care Plus Project Update
- Caring for carers at discharge: Improving hospital to home transitions at end of life.

SUMMER EDITION

JENNIFER PHILIP

(cont'd from page 1)

There have been some great personal achievements of colleagues in palliative care. Congratulations goes to **Dr Beth Russell** who was successfully awarded her PhD based on work around triage in palliative care – some of you might be using the RUN-PC tool which came out of this work.

Congratulations also to **Dr Nagla Ahmed** who was awarded Best Advanced Trainee Research Project by the Australasian Chapter of Palliative Medicine, for his work understanding attitudes to clinical trials (see page 6).

And it is great to hear about and share with you some current research being conducted in the sector. In this newsletter, **Celia Marston** outlines work that she is conducting as part of her PhD – a body of work that she lives and breathes in her practice as a palliative care occupational therapist.

Meanwhile, the **Care Plus implementation study** of early integrated palliative care as a practice change at key illness points for people with cancer heralds the next step in improving access to palliative care as a standard of care.

We heard at a forum last week about the work being undertaken by Palliative Care Research Network which seeks to develop, implement & evaluate a program to enhance Consumer and Community Involvement in palliative care in Australia. This important work will also provide understanding of the best methods to try to consider and measure the impacts of Consumer and Community input in palliative care research, training and service development. [Click here](#) link to view the presentation.

And the Pal-Spectives series concluded for the year with a reflective and moving discussion on the year from a wonderful panel including Carmel Smith, Carrie Lethborg, Meera Agar and Dish Herath – bringing different disciplines, perspectives, geography and wisdom. Again I recommend you view the presentation [Click here](#)

So all these important achievements and events were part of 2021. If all this is possible in a year of COVID and unrest, just think what we might do in a normal year! Enjoy the summer everyone.

RESEARCH IN FOCUS

Our research activities span across four research programs: (1) Service Models for Serious Illness; (2) Evolving Communities; (3) Clinical Trials; and (4) Personalised Care. Our research brings together clinicians, researchers and allied health professionals with a mission to improve equity, access and quality of care in serious illness.

Care Plus Project Update

Jennifer Philip & Kylee Bellingham

Care Plus is a multi-site stepped-wedge implementation study built on extensive foundational evidence with the overarching goal to implement a standardised approach to early palliative care in order to improve health outcomes and reduce hospitalization for people with advanced cancer.

During 2020-2021, the introduction of routine early palliative care was developed and implemented in three tertiary cancer treatment centres: Peter MacCallum Cancer Centre (PMCC), St Vincent's Hospital Melbourne and Lyell McEwin (Adelaide). Adults with one of five targeted advanced cancers who present to the three participating sites now receive a Care Plus referral at pre-defined, disease-specific transition points. Care Plus consists of a series of 3 palliative care consultations, one month apart, and correspondence with referring teams and local GP.

The cancers that are the initial focus of Care Plus across the clinical sites are: multiple myeloma, acute myeloid leukaemia, high grade glioma, diffuse large B cell lymphoma, pancreatic cancer, upper gastrointestinal tract cancers and hepatocellular carcinoma. At the half way point of this study, 106 patients have received Care Plus across all three sites.

The outcomes of the study are:

- implementation outcomes – what is involved, required and what are the best methods to implement early palliative care as a routine part of high quality care?
- and the impact of the intervention itself: health service use, quality of end of life care, and costs of care before and after the introduction of the practice change of Care Plus.

Data being collected to understand these outcomes includes 1. Qualitative data involving interviews with Care Plus patients, health professionals and service providers to understand experiences, acceptability, barriers and opportunities, and 2. Health service use data – linked data from hospital medical records, routinely collected state-based administrative health service datasets (i.e. Medicare/Pharmaceutical Benefits Schedule) and the death registry.

Thus far, 19 clinicians have been interviewed about Care Plus implementation, with interviews still ongoing. Data between hospital, state and Commonwealth datasets will be linked and analysed in the first half of 2022. Moving into the final year of the study, treating teams will continue to refer eligible patients weekly at all three sites, aiming to support at least another 100 patients in the next 12 months.

Caring for carers at discharge: Improving hospital to home transitions at end of life.

Dr Celia Marston

Evaluating how the CSNAT-I may work in an acute oncology setting delivered by treating occupational therapists

People with advanced cancer experience more frequent and complex transitions between hospital and home in their last month of life. This can be a distressing and uncertain time for both patients and carers.

Carers are critical to people being able to return home from hospital for end of life care. However they continue to cite high levels of unmet needs. To date, intervention models for improving care transitions for advanced cancer populations are under reported; and carers a largely absent. The Carer Support Needs Assessment Tool Intervention (CSNAT-I) has shown promise in the UK in facilitating a better discharge home for carers and patients with palliative care needs. The CSNAT-I is a multi-stage carer-led intervention allows needs identification, prioritisation, development of an action plan.

A project funded by the Western Melbourne Integrated Cancer Services (WMICS) and led by Celia Marston, PhD candidate and Clinical Lead OT at Peter Mac Callum Cancer Centre aimed to evaluate how the CSNAT-I may work in an acute oncology setting delivered by treating occupational therapists.

Using a mixed-methods convergent study design, data collected across Royal Melbourne Hospital and Peter MacCallum Cancer Centre revealed high acceptability from both carer and clinicians. 90% of carers completed the pre-discharge elements; and prioritised medical and practical needs over their emotional needs. Carers and occupational therapists viewed the CSNAT-I as a low burden, comprehensive model that provided timely and targeted support. It triggered emotional responses from carers ranging from feeling “reassured” to “confronted” with the reality of caring.

Thematic analysis of the data collected from a series of interviews and focus groups with OTs and care consumers is underway. These findings will reveal the key behavioural factors that influenced the uptake of the CSNAT in this study. Data from this study informs the development of a refined model of the CSNAT-I that will be tested in a feasibility trial in 2022. Thus far, it has provided valuable insights into the importance of considering carers as partners to patients receiving our care; and understanding how and why interventions a likely to work to meet their unique needs.

*Improving discharge home for carers
and patients with palliative care needs*

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NEWS & MEDIA

Embracing flexible work arrangements for gender equality - Prof Jennifer Philip speaking at SWiM Supporting women in MDHS

SWiM aims to inspire and encourage women to seek out and step up to leadership roles in their academic careers, as well as strategically prepare them for academic promotion.

Please click here to listen to the interview - <https://mdhs.unimelb.edu.au/diversity-and-inclusion#swim-supporting-women-in-mdhs>

Indian and Australian health workers reach out on COVID-19

New palliative care training for Sister Doctors in India is supporting patients and families during the pandemic and broadening understanding of care across the Indian Ocean.

<https://pursuit.unimelb.edu.au/articles/indian-and-australian-health-workers-reach-out-on-covid-19>

Welcome to our new Care Plus team members

Kylee Bellingham

Kylie attained a Master of Psychology and Bachelor of Social Science from ACU and has a work history that includes mood disorder research with the Mental Health Research Institute (now known as the Florey Institute) in addition to support work for vulnerable populations with the Salvation Army. She joins us to work on the Care Plus Study as Project Co-ordinator.

Joyce Chua

Joyce is a qualified and practising RN with experience in developing and implementing research, strategy and policy in response to the social, health and wellbeing issues facing a diverse community. She is the Site Co-ordinator for Care Plus at St Vincent's Hospital Melbourne and Peter MacCallum Cancer Centre.

Farwa Rizvi

Farwa comes to us as a mixed-methods clinical and public health researcher with MBBS, and post-graduate Masters' degree in Public Health (MPH) for administration and research activities, and PhD in Public Health (2021) at Deakin University, School of Health and Social Development. She has experience in developing and implementing evidence-based research and policy to provide equitable healthcare to a diverse growing community. Farwa will assist us as a research fellow on the Care Plus Study.

What's happening in our space

NEWS & MEDIA



CONGRATULATIONS Dr Nagla Ahmed

Congratulations are due for Dr Nagla Ahmed, for recently being awarded AChPM Best Trainee Research Project Award. His project entitled: “Attitudes of Palliative Care Practitioners towards Enrolling Patients in Clinical Trials” reported the results of a national survey of 135 palliative care health professionals, and compared his findings to a similar survey conducted 10 years earlier. He found that almost all practitioners were willing to refer patients to clinical trials but this dropped to around two thirds if the trial was randomized, or placebo controlled. Despite significant clinical trial activity in the sector nationally, there was little shift in attitudes over the ten years. Nagla’s study has been accepted for publication in Journal of Palliative Care.

PAL-SPECTIVES SERIES

**Local and international research and
conversations coming your way in
2022!**

What's happening in our space

PUBLICATIONS

The underrepresentation of palliative care in global guidelines for responding to infectious disease outbreaks: a systematic narrative review

Meghan de Boer, Rachel J Coghlan, Bethany Russell, Jennifer A M Philip
International Health, ihab075,

In 2020 Meghan De Boer, at that time a medical student, undertook a research project with Palliative Nexus as part of the MDRP rotation in her training. With the COVID-19 pandemic unfolding at that time, Meghan was interested if palliative care was included within global guidelines for responding to infectious disease outbreaks. She undertook a review exploring the published and grey literature, examining content, depth and breadth of palliative care inclusion.

Of the 43 guidelines included in the review, most (n=26, 56%) did not mention palliative care. Of those that did, breadth of coverage (meaning the various domains of palliative care eg. Symptom relief, spiritual support, etc) was low in 9 (20%), moderate in 6 (13%) and high in 4 (9%). Most frequent aspects of palliative care that were included were Information/communication, advance care planning and end-of-life care (9, 20%) followed by access and psychosocial care (8, 18%). Least covered was the area of bereavement support (4, 9%). And of those 19 articles that did mention palliative care, the depth to which this was covered was minimal in 18 (95%) tending to highlight the need for access to palliative care but without details on systems or measures required to enable this access. Just one article explored palliative care in greater depth.

Meghan concludes there is “an opportunity for the development of guidelines that include information on palliative care implementation in the context of infectious disease outbreaks in order to reduce the suffering of key vulnerable populations worldwide”.



*Research - working together to improve
the lives of those with serious illness*

PUBLICATIONS

Sample of recent publications

[Advanced respiratory disease: managing symptoms in the last years of life, Respiratory Medicine Today.](#)

[Interests and conflicts when writing, reviewing and editing papers on voluntary assisted dying, Intern Med J](#)

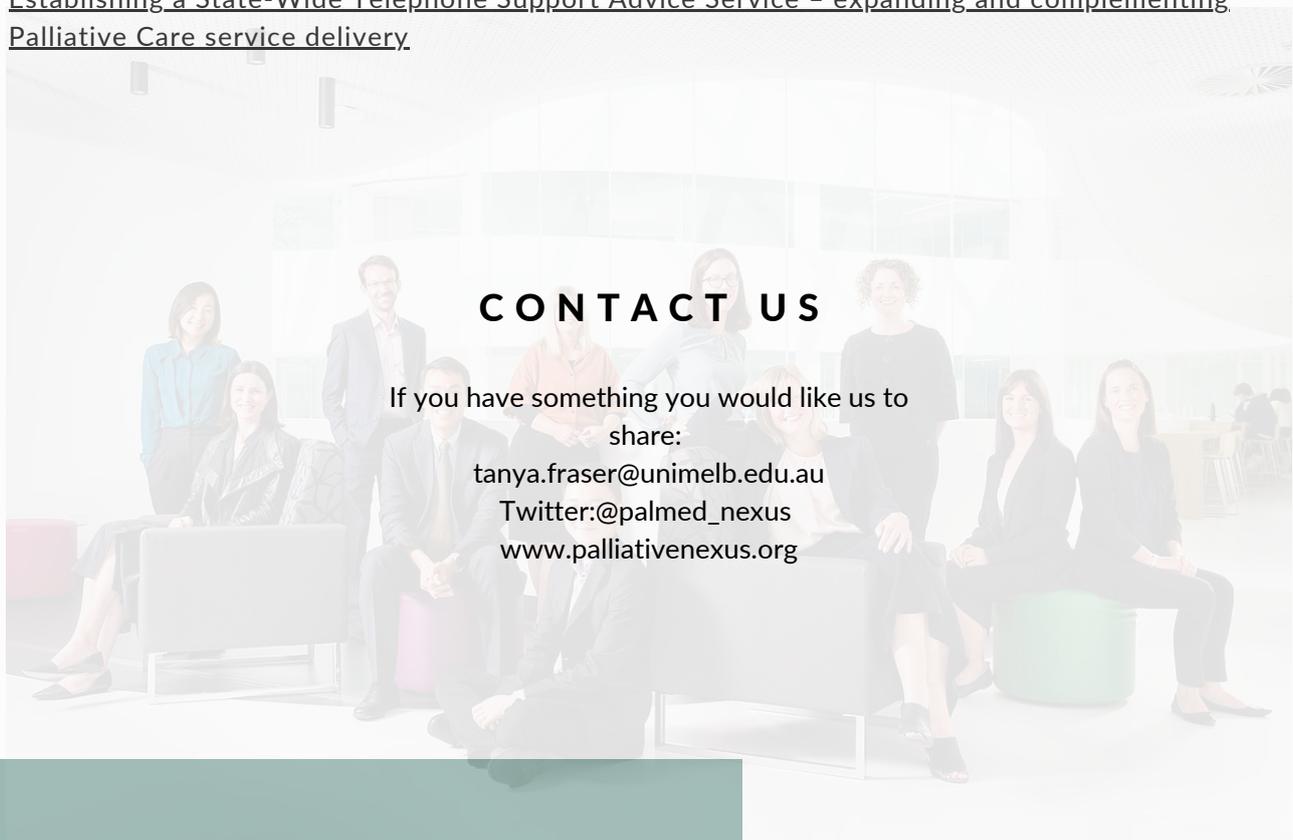
[An exploration of the perceptions, experience and practice of cancer clinicians in caring for patients with cancer who are also parents of dependent-age children.](#)

[517 Challenges in data linkage-experiences from an upper gastrointestinal cancer data linkage study.](#)

[Negative media portrayal of palliative care: a content analysis of print media prior to the passage of Voluntary Assisted Dying legislation in Victoria.](#)

[End of life in hospitalised prisoners: a group comparison of palliative medicine and hospital use."](#)

[Establishing a State-Wide Telephone Support Advice Service - expanding and complementing Palliative Care service delivery](#)



CONTACT US

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the lives of those with serious illness*