Journalist Linda Doherty reported on the 2021 Oceanic Palliative Care Conference for the Croakey Conference News Service. Researcher Alison Barrett live-tweeted and broadcaster Cate Carrigan created a CroakeyVOICES podcast of key conversations.

Croakey Health Media is a non-profit public interest journalism organisation based in Australia.  
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Lessons and challenges for palliative care amid a pandemic

Beginning and Ending by BABA: entry in the 2021 Palliative Care Australia Art Competition

Below, Croakey journalist Linda Doherty previews the conference discussions.

Linda Doherty writes:

The COVID-19 pandemic has disrupted so many of the end-of-life practices that families and other loved ones took for granted, not just in being able to attend funerals and other burial rites, but even being able to sit by the bedside and hold the hand of a dying relative or friend.

Professor Meera Agar, chair of Palliative Care Australia, said that disruption has highlighted the importance of human connection for our health and wellbeing, particularly in palliative care where social and spiritual care complements physical care for complex health needs and yet is still so often on the periphery of care.

“There’s a tension when you’re also trying to develop a public health response but it’s highlighted how much we value these practical things, this human connection for health and wellbeing, as well as the rituals around grief and bereavement,” she told Croakey.
“From very early on in the pandemic we felt there was a huge role for palliative care because we bring experience in dealing with complex health needs and balancing multiple decisions to optimise physical, social and spiritual care.”

The impact of the pandemic on palliative care was canvassed at PCA’s 2021 Oceanic Palliative Care Conference from 7-10 September.

The conference theme ‘Invest Challenge Change’ urges governments to make good on commitments to invest more in palliative care and to challenge existing thinking that places palliative care on the periphery of health systems.

Challenges for palliative care

Agar, a palliative care medicine physician in south-western Sydney and Professor of Palliative Medicine at the University of Technology Sydney, said the conference theme highlighted the challenges ahead for palliative care.

The World Health Organization describes palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

#21OPCC speaker Dr Naheed Dosani, who provides palliative care to homeless people in Canada, describes it as “the intersection of healthcare with humanity”.

Yet palliative care remains on the periphery of health systems around the world, with continued issues of inequity of access, workforce shortages and lack of community awareness of what palliative care actually involves, Agar said.

Every year in Australia around 40,000 people who die have received palliative care but PCA research shows that an additional 40,000 people could benefit if they better understood what palliative care was and how to access it.

A PCA report last year by KPMG looked at palliative care through an economic lens, finding that an additional annual investment in Australia of $365 million would save $464 million in other health system costs.

“We need investment in both the individual parts – at the hospital level, residential aged care, community aged care, community services – but the glue that synthesises and coordinates all those pieces is often forgotten and people fall through the cracks,” Agar said.

“The challenge is not about doing more of the same. We have to think about what we’re investing in and how we can join up the pieces in what is a very piecemeal system.”

Needs of marginalised communities

The biennial Oceanic Palliative Care Conference, held since 1990, attracts up to 1,000 palliative care practitioners and healthcare professionals from across the Oceania region, including Australia, New Zealand and the Pacific.

This year, for the first time, it will be held completely online due to pandemic lockdowns and travel restrictions, with conference sessions recorded and available for delegates to view for the following 12 months.
With a focus on those who would particularly benefit from palliative care, #21OPCC has sessions on palliative care for children and the elderly; ground-breaking services and programs for marginalised communities, including the homeless, Indigenous Australians, asylum-seekers and LGBTQ+ communities; future investment needs; clinical practice; and international perspectives.

Keynote speakers include Distinguished Professor Patsy Yates, Executive Dean of the Faculty of Health, at Queensland University of Technology; Roberts Yates, Executive Director of the UK Centre for Universal Health; Professor Katherine Sleeman, Laing Galaza Chair in Palliative Care and National Institute for Health Research Clinician Scientist at London’s King’s College; Canadian Dr Hsien Seow, Research Chair in Palliative Care and Health System Innovation at McMaster University, Ontario; and Dr Naheed Dosani, Canadian palliative care physician and health justice advocate.

More than 120 scholarships have been funded by the Federal Department of Health, PCA and Flinders University so that not-for-profit organisations and university students in Oceania and Australia, including Aboriginal and Torres Strait Islander practitioners, can attend the conference.

**Investment in aged care**

PCA CEO Camilla Rowland told Croakey there is a need for more investment in paediatric palliative care and better integration of children’s services with primary care, as well as specific palliative care and end-of-life strategies for aged care, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse (CALD) communities and people with disability.

“We’d certainly like to see a far greater investment in palliative care in aged care as core business. At the moment in Australia palliative care is not offered in most aged care facilities,” she said.

The Royal Commission into Aged Care Quality and Safety has provided an opportunity to provide advice to government that further investment for the palliative care workforce to attend aged care facilities is needed, as well as training for the aged care workforce in palliative care, she said.

However, Rowland said palliative care is for anyone of any age – from babies to older adults – who have been diagnosed with a life-limiting illness, and it can be provided alongside curative treatments, or when those treatments have ended.

PCA is working with Paediatric Palliative Care Australia and New Zealand to develop the Federal Government-funded Paediatric Palliative Care National Action Plan to support health professionals respond to the specialist needs of children with life-limiting conditions, as well as the needs of parents and carers.

“Increasingly we’re really thinking from the perinatal period,” Agar said.

“For parents who are about to have a baby with a life-limiting illness there needs to be good palliative care. It’s a highly specialised area of expertise so we need to look at access as many children will spend a large proportion of their time in the family home.”

PCA’s annual National Palliative Care Community Survey this year found that awareness of palliative care was high among Australians but most people did not understand its scope. Only four in 10 Australians were aware they could first ask for palliative care when they were diagnosed with a terminal, chronic or degenerative illness.

Rowland said the conference would bring energy and expertise to conversations about palliative care from a workforce that was “genuinely passionate about the quality of end-of-life care”.

“To be part of someone’s journey, in the sense you are helping them have quality of life, is incredibly rewarding and it really cuts through all echelons of society,” she said.
Palliative care must get political on injustice and inequity, conference told

Introduction by Croakey: The 2021 Oceanic Palliative Care Conference opened with a rousing call for palliative care professionals and services to fight racism and other injustices in their sector and the broader health system and to put equity at the heart of their work.

It came from Dr Naheed Dosani, a health justice advocate and founder of a mobile palliative care service for the homeless in Toronto, who delivered the opening plenary session of the three-day online conference, which has attracted more than 1,000 delegates.

The conference also heard a rallying cry for political action from British political health economist Associate Professor Robert Yates, who said the National Health Service had been born amid the devastation of post-World War Two, showing that, “at times of great crisis”, leaders can turn to transformational health reform, particularly among growing awareness of structural gaps and failures.

Opening the event amid ongoing COVID-19 lockdowns in New South Wales, Melbourne and the Australian Capital Territory, the chair of Palliative Care Australia, Professor Meera Agar, said the pandemic had “had a devastating impact on the way we work, even the circumstances in the way we die”.

It’s “the defining moment in our lives,” she told delegates.
Linda Doherty writes:

Palliative care services and professionals must “get political” and address structural barriers to end of life care like racism, transphobia and colonialism to improve access for communities that are marginalised, according to leading Canadian palliative care physician Dr Naheed Dosani.

Dosani told the Oceanic Palliative Care Conference 2021 that more focus was needed in palliative care on equity and the impact of the social determinants of health – such as income, gender, employment, housing and education – which accounted for 60 per cent of what made people sick.

Inequities in the social determinants of health led to poorer health outcomes, including poor mental health and shortened life expectancy, and were caused by “racism, sexism, transphobia, xenophobia, classism, colonialism, ableism, capitalism and imperialism”, he said in the opening keynote address from his home in Toronto.

“We can create health justice through an equitable approach to palliative care. Death is a social justice issue,” he said.

“Getting political is in your lane,” Dosani told delegates, urging them to put equity at the centre of service provision.

“Don’t listen to people who say it’s not in your lane. What does that mean exactly when we consider there’s an entire population of people who don’t have adequate access to palliative care because of factors like income and racism? Do we really have a choice to not get political?”

The “dual vulnerability” of a life-limiting illness and poverty was evident across the world, and, he said, saw homelessness cut life spans in half.

Dosani outlined the scale of homelessness in Australia, where around 116,000 people are reported as homeless on any given night. Aboriginal and Torres Strait Islander people were 14 times more likely to become homeless than non-Indigenous Australians.

Yet there was no Australian data on the number of people who died while homeless, or if their deaths were premature or preventable, Dosani said.

“What we’ve learnt in Canada is that for every [homeless] person in a shelter there’s another 23 we don’t see,” he said.
Palliative care must get political on injustice and inequity, conference told #21OPCC

Making a difference

Dosani was a resident doctor training at a homeless shelter in Toronto when he met Terry, a homeless man in his early 30s with terminal cancer, mental health and addiction issues. He worked on a pain management plan to give Terry comfort in his final stage of life but returned to the shelter to find that he had “fallen through the cracks” of the healthcare system and died of an overdose on the street.

Profoundly affected by Terry’s death, Dosani completed his final year of medical training as a palliative care physician and founded PEACH (Palliative Care And Care for the Homeless) in 2014. It began with just him, “a street nurse and a Honda Civic”, providing outreach to homeless people “where they are”, on the street, in parks, under bridges, in shelters and boarding houses.

(Watch this rap from Dosani on his early work in palliative care for people who are homeless).

PEACH is now funded by Ontario’s Ministry of Health and brings housing, mental health and healthcare professionals together to provide community-based mobile and hospice palliative care to Toronto’s most vulnerable.
With a caseload of 130 people at any one time, the service takes a human rights-centred approach and advocates harm minimisation against a backdrop of rising opioid overdose deaths in Canada.

The model of care has been replicated in cities around the world and led to the development of Journey Home Hospice, Toronto’s first hospice for people experiencing homelessness.

“The hard data shows PEACH is actually making a difference,” Dosani said.

Almost two-thirds of clients did not need to access hospitals before their deaths, reducing healthcare costs; 83 percent were reconnected with family and friends; and 80 per cent died at a place of their choosing, whether that was “a fancy hospice, drop-in respite, rooming house, and we worked to make that possible”.

**Pandemics as “guided missiles”**

Dosani, who holds faculty appointments at the University of Toronto, University of Ontario and McMaster University, is the son of refugees who fled war-torn Uganda in the 1970s.

He was also medical director for a COVID-19 Isolation/Homeless Program in the Greater Toronto municipality of Peel, one of Canada’s regions hit hardest by the pandemic in 2020.

The pandemic had put homeless communities around the world at greater risk of symptomatic infection and mortality and in Canada had resulted in further isolation and marginalisation, encampments, and “the criminalisation of poverty”, he said.

“Pandemics are like guided missiles,” Dosai wrote in April in the *Ontario Medical Review*.

> “They target the most vulnerable. The disproportionate effects of COVID-19 on three groups – racialised communities, essential workers and people who experience homelessness – are all textbook examples of its devastating impact.”

In Toronto, Black, Indigenous and People of Colour comprise 52 percent of the population but accounted for 83 percent of COVID-19 cases in the first wave in 2020.

“Those numbers are shocking but not surprising. Many members of racialised communities face routine disadvantages and our institutions often perpetuate them at a systemic level,” Dosani wrote.

Dosani said that overt and covert racism was endemic in palliative care – and in healthcare in general – where women of colour in Canada would do their hair or make-up before presenting to emergency departments “because otherwise they won’t be treated appropriately from a pain perspective”.

A national controversy emerged in Canada in late 2020 when a 37-year-old Atikamekew woman streamed on Facebook Live the racial slurs being thrown at her by staff as she lay dying.

“Racism is a public health emergency,” Dosani said, observing that Canada and Australia “share similar journeys when it comes to reconciliation, truth and proper representation and understanding of our Indigenous communities”.

“We have a bloodstained colonial past and I know there are a lot of discussions similar to this happening in Australia because racism is very real at a superficial level, but it’s systemic racism in healthcare that’s very real, too.”
Speak up for access

Dosani urged delegates at the Oceanic Palliative Care Conference to increase their advocacy for palliative care for marginalised communities at any level, from speaking up within local networks to lobbying government policymakers.

“Your advocacy may look different to mine but we need to harness our collective power and improve palliative care access for people experiencing structural vulnerability,” he said. “It’s not just about clinical care, it’s also about advocacy.”

British political health economist Roberts Yates also called on the palliative care sector to increase political advocacy to secure a better funding share under publicly-funded universal health coverage where “all people receive the quality health services they need without suffering financial hardship”.

Yates, the Executive Director of the Centre for Universal Health at Chatham House in London, said decisions on funding health services were inherently political, despite the overriding principles of scientific evidence and health economics.

“We in the palliative care movement need to recognise this and engage in the politics,” he said.

“We’ve seen in the pandemic here people in long-term residential care and hospices having a really tough time, denied access to their families in their final hours and people are getting really angry, and justifiably so,” he said.

But these were the types of inequities that should be exploited to argue for more funding for palliative care, he said. While health systems around the world were reeling from the impact of COVID-19, there was also an “opportunity for radical change” to improve fairness and equity, as the UK had seen in the post-World War Two creation of the National Health Service.

The impact of growing public demands to address gaps in health and social care was to be seen “in real time” in the UK now, with Prime Minister Boris Johnson proposing a health and social care levy that will break an explicit election promise.

Read these Twitter threads:

On Dr Naheed Dosani’s keynote from Croakey contributor and researcher Alison Barrett/Croakey News and from palliative care specialist Rachel Coghlan/WePublicHealth.

On Robert Yates’ presentation from Rachel Coghlan/WePublicHealth and from Croakey editor Marie McInerney
Palliative care must get political on injustice and inequity, conference told #21OPCC

Further reading

Death is a social justice issue: Perspectives on equity-informed palliative care

Also via Twitter

Why doesn’t the community talk more about SDOH and impact on pal care access says @NaheedD Shocking story of Canadian hospital that put spikes on grates so homeless people couldn’t sleep there and get warmth #21OPCC @WePublicHealth @Pall_Care_Aus @CroakeyNews
You can track Croakey’s coverage of the Conference here.

80% of people we cared for died where they wanted to; in the homeless centre, the respite centre, and we worked to make that possible. People experiencing #homelessness were hanging by a thread before #COVID19, & that thread really did snap @NaheedD #21OPCC

Homelessness is a continuum and lack of housing takes many forms - poor conditions and episodic housing or those who spend most of their resources on housing without much left for anything else. #21OPCC

@NaheedD ‘my patients aren’t vulnerable’ they are strong and resilient - it’s structural vulnerabilities around them we need to focus on #21OPCC

Racism in healthcare - When people with palliative care needs feel they have to do their hair and makeup before presenting to emergency department or their pain needs will not be met #21OPCC @NaheedD

#21OPCC @NaheedD plenary - describes reflective ‘grief circle’ for the team after a death - what a great way to honour the person, the team, and prepare to keep going - @LASANational @ACSANational @chaaustralia let’s get this happening in aged care as standard practice. @PCACEO
You can track Croakey’s coverage of the Conference here.

#21OPCC

Palliative care must get political on injustice and inequity, conference told

@ELDAC_agedcare

#RiskManagement has become a barrier to people dying at home. I wouldn’t want any of my colleagues to be at risk in providing #PalliativeCare, but many of the housing organisations have policies that make providing palliative care impossible @NaheedD #21OPCC

@kate_sweetenham

#21OPCC. Fabulous start to the Oceanic Palliative Care Conference 2021 with Dr Naheed Dosani bringing the need for health justice to the fore

@NautyMaddison

#21OPCC off to an incredible start with @NaheedD. Working in Palliative Care community development - I am inspired to reach out to homelessness organisations in SWS to support workers and members of our bereaved homeless communities.

@WePublicHealth

Replying to @WePublicHealth

"Why does the palliative care community not dig deeper into the social determinants of health?" "What lies at the roots? The structural determinants of health..." Great questions from @NaheedD. @baumfran - your thoughts here always welcome! #21OPCC @rachelcogs

@WePublicHealth

Replying to @WePublicHealth

Break down the silos between palliative care and housing, shelter and other social services. The solutions lie beyond healthcare alone. Such an important message for us here in Australia and the region. #21OPCC @Pall_Care_Aus @CroakeyNews
#21OPCC opening and acknowledgements

What a beautiful setting for Welcome to Country - Violet Sheridan on Ngannawal Land. #21OPCC

This year’s #21OPCC will deliver a final statement on behalf of all delegates, with recommendations for the future of #palliativecare in Australia and our region. We can all contribute to this! It will build on the Perth Statement from 2019 - see here: palliativecare.org.au/wp-content/upl...

@GregHuntMP discussing the importance of additional funding and focus on #palliativecare in #agedcare - recommendations from the Royal Commission on Aged Care. Thanks to @PCACEO and the team at @Pall_Care_Aus for the work you do around the country. #21OPCC officially open!
You can track Croakey’s coverage of the Conference here.

Minister for Health and Aged Care @GregHuntMP gives the opening address of #21OPCC.

"At this conference, I invite you to come with ideas and suggestions as to how to further improve #palliativecare. We do have a wonderful system in Australia because of you and thanks to you."

'All of us here recognise that #PalliativeCare is a vocation like no other; all of us are deserving of recognition. Thank you for your tireless efforts to your patients, families, & your colleagues in the most difficult & sometimes unimaginable circumstances' @meera_agar #21OPCC
Palliative care must get political on injustice and inequity, conference told

#21OPCC

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You can track Croakey’s coverage of the Conference here.

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Ten takeaways
See this selection of tweets from Croakey contributor Alison Barrett, who is live-tweeting #21OPCC at @CroakeyNews.

A great day of presentations today at #21OPCC
If you missed any sessions, here are ten key quotes which give a brief overview of the day.
"Death is a social justice issue" - @NaheedD #equitiequityequity

"It’s really hard to give palliative care {to people experiencing homelessness} if you’re not advocating for housing" - also @NaheedD #21OPCC

"The most important thing to get right is how you finance your health system" - @yates_rob on Universal Healthcare Coverage reform #21OPCC

"Dying in Australia is more institutionalised than almost anywhere else in the World" - Louise Mayo about research that motivated the development of 'Leo’s Place', palliative care respite house in ACT. #21OPCC

"The expectation for paramedics to treat and refer in complex end-of-life care situations, rather than revert to the instinctive position of hospital conveyance, is a relatively recent evolution for the profession" - Madeleine Juhrmann #21OPCC
Palliative care must get political on injustice and inequity, conference told 

#21OPCC

"Think about all the work we are all doing in public education and public awareness campaigns. Now add the local education and support on top of that. All this is building a more knowledgeable and skilled general public." - @KezNoo about improving Death Literacy #21OPCC

"Health systems are dynamic and need to be taken into consideration in study design" - Melanie Lovell, upon reflection of trial to address cancer pain, an unmet need in many cancer patients. #21OPCC

"Able to leave their loved one behind and know they'll be looked after" - James Connor on one of the key benefits identified about 'Leo's Place.' #21OPCC

"We all deserve the best end to life as possible" - Vicki Barry about the benefits of proactive planning for the end-of-life #21OPCC

"Ultimately, the program is all about making memories" - Claire Treadgold about Starlight Moments #21OPCC
Threads to follow

Check out these Twitter threads from multiple sessions at #21OPCC from Alison Barrett at @CroakeyNews:

Holistic care, including death doulas, Your Departure Land, spiritual care, and advance care planning: read here

Workshop on Project Hamrahi ("Fellow Traveler"), a collaboration between Australasian Palliative Link International (APLI) and Pallium India: read here

Workshop on end of life law for clinicians: read here

Innovate and change session, including palliative paramedicine and Leo’s Place – a world’s first, non-clinical, palliative care respite house: read here.
Creating a cocoon: plans underway for Australia’s first paediatric palliative care plan

Introduction by Croakey: Strong paediatric palliative care was able to “create a cocoon” around Simon Waring’s four-year-old son Marmaduke, allowing him to be surrounded by love at home.

The 2021 Oceanic Palliative Care Conference has heard of efforts to provide such care for children at end of life in a range of settings and locations, and through the development of Australia’s first National Paediatric Palliative Care Action Plan.

Linda Doherty writes:

Simon Waring’s grief at the loss of his son, Marmaduke, instinctively turns to gratitude for the rich but short life he was privileged to share and for the paediatric palliative care that allowed the four-year-old to be surrounded by love in his family home.

Waring, a marketing and communications professional, has lived experience of palliative care for both adults and children.

Marmaduke was diagnosed at 15 months with neuroblastoma, a cancer that occurs most often in infants and young children. He died three years later, in 2012, just five weeks after Millsom, his mum and Waring’s wife, died from breast cancer.
Waring says the family’s experience of adult palliative care for 47-year-old Millsom was satisfactory but due to their circumstances was restricted in scope, flexibility and length.

“However, our experience of paediatric palliative care in both the hospital and at home was highly involved, lengthy and positive,” says Waring, a member of Palliative Care Australia’s national consumer panel, who tweeted for @WePublicHealth from the Oceaniac Palliative Care Conference.

In an interview with journalist Cate Carrigan for Croakey Voices, Waring talks about how palliative care allowed him and his wife, Marmaduke and his three siblings to enjoy precious time together with psycho-social and medical support.

“We were able to create a cocoon around my son at home, where he was surrounded by family. He was always in touch with a loved one – both physically and emotionally – and it was only really possible through the support of the palliative care team.”

Best practice care

The experience of Waring and other families is influencing the development of the National Paediatric Palliative Care Action Plan, which aims to ensure that children with a life-threatening or life-limiting condition and their families receive best practice care and timely support and information, from perinatal palliative care through to palliative care for young adults.

The National Paediatric Palliative Care Action Plan: Background Literature Review, which reviewed 369 national and international investigations for Palliative Care Australia (PCA), has identified key priorities for the national plan as:

- patient- and family-centred care
- a multidisciplinary approach
• early integration of specialist paediatric palliative care
• advance care planning
• providing care in a variety of settings, and
• considering the specific needs of culturally and linguistically diverse communities, including addressing racism, discrimination and cultural stereotyping of Aboriginal and Torres Strait Islander people.

Lead author Associate Professor Stuart Ekberg, senior lecturer in the Faculty of Health at Queensland University of Technology, told the conference that the care of children with life-limiting illnesses, an estimated 25,000 Australian children, was extremely complex.

That was “due to their physiological resilience, the uncertain trajectory of their illness, the role of parents or guardians as decision-makers, and the ongoing development of a child – physically, emotionally, cognitively, socially, culturally, and spiritually,” he said.

Conference delegates heard that the need for paediatric palliative care will increase as the number of children with life-threatening or life-limiting conditions, currently estimated at 21 million children and young people worldwide, continues to rise.

Ekberg said specialist palliative care services for children are available in most Australian states and territories, but the pace of development has been slower than in other Western countries such as the United Kingdom.

The $3.25 million Federal Government-funded project to develop the national plan is a collaboration between PCA and Paediatric Palliative Care Australia and New Zealand, and is due for completion in 2022.

According to the review, children receiving paediatric palliative care may have conditions only seen in childhood, with half of all life-limiting conditions broadly grouped as neurodegenerative disorders, metabolic disorders, genetic conditions and congenital anomalies, cardiovascular and respiratory diseases and acquired brain injuries.

Diseases seen in adult palliative care, by comparison, often relate to conditions as a result of lifestyle and ageing such as cancers, cardiovascular disease and dementia.
Ekberg said one of the strongest themes to emerge from the review was the importance of patient- and family-centred care through measures such as continuity of care by clinicians who are known and trusted by the child, and better access for families to advanced care planning.

Many children likely to benefit from advanced care planning did not receive it, or received it close to the end of their life when its usefulness may be limited, he said.

Family-centred care extends beyond a patient’s parents or guardians and includes other family members, such as a patient’s well siblings.

“Depending on their individual circumstances, there is scope for even very young patients to participate in their own care . . . parents are typically the most expert about their children, and thus their involvement through family-centred care is essential to maximise quality of services,” the review said.

### Conclusions

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**From Associate Professor Stuart Ekberg’s presentation**

### Rural and regional access

The review also notes that equitable access to palliative care is particularly difficult in regional, rural and remote parts of Australia due to vast distances and limited services outside of major cities.

There are seven specialist paediatric palliative care services and three dedicated children’s hospices covering a geographical area of 7.6 million square kilometres on the mainland and 32,160 square kilometres of islands – and no specialist services in Tasmania or the Northern Territory.

A multidisciplinary approach was suggested in the literature review to improve the quality of care in all parts of Australia. It should extend beyond specialist paediatric palliative care to include neonatal intensive care and community healthcare services, including community palliative care, it said.

One such strategy is the **Quality of Care Collaborative Australia** (QuoCCA) ‘pop up’ model in rural and remote Australia, where specialist paediatric palliative care services support local acute- and community-based services to care for individual children at times of need, from diagnosis and referral through to bereavement.

The QuoCCA initiative is “the clearest example of government-funded collaboration” that had been evaluated across Australian states and territories, the literature review found.
“The ‘pop-up’ approach establishes a tailored network to help facilitate the ‘right care in the right place at the right time’.

“Evidence suggests this approach has enabled QuoCCA to operate successfully across jurisdictional boundaries to improve quality of care, access to care, skills within the clinical workforce, and knowledge within the community,” the review found.

A QuoCCA presentation at the conference said the pop-up model provided for the unmet palliative care needs of children in rural and regional Australia and “builds on the strengths and humanity of local health professionals to empower local teams to provide best care”.

Telehealth is also being trialled in Queensland to improve access to palliative care for the 33 percent of young people with life-limiting conditions who live in regional and remote parts of the state. Many need to travel to city hospitals for care, isolating them from local community supports.

Paediatric Palliative Care Services at Queensland Children’s Hospital in Brisbane established an interprofessional telehealth outreach collaboration linking families, local healthcare professionals and communities to their palliative care expertise.

The trial resulted in 70 percent of paediatric palliative care services being delivered in regional communities in homes, local hospitals and clinics and 18 of the 22 children who died were able to receive end of life care at their home or in their local hospital, the conference heard.
Body, heart and mind

The importance of holistic and spiritual care for children and acknowledging their worries like “who is going to look after my goldfish?” were emphasised at the conference.

A session called ‘Rosie’s Story’ led by Adjunct Associate Professor Claire Treadgold explained how ‘Starlight Moments’ was developed after research to give small, positive moments to distract children from serious life events.

Treadgold, National Manager, Research & Evaluation at Starlight Children’s Foundation, said eight-year-old Rosie had died a month ago but her family had given permission to share the story of their daughter who was “full of life” and loved unicorns.

Rosie was diagnosed with Bardet Biedl Syndrome and developed chronic kidney disease but that did not stop her enjoying a home Lego treasure hunt as her Starlight Moment.

The Starlight Moments pilot started in 2018 with the Victorian Paediatric Palliative Care Program and has expanded to include the Sydney Children’s Hospital Network. The Starlight Foundation and clinical teams collaborate to understand each family’s interests and challenges, with each ‘Moment’ specific to their needs to create positive memories and family connection.

Listen to Cate Carrigan’s interview with Claire Treadgold.

You can also read this full Twitter thread of the paediatric palliative care session by Alison Barrett, or via this PDF version.

Also shared at the conference:
Ten Twitter Takeaways

Another full day of interesting and insightful discussions about #palliativecare at #21OPCC. Following are ten key quotes for an overview of the second full day of presentations.

"When the doctor has time to sit and listen, this has a huge impact on the patient" - Dr Diana Ferreira @diana_mbhf - great insight from the patients' perspective as a cancer patient #21OPCC

"Death is not linear" - Dr Katrin Gerber @NAgeingRI #21OPCC

"Delta strain affecting epidemiology [of #COVID19 deaths] as younger cohort of patients now affected" - Dr Jia Yin Tay #21OPCC

"Simplicity of congregating was taken away, which is really important in #palliativecare staff" - Michelle Wood from Banksia Palliative Care about the impact #COVID19 had on supportive care for staff #21OPCC
Creating a cocoon: plans underway for Australia’s first paediatric palliative care plan

"Long way to travel to care, long way for care to travel to the people that need it" - Judy Hollingworth about some of the challenges providing palliativecare in regional NSW #21OPCC

"Collaboration is not about reinventing, but sharing resources" - A/Prof Ghauri #21OPCC

"We have expertise, but we’re not actual experts" - @OdetteSpruyt on the value of reciprocal learning #21OPCC

"Family and community are central to the way of life" - Dr Malama, about how in Samoa traditional beliefs may impact how people engage with western health systems #21OPCC

"Everything is on the shoulder of family and communities" - Dr Christian Ntizimira @ntizimira - similar to experiences in Samoa, family and communities are involved in meetings to decide on palliativecare pathway and may involve 20-30 people. #21OPCC

"Connect our mind to the hearts is the best way to decolonise. Our patients don't deserve politics" - also Dr Christian @ntizimira #21OPCC
Threads to follow

What is needed for better outcomes for breakthrough cancer pain?

A concurrent session chaired by Professor Gregory Crawford from Adelaide University, Professor Andrew Davies from Trinity College, Dublin, Emeritus Professor Maree Smith from the University of Queensland, palliative care researcher and cancer patient Diana Ferreira, and Dr Jessica Lee from Concord Centre for Palliative Care.

Thread by Alison Barrett at @CroakeyNews: read here

Collaboration and integration: A interdisciplinary approach to care

Includes: palliative care collaboration in a disadvantaged rural NSW region, The Advance Project (team-based initiation of advance care planning and palliative care in general practices), an evaluation of the paediatric palliative care outreach collaborative for children and families living in regional, rural and remote Queensland, the work of a SMART (symptom, management and referral team) clinic for non-malignancy patients and their carers, a focus on spirituality, and an example from West Moreton in Queensland of true integration to benefit a whole community.

Thread by Alison Barrett at @CroakeyNews: read here.
You can track Croakey’s coverage of the Conference here.

Creating a cocoon: plans underway for Australia’s first paediatric palliative care plan

#21OPCC

Croakey News @CroakeyNews

#SpiritualCare is not simply about religion, but most people have questions at the end-of-life and a spiritualcare provider may be able to help them with palliativecare #21OPCC

Creating a cocoon: plans underway for Australia’s first paediatric palliative care plan
#21OPCC

Croakey News @CroakeyNews - 12h

Great to see #21OPCC trending!

CroakeyVoices @CroakeyVoices - 20h

#21OPCC conversation trending on twitter with fascinating conversation on international approaches to Palliative Care @croakeynews @OdetteSpruyt @ntzimira @Dr Malama Tafuna'i.
Tweeting up a storm on palliative care, including on the Waiting Room Revolution

Introduction by Croakey: Experts in palliative care took with gusto to Croakey’s rotational account @WePublicHealth during the 2021 Oceania Palliative Care Conference, live tweeting multiple sessions and adding insights from their expertise and lived experience.

As well as Palliative Care Australia, they included:

- Rachel Coghlan, a palliative care physiotherapist, PhD candidate at the Centre for Humanitarian Leadership, and a member of the Australian Palliative Care COVID-19 Working Group

- Simon Waring, who experience of palliative care extends to both adult and paediatric oncology, as a full-time carer to his son Marmaduke and his wife Millsom

- Associate Professor Leeroy William, President of the Australian and New Zealand Society of Palliative Medicine.

Below is just a selection of their tweets through #21OPCC, including William’s Twitter conversations with keynote speaker Dr Hsien Seow, on the Waiting Room Revolution, plus bonus links to Twitter threads and further reading, plus more tweets from delegates at the end…
Day 1: Palliative Care Australia

This week @Pall_Care_Aus are excited about taking you on a journey into the world of #palliativecare, as we deliver the virtual Oceanic Palliative Care Conference (#21OPCC) from 7-10 Sept. We hope you will join us in important conversations about palliative care & end-of-life.

In today’s #WPPCAN event, ‘Networking in the network’, 50+ people joined to discuss the need for greater opportunities for Pacific people to share & have their voices heard, & the importance of putting pressure on govs to better address gaps in #palliativecare #21OPCC
You can track Croakey’s coverage of the Conference here.

#21OPCC
@WePublicHealth

@Pall_Care_Aus patrons, the Governor-General, the Hon. David Hurley & Her Excellency Mrs Linda Hurley, join PCA’s National Palliative Care Awards to acknowledge the service and commitment of all in the palliative care sector. #palliativecare #21OPCC

Palliative Care Australia
@Pall_Care_Aus

Congratulations to all of the winners of the National Palliative Care Awards 2021! The awards recognise the innovation, teamwork & emerging talent in Australia’s #palliativecare sector. We thank you for the outstanding contributions you have made. #21OPCC

Palliative Care Australia
@Pall_Care_Aus

🌟 Voting for the 2021 PCA Art Competition is now open!

View the fantastic artworks in the online Gallery and vote for your favourites.

VOTE ➡️ ow.ly/QaJo50G5cBR

#palliativecare #artcompetition

Art Competition
Live as well as possible, as long as possible.

Croakey
“Conference News Service”
Further reading

National Palliative Care Awards 2021

CareService blog series:

- **Virtual 21OPCC conference set to reach hundreds of professionals in the Oceanic region:** Palliative Care Australia
- **Investment in palliative care research critical:** Professor Meera Agar
- **Funeral experiences during COVID:** Deb Rawlings, Senior Lecturer, Palliative Care, Flinders University and Dr Lauren Miller-Lewis, Lecturer – Positive Psychology, CQU University
- **Project Hamrahi – the value and lessons of mentoring programs:** Associate Professor Odette Spruijt, Australasian Palliative Link International
- **Death literacy for over 55s:** Dr Kerrie Noonan, Director and Clinical Psychologist, Death Literacy Institute
- **PaCE – the Palliative Care Education Directory App:** Kylie Ash, National Project Manager PCC4U and Sharon Wetzig, Learning and Development Coordinator, Palliative Care Education and Training Collaborative
- **Training can help health professionals understand the role spirituality plays in health care:** Associate Professor Megan Best, Research Associate, Institute for Ethics and Society, University of Notre Dame Australia
- **Palliative Care Needs Rounds: influencing policy, funding and practice:** Juliane Samara, Nurse Practitioner, Calvary ACT Specialist Palliative Aged Care
- **Heart failure patients’ use of hospital services in the last year of life – timely palliative care is needed:** Dr Gursharan Singh, Research Fellow, Centre for Healthcare Transformation & Cancer and Palliative Care Outcomes Centre, School of Nursing, QUT
Day 2: Rachel Coghlan

Here's me! I am a palliative care physiotherapist @CalvaryCareAUS, a researcher on palliative care in humanitarian crises @centrehl and a Board Director @Pall_Care_Aus #21OPCC

Tomorrow we welcome #palliativecare expert @rachelcoggs @WePublicHealth, where she will share her insights & reflections throughout the first full day of #21OPCC. Rachel currently works as a palliative care physiotherapist at Calvary Health Care Bethlehem in Melbourne.

"What is a life worth?...If we can't get it right at the end of life, what are we doing? Where are we going? And how are we improve this?" @NaheedD on #palliativecare equity and for people experiencing homelessness. #21OPCC

Reminds me of some of the issues faced in humanitarian emergencies. How do you successfully deliver #palliativecare when even the basics of food, water and shelter are hard to come by? Issues and trade-offs faced where there are inequities in many contexts. #21OPCC @rachelcoggs

Seven lessons to improve #PalliativeCare for people experiencing structural vulnerabilities #21OPCC

1) the survival imperative

Lesson 1: The survival imperative

- Structural vulnerabilities shape the lives of people experiencing homelessness summarizing their experiences, needs, aspirations...
- Formal Health care providers need to acknowledge the everyday challenges that participants faced to survive. 1. How difficult, resource poorer people felt that their ability to face palliative care.
- Only by addressing obstacles such things as housing, food security, income, and transportation would our participants get quality care at the end of life.
You can track Croakey’s coverage of the Conference here.

Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC
Further reading

Palliative care, COVID-19 and humanitarian action: it’s time to talk: Humanitarian Law and Policy, Rachel Coghlan

Broaden the narrative this World Humanitarian Day: honour those who comfort the dying: The Lancet, Rachel Coghlan

Death Is a Social Justice Issue: Perspectives on Equity-Informed Palliative Care

KPMG Palliative Care Economic Report

Twitter thread: Plenary address by UK political health economist Associate Professor Robert Yates or read as PDF here

Twitter thread: The Future of Palliative Care in the Home or via PDF version

Twitter thread: Project Hamrahi or via PDF version

Twitter thread: Workshop on end of life law for clinicians or via PDF version

Twitter thread: Workshop on death literacy or via PDF version
Day 3: Simon Waring

Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC

These beautiful people brought me to this community! My son Marmaduke died at home in an extraordinary environment; enveloped in love, and surrounded by the familiar. So much is possible at end of life. Empower families. #21OPCC @Pall_Care_Aus

So true. ‘Communication collaboration’ and ‘mutual learning’. Having met parents and consumers from across the globe in CCI, there is a common palliative care language, but many different approaches tailored to their communities. @IntChildCancer #21OPCC #palliativecare
You can track Croakey’s coverage of the Conference here.

Definitely take a look at the #21OPCC art competition (on the blue navigation screen to your left). It’s now the sixth year of Palliative Care Australia’s art competition! Voting is open until next Wednesday Sept 22nd. Some amazing work! dyingtotalk.org.au/art/gallery/ #Pall_Care_Aus

Yes! Using music to connect in palliative care, illustrated at #21OPCC today. What resonated was Clare Seward explaining how this is also a source of her own self-care. Avenues of self-care (whatever form they take) are critical for everyone! #palliativecare @Pall_Care_Aus

Good hearing about carer checklists being introduced to GPs, practice managers and nurses in the Advanced Project research. The carer in palliative care so often exhausts their physical and emotional resources. They must receive appropriate support. #21OPCC @Pall_Care_Aus

I received the tweeting baton from Rachel Jane Coghlan on @WePublicHealth as Day Two closed, and it will pass shortly to Leeroy William - for the final day. Thank you to one and all! A great conference. @rachelcogs @drieeroyw #palliativecare @Pall_Care_Aus @CroakeyNews

Further reading

Creating a cocoon: plans underway for Australia’s first paediatric palliative care plan, at Croakey by Linda Doherty, includes interview by Cate Carrigan with Simon Waring.
Day 4: Dr Leeroy William (including with keynote speaker Dr Hsien Seow)

As previously announced, I'm at the tweet-helm today!
Leeroy William @driero y - pall care doc from Melbourne and @ANZSPM President. Thanks to @WePublicHealth! #palliativecare @ANZSPM @CareSearch @Pall_Care_Aus

Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC

Q: How do we deal with death as a taboo?
A: Need to innovate and make it work for you. Use the right language and what resonates across cultures.

#21OPCC @WePublicHealth - Sep 10
#21OPCC palliativecare
@HSeowPhD @SammyWinemaker
@WaitingRoomRev @ANZSPM @CareSearch @Pall_Care_Aus

I think the idea is to make #palliativecare not about dying, but about living well with serious illness. Sounds obvious. But how to do this? That's the "silver bullet." Language matters. The metaphors—the 7 keys—of @WaitingRoomRev are one of the ways that seem to be working.
Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC

Need to deal with the base of the mountain! #21OPCC #palliativecare
@ANZSPM @CareSearch @Pall_Care_Aus @HSeowPhD @SammyWinemaker

#21OPCC @WePublicHealth - Sep 10
Need to zoom out and see the bigger picture!
#21OPCC #palliativecare
@HSeowPhD @SammyWinemaker
@ANZSPM @CareSearch @Pall_Care_Aus

12100 Retweeted
Hsien Seow PhD @HSeowPhD

Replied to @WePublicHealth @SammyWinemaker and 3 others

#zoomout is 100% what illness understanding (e.g. illness trajectories) and illness education is about... followed by discussions about preferences, values, goals of care... which is the foundation for #ACP #advancedcareplanning. But in plain language.

Palliative Care CAG @PC_CAG - Sep 10
*Hope for the best, plan for the rest* - @HSeowPhD

#21OPCC @WePublicHealth @Pall_Care_Aus #palliativecare

12100 Retweeted
Hsien Seow PhD @HSeowPhD

Replied to @PC_CAG @WePublicHealth and @Pall_Care_Aus

This statement from our @waitingroomrev podcast can empower health care providers to introduce #palliativecare approach earlier, without feeling like they are going to make patients depressed, are abandoning them, or giving up on them.

You can track Croakey’s coverage of the Conference here.

Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC
You can track Croakey’s coverage of the Conference here.

Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC

Hsien Seow PhD @HSewPhD - Sep 10
People want hope. Public activation is the key to change the system.
#21OPCC #palliativecare
@HSewPhD @SammyWinemaker
@WaitingRoomRev @ANZSPM
@CareSearch @Pall_Care_Aus

1 3 3

Hsien Seow PhD @HSewPhD - Sep 10
Showing people how to be hopeful and prepared, and giving them tools to improve their experience—this is what is hopeful. Hope evolves when they have information. Or else they get stuck in false hope. @WaitingRoomRev @SammyWinemaker

1 2 2

#21OPCC Retweeted

Hsien Seow PhD @HSewPhD
Replies to @HSewPhD @WePublicHealth and 5 others

We cannot always change the outcome of the illness, but we can change the experience! That’s really the heart of #palliativecare

#21OPCC @WePublicHealth - Sep 10
The first 3 keys. Medicine is good at being in the weeds of the disease.
#21OPCC #palliativecare
@HSewPhD @SammyWinemaker
@ANZSPM @CareSearch @Pall_Care_Aus

1 3 5

#21OPCC Retweeted

Hsien Seow PhD @HSewPhD
Replies to @WePublicHealth @SammyWinemaker and 3 others

Do you know how many times I have had family members tell me they are getting blood work (and spending their entire day’s time and energy to do it). When I ask, why are you doing this? They do not know!
You can track Croakey’s coverage of the Conference here.

Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC

#21OPCC
@WePublicHealth

Invest in the community and it will pay for itself. Invest in aged care - keeps people out of ED Invest in hospital = savings to healthcare
#21OPCC #palliativecare
@ANZSPM @CareSearch @Pall_Care_Aus

#21OPCC
@WePublicHealth

People still misunderstand palliative care! Need to keep explaining it’s not about death and dying...it’s about living well until you die!
#21OPCC #palliativecare
@ANZSPM @CareSearch @Pall_Care_Aus

#21OPCC
@WePublicHealth

Building a workforce to meet the needs of palliative care.
Yates - Advocacy is important, but this conf makes us think about exploring the needs of the individual in-depth, but also at a systems level.
#21OPCC #palliativecare
@ANZSPM @CareSearch @Pall_Care_Aus
You can track Croakey’s coverage of the Conference here.

Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC

Further listening

The Waiting Room Revolution podcast with Dr Hsien Seow and Dr Samantha Winemaker.

Also tweeting beautifully...

Looking forward to the next 3 days at #21OPCC
#palliativecare #bereavement #deathliteracy
As we start the #21OPCC online conference, I was reminded that there is no such thing as #multitasking. When you watch a presentation while checking your emails & responding to a colleague, you are just quickly switching back & forth between tasks, i.e. you miss a lot of content.

#21OPCC

For an immersive conference experience, put your out-of-office reply on, turn your emails off and fully enjoy the opportunity to connect with so many amazing #PalliativeCare champions.

With so much great content on the #21OPCC program, I would love to hear your recommendations for sessions to catch up on. And, isn’t it great we can access sessions later?! - Alison

WHAT DO YOU SUGGEST?
You can track Croakey’s coverage of the Conference here.

Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC

Marie McInerney @marleemcinerney · Sep 9
Meanwhile some great #21OPCC Twitter analytics here - great to see so many people involved in the palliative care conversations. incl @meera_agar @drericoryw @rachelcoga @KezNoo @deb_rawlings @CareSearch and @NaheedD @Pall_Care_Aus

The #21OPCC Influencers

The Numbers

23.091M 2,484
223
21

Great to see all the tweeting and social media! Looking forward to more tweeting today.

Kerrie Noonan @KezNoo

Replying to @marleemcinerney @meera_agar and 6 others
You can track Croakey’s coverage of the Conference [here](#).

Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC

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**Alison Barrett**
@AllisonSBarrett

It’s been a great experience live-tweeting at #21OPCC with @CroakeyNews team @mariemcinerney @CateeC @lindadoherty21 @CroakeyVoices as well all who have shared the @WePublicHealth baton.

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**Marie McInerney** @marleemcinerney · Sep 10

@drleeroyw at @WePublicHealth and @AllisonSBarrett at @CroakeyNews are smashing the #21OPCC live tweeting today - too much for me to RT right now. Tune in and it’s like you’re there.

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Tweeting up a storm on palliative care, including on the Waiting Room Revolution #21OPCC

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Croakey
“Conference News Service”
How do we ensure good and dignified deaths in COVID-19 and beyond?

Image: Onder Ortel via Unsplash

Introduction by Croakey: Palliative care has been both overwhelmed and overlooked during the COVID-19 pandemic, but the specialty has also gained important insights on the need to focus more on social justice and ensure people are still able to have good and dignified deaths and farewells “through the devastating, lonely challenges of isolation” that COVID-19 imposes.

The pandemic was the focus of many sessions and discussions at the Oceanic Palliative Care Conference 2021, as Croakey journalist Linda Doherty reports below. Listen also to an audio interview from Cate Carrigan, who is producing a #21OPCC CroakeyVoices podcast as part of the coverage.

Our latest report from #21OPCC also includes Ten Twitter Takeaways from Croakey columnist Alison Barrett, who live-tweeted the three-day conference at @CroakeyNews.
Linda Doherty writes:

When COVID-19 hit Australia last year demand for community-based palliative care surged, particularly when lockdowns restricted access for patients, families and health professionals to hospital services and medical specialists.

The important role of community palliative care was also highlighted in the United Kingdom’s rolling waves of COVID-19 as more people chose to die at home or in residential aged care facilities than in hospitals or hospices.

COVID-19 has led to much searching in the palliative care community for how to provide the best possible end of life care for those who die from COVID-19 or other causes during the pandemic, and for how best to care for the palliative care workforce who may be fearful and overwhelmed.

Among those who sought to do so was Michelle Wood, the Executive Officer of Banksia Palliative Care, which operates in Melbourne’s north-eastern suburbs.

Wood told the Oceanic Palliative Care Conference that her team’s workload rose by more than 25 percent during Melbourne’s extended second wave lockdown last year but 80 percent of clients were still able to be supported to die in their preferred site.

“Community palliative care is incredibly important when there are worldwide pandemics and people don’t want to go into hospitals,” she said.

In a later interview with Croakey’s Cate Carrigan, Wood said that every aspect of the service changed and grew, including managing more referrals, more admissions, and higher complexities for patients in their homes who avoided hospitals despite worsening symptoms because of fear of COVID-19 and visiting restrictions.

Her service saw a higher burden on the carers of those at the end of life, while her own teams worked in a climate of fear and had personal issues to deal with, like partners being laid off work and juggling home-schooling children, and even the “simplicity of being able to congregate” for emotional support was restricted.

“But we were still able to see each other, have a chat and debrief from 1.5 metres or more,” Wood said.

And, she told the conference, “the story goes on because we are still in lockdown, still unsure about every day,” she said, amid warnings from health and government leaders that COVID-19 hospitalisations and deaths in NSW and Victoria are not expected to peak until October.

Despite the complexities of the pandemic, including frequent changes to public health orders and restrictions, Wood said patients still required face-to-face symptom management, end-of-life care and bereavement support.
The “unsung heroes” in her team did not have the same support and level of infection control that hospitals provided but with ingenuity and willingness navigated the lockdown without a single staff or client infection.

And when Banksia Palliative Care could not access enough personal protective equipment (PPE) supplies, it got help from an unexpected quarter, with local tattoo parlours – shut down because of the lockdown – offering their supplies of gloves and hand gel.

“That actually made a big difference to keep everyone safe,” she said.

## UK hit early and hard

COVID-19 hit the United Kingdom early and hard, with more than 130,000 deaths revealing the need for improvements in palliative care for patients near the end of life, Katherine Sleeman, Laing Galazka Chair in Palliative Care, at King’s College London told the conference.

Despite the UK being a world leader in palliative care, provision was still “inadequate and unequal”, even prior to COVID-19, with an estimated 100,000 people a year who die unable to access services, she said.

People in disadvantaged areas or circumstances were less likely to receive palliative care and the gap in access for the rich and poor was increasing.

Sleeman said palliative care services were overwhelmed during the early pandemic, there was a “massive shift” in place of death – with more choosing to die at home or in aged care facilities – and widespread shortages of staff and safety equipment.

To bridge the research gap for pandemic palliative care and services, hundreds of practitioners turned to Project ECHO, a videoconferencing initiative of Hospice UK, to brainstorm solutions and share resources.

A rapid systemic review drew from Severe Acute Respiratory Syndrome (SARS) outbreaks in Asia in the early 2000s that provided lessons such as the need to move resources out of hospitals and into community settings where patients preferred to be cared for, for standardised data and monitoring, and for having enough essential staff, medicines and safety equipment.

“Palliative care was an essential frontline pandemic service but services felt under-recognised and were often overlooked, which impacted on what they could deliver,” Sleeman said.

But she said the pandemic was also a once-in-a-generation opportunity to reinforce the lessons learnt – the need for better integration of palliative care teams across all healthcare settings to identify and tackle inequities, recognition and support for care homes, and the establishment of collaborative networks of clinicians, academics, policymakers, patients and the public.
Sleeman said the Marie Curie Better End of Life Program was continuing to investigate how COVID-19 had affected dying, death and bereavement in the UK and what could be learnt to improve outcomes and experiences through evidence-informed policy engagement.

One of the first Australian studies to examine the end of life symptom experience of people dying of COVID-19 has shown that the number of referrals to palliative care was “alarmingly low”.

Royal Melbourne Hospital presenters Rachel Everitt and Jia Yin Tay told the conference that the aim of their study, COVID-19 end-of-life care: symptoms and supportive therapy use in an Australian hospital, was to help clinicians anticipate palliative care needs of COVID-19 patients.

The study found that breathlessness was the most frequent clinician-reported symptom in the final three days of life, followed by agitation and pain, with most patients requiring dose escalation of opioids and midazolam, a continuous sedative infusion.
The study team suggested that “higher starting doses of opioids and sedatives may help reduce prevalence and severity of breathlessness and agitation near death”.

The Royal Melbourne Hospital cohort of 58 patients had a median age of 87 years and died after a median of 11 days in the hospital’s acute medical and aged care wards and the intensive care unit between 1 January 2020 and 30 September 2020.

But just eight of the patients were referred to palliative care and Tay said more research was required to investigate the barriers to care, particularly now that the Delta strain was affecting much younger patients than the cohort studied.

“Hopefully we will be able to transform these deaths into meaningful lessons on how we can support patients with COVID through the devastating, lonely challenges of isolation in order for them to have good and dignified deaths,” she said.

The role of telehealth

The pandemic also saw the rapid escalation of telehealth and a large study of its use in palliative care at three Melbourne acute hospitals delved into perceptions of acceptability by clinicians and patients.

Professor Jennifer Philip, Chair of Palliative Medicine at the University of Melbourne and St Vincent’s Hospital, said telehealth was transformational and offered new opportunities.

But, she said, it was ultimately viewed by both clinicians and patients as “second best”.

The study of findings from 928 clinician surveys matched to 125 patient surveys found patients embraced telehealth more than clinicians, for the convenience and continuity of care or when patients were simply too unwell to travel to physical appointments.

But there was a sense that telehealth was “vending machine” transactional care that affected the physicality of care, connections and therapeutic relationships between palliative care professionals and patients.

Philip said a hybrid model of care was likely to emerge in the future, with a mix of face-to-face appointments and telehealth.
“We’re all a bit scared at the end of life but you know some reassurance to look at someone’s face or even a touch on the shoulder or a shake of a hand makes a huge difference,” she said.

**Inequities exposed**

Eighteen months down the track, COVID-19 has exposed just how hard it is for people from more marginalised communities to access palliative care, leading palliative care expert Distinguished Professor Patsy Yates told the conference at a closing plenary session to sum up key issues canvassed by participants.

Yates said the pandemic disruption had been felt “emotionally and practically” across the palliative care sector.

It had exposed inequities “in terms of access, inequities in quality and the way palliative care is delivered” to many under-served groups, she said.

The conference heard these groups included people who are homeless, Aboriginal and Torres Strait Islander people, sexuality and gender diverse communities, culturally and linguistically diverse communities, including asylum seekers and refugees, illicit drug users and people in prison.

“We’re at a significant time of disruption. [COVID-19] has exposed some real gaps and the fragility of our healthcare system and our palliative care system,” said Yates, Executive Dean of the Faculty of Health, at Queensland University of Technology.

“The social justice aspect of palliative care has always been there, but it was just so prevalent in many of the [#21OPCC conference] conversations, to make sure that all people locally and globally can benefit from what palliative care can provide.”
That imperative has been underscored by a new UK report, signalled last week at the conference by Katherine Sleeman, from a consortium of British universities and palliative care research centres that have investigated the negative impact of COVID-19 restrictions and health policies on ethnic minorities.

The study, *Palliative care for patients with severe covid-19*, found that visitor restrictions, for example, removed patients’ psychosocial support and advocates as well as their personal and professional translators, which were “for many, their only means of communication”. It noted that ethnic minority groups in the UK traditionally also had large numbers of family members involved in providing care, support and decision-making.

“There is a key lesson from this research,” warned study co-author Dr Jamilla Hussain, NIHR Clinical Lecturer at Wolfson Palliative Care Research Centre.

“To provide good end of life care for marginalised groups we need to move away from business as usual which has ingrained health inequalities – and many palliative care services did not do this during the first wave of the pandemic.”

**Read the following Twitter threads of COVID related sessions**

- Palliative Care and COVID-19, tweeted by Alison Barrett/Croakey News: or read via [this PDF](#)
- The future of palliative care in the UK: Learning from policy and practice in a pandemic: Katherine Sleeman plenary tweeted by Rachel Coghlan and by Marie McInerney, or read via [this PDF](#)

**Further reading**

- Palliative care during the COVID-19 pandemic – Palliative Care Australia report
- Palliative care and the COVID-19 pandemic, The Lancet
- Palliative Care, COVID-19 and Universal Health Coverage Report
How do we ensure good and dignified deaths in COVID-19 and beyond? #21OPCC

Related tweets

Lecroy William @dileeryw

Thinking of our colleagues who cannot attend the conf due to COVID affecting their workplaces. Kia kaha #21OCP #palliativecare
@PCOPallCare @PallMedEd @PCNAust @comms_ahea @PCSWA1 @AusPallLinkInt @ANZSPM @CareSearch @WePublicHealth @Pall_Care_Aus @PC_CAG

Leeroy William @dileeryw

Replying to @WePublicHealth @KozNoo and 4 others
Care in the terminal and deteriorating phases can effect the bereavement phase. COVID exacerbates these phases, but emphasizes the importance of what we need to do.
#21OPCC #palliativecare @PallMedEd @PCNAust @comms_ahea @PCSWA1 @ANZSPM @CareSearch @Pall_Care_Aus @PC_CAG

@WePublicHealth

What is the opportunity for #palliativecare? Pandemic has exposed huge gaps in palliative care. Many countries planning radical overhauls of their systems. Need to keep the pressure on! Here's an Editorial from The Lancet related to this: thelancet.com/journals/lancet... #21OPPC

Palliative care and the COVID-19 pandemic
Palliative care services are under-resourced at the best of times. The 2017 Lancet Commission on Palliative Care and ... thelancet.com

Rachel Coghlan @rachelcogs

Essential frontline role of #palliativecare professionals not recognised early in the pandemic in the UK. Diversion of #palliativecare resources also seen in other contexts around the world. Priority given to saving lives. Something we see often in #humanitarian crises. #21OPCC
How do we ensure good and dignified deaths in COVID-19 and beyond?

Rachel Coghlan
@rachloogs

Was #palliativecare quiet? No! People staying home. Care shifted into the community. Agile and innovative response required. Mirrors what we have seen here in #COVID19Aus #covid19vic #21OPCC

Rachel Coghlan
@rachloogs

Home deaths have been sustained even between #COVID19 waves. Why? Are they dying unexpectedly? Are they choosing to die at home? Are they not wanting to enter hospital or hospice care because of visitor restrictions? More research needed #21OPCC

#21OPCC
@WePublicHealth

Due to COVID-19, some SH care services are now virtual! Through telehealth, we can improve access to care by reducing costs, improving convenience and broadening scope of care. In what ways is virtual care the future of SH care?

#21OPCC
@WePublicHealth

@Pall_Care_Aus and the Australian COVID-19 Palliative Care Working Group has done important work during COVID-19 on expanding access to telehealth for palliative care. Recognises this is not a panacea, but needs investment. palliativecare.org.au/pca-calls-for-... @meera_agar @PCACEO #21OPCC

PCA calls for expanded telehealth capacity for palliative care... PCA has provided a submission to the Department of Health calling for expanded telehealth capacity through the MBS ... palliativecare.org.au

#21OPCC
@WePublicHealth

The COVID-19 crisis a catalyst for #UHC or for #palliativecare? Let’s hope so....but we’ve got some work to do. #21OPCC
Ten Twitter Takeaways

See the Ten Twitter Takeaways from the final day of #21OPCC from Croakey contributor Alison Barrett, who live-tweeted #21OPCC at @CroakeyNews.

To wrap up the final day of #21OPCC, here are ten key quotes that give an overview of topics discussed today.

“Cultural aspect of what death and dying mean. Other countries do that so much better than what we do in Australia.” - Prof Patsy Yates #21OPCC @pastyymates

“Aged care facilities want to provide great care - if funded appropriately, we can do that better, capacity can be built.” - Peter Jenkin #21OPCC

“Supporting carers in palliative care space is so very important” - Lana Glogowski #21OPCC

"Carers are the critical link to achieving end of life care at home" but they often reach their capacity. - Celia Marston #21OPCC

“I want people to realise that everyone needs an advance care plan” – Chris when discussing the Advance Care Yarning App #21OPCC
How do we ensure good and dignified deaths in COVID-19 and beyond?

#21OPCC

"There is no doubt in all the talks I’ve had with Elders, it’s needed" – Lorraine McMurtie on the Advance Care Yarning App #21OPCC

"One of the things that just came out all the time was the importance of trust, respect and relationships" - Rosemary Leonard on findings from their research about how Aboriginal and Torres Strait Islander and people from CALD communities experience death, dying and caring #21OPCC

"Palliative care was a calling, it chose me, more than I chose it" - Dr Hsien Seow @HSeowPhD #21OPCC

"From the top of the mountain, we can make an avalanche, but we can’t move the mountain" - also Dr Hsien Seow @HSeowPhD about how there will never be enough #palliativecare specialists but there are opportunities to engage others #21OPCC

"#21OPCC stimulated a lot of thought about what #palliativecare workforce needs to do moving forward" - Prof Patsy Yates @patsymyates
Introduction by Croakey: In the early days of the COVID-19 pandemic, Australian film-maker Jason van Genderen and his family made a short video of what they had done to support his mother during home isolation. It attracted a global audience.

Van Genderen shared the experience and his journey “of using story as a healing tool, a connective tool and a coping tool” at the Oceanic Palliative Care Conference, as Croakey journalist Linda Doherty reports below in a timely post for #DementiaActionWeek.

See also below for a Twitter thread by Croakey’s Alison Barrett of the presentation by Canadian specialist Dr Hsien Seow on the Waiting Room Revolution. The co-host of a podcast, he talks about the benefits of stepping in with palliative care before ‘the 11th hour’ to help people feel more in control, confident, and prepared throughout their illness.
Linda Doherty writes:

Jason van Genderen was an award-winning short filmmaker with a thriving production company when the COVID-19 pandemic hit early last year, around the time his mum’s advanced dementia meant she required an escalation in home care.

“I took the downturn in work as an opportunity to give myself the space to care for my mum the way I had to and to understand and appreciate the value of what storytelling could do in palliative care,” the Tropfest award winner told Croakey ahead of his presentation, titled ‘80 million views: A fast story of slow loss’, at the recent 2021 Oceanic Palliative Care Conference.

Be proactive, not retrospective, is his message: document today what you can keep for tomorrow with storytelling as a healing tool that can help normalise loss.

“We can capture the good in our journey and capture as much as possible of our loved ones. It’s a celebration of a life and it doesn’t have to be broadcast to the world, just be real and inclusive of the person,” he said.

Van Genderen’s mum, Hendrika, was living with his family last year when the first NSW pandemic lockdown occurred, disrupting her weekly shopping routine.

To bring back that familiarity, van Genderen created a ‘supermarket’ in his Central Coast kitchen and took ‘Oma’ – the Dutch word for grandmother, as she is known – out to “the shops”, complete with trolley and shopping list, his wife Megan and toddler Evie behind the counter and five-year-old son Arty on the till.

As with all his films, van Genderen shot the supermarket video on a mobile phone and posted it early one evening on his Facebook page @Omas Applesauce – “Our little family #DoingDementiaDifferently”.

By the end of the week the video had been viewed nine million times and went on to feature on Australian television and in the United States on Good Morning America and The Late Late Show with James Corden.

A Facebook series of van Genderen’s videos about his mother and “what it’s like to lose someone slowly, bit by bit, day by day” has been viewed 80 million times worldwide and a short film, Everybody’s Oma, is in post-production.

“The whole experience of palliative care has really changed me and my direction as a storyteller,” he says.
“How many people have you met who get so caught up in the palliative care journey that when there’s an end of life we look back and say, ‘I wish I’d done that interview, I wish I had some proper photos’, or asked questions about their career or childhood, and then it’s gone and we lament the fact we have broken stories in our families.”

Oma, 88, is now in a residential aged care facility where strict lockdowns prevent face-to-face contact but van Genderen and his family visit often and hold up signs and questions to her window.

Finding a loophole in the rules, they have been able to relocate Oma’s cat, Hailey, to the nursing home because while humans can’t visit, pets can.

Van Genderen reflects that now in his late forties, he’s spent half his adult life caring for parents with serious illnesses.

Hendrika and her husband Jan, who became a talented sculptor after his retirement, migrated to Australia from The Netherlands in 1957.

Jan died 11 years ago after living with cancer for 10 years and shortly afterwards Hendrika mother was diagnosed with Alzheimer’s disease and vascular dementia.

‘The Unspoken’, van Genderen’s film made while his father was still alive, was perhaps the beginning of the filmmaker’s desire not to have regrets following the death of a loved one and to celebrate the moment.

“I wanted to give him some words about how I felt about him, instead of saying it in a traditional eulogy after he died,” he says.

Two years ago he made Beholder, a retrospective of his father’s sculptures to raise recognition of his work.

Van Genderen’s success as a short film-maker started on the global stage in 2008 when he won Tropfest New Work with Mankind is No Island, a film about homelessness using found signage in Sydney and New York and shot on a $57 Nokia mobile phone.

The Unspoken was Tropfest Australia 2011 runner-up and Beholder won the 2019 Moment Invitational in New York.

As Oma becomes frailer, van Genderen has decided not to film her anymore and is instead turning to his 132,000-strong Facebook community to help others use storytelling “to look inwards and find simple ways to maximise the time you have now in a fun, collaborative process with your loved ones”.

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The Waiting Room Revolution

Palliative care is still too often delivered at end of life or the “11th hour” rather than earlier in a life limiting disease, leaving many patients and families saying “I wish I had known that sooner”, Canadian palliative care specialist Dr Hsien Seow told the conference while delivering the Ian Maddocks Guest Lecture.

Public health researcher Alison Barrrett livetweeted the presentation at @CroakeyNews. Below is an edited version (or read a PDF version here).

Alison Barrett tweets:

This morning’s plenary is given by Dr Hsien Seow, the recipient of the Ian Maddocks Guest Lecture, given to the best submission by an author under the age of 40 who is engaged in the study or delivery of palliative care.

Meera Agar, Palliative Care Australia chair, provides history of Ian Maddocks Guest Lecture. Emeritus Prof Maddocks was integral in establishing Palliative Care Australia.

Dr Seow is the Canada Research Chair in Palliative Care. As part of his research, he created the Waiting Room Revolution podcast.

“Palliative care was a calling, it chose me, more than I chose it”. Thinks about how his research can improve patients’ outcomes.

He knows what it’s like to have an illness journey without palliative care as his mother had breast cancer.

He and his family were not prepared for what was happening #21OPCC
As with many patients, palliative care often not delivered until the 11th hour. His motivation and research focuses on how palliative care can be delivered earlier.

“From the top of the mountain, we can make an avalanche, but we can’t move the mountain”. We will never have enough specialists. Asks who else can be engaged.

Early palliative care provides a significant opportunity for people with serious illness.

Clinicians say: We have done the palliative care clinical training, but sometimes it is hard to operationalise early.

Dr Seow met Dr Samantha Winemaker, who provides palliative care in patients’ homes. Focus of education in palliative care is focused on specialists but does not include patients or caregivers.

Huge opportunity to move the mountain by focusing on the base.

Want to address questions about what people wish they knew, what to expect when you’re dying.

Enter the Waiting Room Revolution podcast. The seven keys are titles of episodes.
Dr Hsien moves on to a secondary story they weren’t expecting.

We live in a death-denying society. Until that is figured out, palliative care will never be priority.

People don’t want to prepare for their death, but they do want to know what’s ahead.

Asks “do we avoid using the term palliative care?” in a death-denying or death-avoiding society.

Use of metaphors in the early conversations may help people through the journey.

Education is clinically-focused, but so much about palliative care is about the art of communication and helping people understand where they are at. Difficult, but beautiful.

Another question – when is it palliative? When should the conversation be introduced?
CroakeyVOICES talks equity, COVID-19, and getting political at the 2021 Oceanic Palliative Care Conference

The impact of COVID-19 on palliative care, the need to address inequity of access for marginalised people such as those who are homeless or seeking asylum, and ensuring palliative care is not an “eleventh hour” option were just some of the themes at the 2021 Oceanic Palliative Care Conference.

More than 1,000 delegates and presenters from Australia, New Zealand, the Pacific, Canada, Africa and the United Kingdom came together for the four-day virtual gathering, which included sessions covering clinical, paediatric, aged and holistic care, and COVID-19.

CroakeyVOICES journalist and broadcaster Cate Carrigan took up some key themes with a range of OPCC speakers and presenters offering their innovative solutions, calls to action, and ideas for the future:

- **Dr Naheed Dosani**: Canadian palliative care physician and health justice advocate. Founder of the Palliative Education and Care for the Homeless (PEACH) program in Toronto, Canada.

- **Margaret O’Connor**: Emeritus Professor of Nursing and Midwifery at Monash University.

- **Michelle Wood**: Executive Officer – Banksia Palliative Care Service Victoria.
• **Maddison Naulty**: Health promotions officer South Western Sydney Local Health District, working on the **Groundswell Program**.

• **Simon Waring**: Palliative Care Australia **consumer panel member**.

• **Melissa Reader**: Managing Director and CEO, **The Violet Initiative**.

• **Helen Callanan**: **Death doula and doula trainer**.

• **Judy Hollingworth**: Former Chair of the **Manning Valley Push for Palliative** (MVP4P), and a Spiritual Care Practitioner.

• **Dr Hsien Seow**: Canada Research Chair in Palliative Care and Health System Innovation, co-host of the **Waiting Room Revolution** podcast.

• **Professor Meera Agar**: Chair of Palliative Care Australia, Professor of Palliative Medicine at the University of Technology Sydney.

• **The song “His Way” used with permission of Creative Legacy Project artist Krishna Umali**.

This podcast is part of the **Croakey Conference News Service** coverage of #21OPCC. See our full coverage via **this link**.

Listen here: **Invest Challenge Change – Palliative care conference tackles equity of access and a global pandemic in 2021**

Contact CroakeyVoices via:

Email: cate.carrigan1@gmail.com

Twitter: @croakeyvoices
One day teacher, one day student: two-way learning urged in global palliative care

Introduction by Croakey: Western palliative care experts and programs need to support the development of palliative care systems in poorer nations, including in the Pacific and Africa, in ways that are rooted in local experience, culture, contexts and belief systems and do not ‘other’ different ways of delivering care.

That was one of the key messages from an international panel plenary session at the Oceanic Palliative Care Conference, which issued its own statement, urging ongoing international support that respects traditional and local practice.

It said “top-down teaching programs are inappropriate and ineffective in all contexts” and that curricula should be developed in partnership with local communities to ensure uptake, “based on relevance and respect for all cultures and beliefs concerning illness and the roles of families and communities.”
Rwandan specialist Dr Christian Ntizimira told the conference he had been shocked on his first visit to the United States to see patients alone in a big hospital room, flanked by a television and photos of loved ones, compared to Rwanda where patients were surrounded by their loved ones, who would be involved in paying their bills and feeding and nursing them.

“In the context of Rwanda, everything is in the shoulder of the families and their communities,” he said, adding that when clinicians call a family meeting at a hospital, “it’s 20 or 40 people who have to come, (who are) connected to the patient.”

Nitzimira, who delivered a keynote address at the 2019 conference, urged experts from different contexts to learn from each other, to be: “one day teacher and one day student”.

In this article you can read Twitter threads and interactions on the international session, and, below, the conference statement which has now been endorsed by participants.

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**Working together globally**

The International Panel Session title was: Working together for better palliative care: what would true international collaboration with impact look like? It featured:

- Rachel Coghlan (Chair): Board Member, Palliative Care Australia, PhD Candidate, Centre for Humanitarian Leadership, physiotherapist, palliative care
- **Dr Christian Ntizimira**: Executive Director, African Center for Research on End of Life Care (ACREOL), Rwanda
- **Dr Malama Tafuna’i**: Pacific Research Fellow, Centre for Pacific Health, Va’a O Tautai, Division of Health Sciences, University of Otago
- **Associate Professor Ghauri Aggarwal**: Senior Staff Specialist, Concord Centre for Palliative Care, Concord Hospital, New South Wales
- **Associate Professor Odette Spruijt**: Founder and Chair, Australasian Palliative Link International, WPPCAN
You can track Croakey’s coverage of the Conference here.

One day teacher, one day student: two-way learning urged in global palliative care

Croakey’s Alison Barrett live tweeted the session at @CroakeyNews. Below is a selection of her tweets:

Palliative care in lower-middle income countries is “woefully” poor, says Rachel Coghlan.

Curing and conquering all diseases has become healthcare priority, with palliative care not receiving as much focus.

A/Prof Ghauri – Asia-Pacific region huge and diverse region. Core is building networks between countries.

APHN (Asia Pacific Hospice Network) facilitated a network approach and initiatives. Coordination and collaboration – at onset work with local government at highest level.

Identify local champions, will result in identifying local needs. Advocate for Palliative Care to be a core business.

“Collaboration not about reinventing but sharing resources” – A/Prof Ghauri

Train the trainers and empower nurses. Countries such as Aust, NZ have advancement in areas that could be shared with LMIC.

A/Prof Odette Spruyt talking about IHPC invited Western Pacific region to provide some advocacy to @WHO about pandemic response.

Network in region to focus on advocacy and raise awareness of need to increase access to palliative care and improved pain medication.

Christian – in the context of Rwanda, advocacy process is slow, mostly about access in region. #COVID19 situation are trying to rethink about how advocacy can be done.

What has been done – Rwanda was the only country in Africa which had palliative care policy 10 years ago. Now, 10-15 countries have.

In Rwanda context, “everything is on the shoulder of the family and communities” – family meetings to decide on palliative care pathway may involve 20-30 people.
Dr Malama talks about palliative care in Samoa – one barrier to service includes cost.

Other barriers in Samoa: limited health literacy, people often present late in illness, palliation only thing to do. Pain relief another issue.

Informal caring is the fundamental of palliative care in many LMIC around the world.

One model for end-of-life care for all won’t work – Rachel. One size doesn’t fit all.

Christian – collaboration exists but need to emphasise critical elements. If to create a strong situation of collaboration, need to look at traditional palliative care and learn from each other.

Talks about how, in US, he was surprised to see a patient on own in big room with TV and pictures, different to scenario in Rwanda where large family surround the patient.

Dr Malama – Western health system dominant in Pacific region now. Own cultural traditional beliefs embedded in health.

Traditional beliefs may impact how people engage with Western health systems #21OPCC “Family and community are central to way of life” – Dr Malama, similar experiences in Rwanda.

Extra listening:

‘Networking in the Network’ with the Western Pacific Palliative Care Advocacy Network (WPPCAN). Introduction by Associate Professor Odette Spruijt, founder of Australasian Palliative Link International (APLI) which fosters links in palliative care throughout the Asia-Pacific region.

Reflections on the international panel session

Panel chair Rachel Coghlan tweeted her reflections on the session. You can read them below or via Twitter here.

Panel chair Rachel Coghlan tweeted her reflections on the session. You can read them below or via Twitter here.
My takeaways now that I’ve had time to reflect and de-stress.

Traditional palliative care existed before modern palliative care.

We need to unfix ourselves from our own models.

In mature palliative care systems, we may have expertise, but we are not always the “experts”.

We need the best forms of collaboration and communication. Mutual learning is key.

Connecting with communities, and connecting with identities is critical.

Decolonising palliative care is not about North and South, East and West – it is about truly connecting minds and hearts. Communities, and patients, don’t care about politics.

Never think that your way, or your language, or your definition of a word is the “right” way. Differences in language and definitions exist. Privacy, diagnosis, dignity, family, mean different things in different contexts.

Informal caring by families and communities is a fundamental building block for developing palliative care. We need to look for what already exists in communities organically, and build from there.

Everyone can be an advocate for palliative care. Advocacy can seem complicated, and messy, and formal, but we can all play a role.

Education and training for palliative care is important, but education needs to happen within the contexts where it is needed. Communities need to be involved in developing curricula. Top-down, paternalistic approaches are ineffective, and inappropriate.

We need to keep the space open, to make the space grow, to evolve, gently, together. All voices are important – from the specialists down to every community member.

Governments have a critical role. We can all advocate to governments. The Australian Government has a role to play in greater investment for palliative care in our region.

And THAT is how we achieve true international collaboration for better palliative care with impact.
Further reflections

You can track Croakey’s coverage of the Conference here.

One day teacher, one day student: two-way learning urged in global palliative care

#21OPCC
2021 Oceanic Palliative Care Conference statement

INVEST

• Build the palliative care workforce by investing in training and mentoring, position establishment and retention strategies to ensure sufficient specialist palliative care physicians, nursing, allied health professionals and volunteers across the Oceanic region to deliver high quality, culturally appropriate palliative care.

• Invest in sustainable regional and international collaborative partnerships to facilitate the exchange of knowledge, support development of quality palliative care services and access to essential medications across the Oceanic region.

• Invest in telehealth and technology to ensure people with palliative care needs and families, clinicians and services are connected in meaningful ways that supplement face-to-face care, and facilitate strong communication channels.

• Invest in staffing, education, and systems to ensure that quality end of life is core business across all aged care and disability care settings.

• Increase investment in palliative care and end-of-life research and data collection and data sets, to ensure contemporary evidence informs policy and practice.

• Fund evidence-based grief and bereavement services for families and carers across all palliative care services in hospitals, aged care and in the community.

• Invest in targeted palliative care outreach services that provide care and support to people who are homeless.

CHALLENGE

• Critically challenge legislative frameworks to ensure they support the right to palliative care for all who need it, when they need it, and where they need it.

• Challenge the barriers that contribute to community silence around death, dying, palliative care, and grief and loss.

• Challenge funding and service models which cause inequity of access to quality palliative care services based on geography, gender, sexuality, bodily diversity, disability, cultural identity, values, socio-economic status, housing status, incarceration, age and stage in life-limiting illness.

• Challenge governments in the region to strive for Universal Health Coverage (UHC) which includes palliative care.

• Challenge education providers to ensure that the palliative care is part of all undergraduate medical, nursing and allied health degrees.

CHANGE

• Change any practices within health and aged care systems that inhibit early referral to palliative care services.

• Change all pandemic, disaster and crisis preparedness, planning and response to be inclusive of the role of palliative care and the needs of those requiring palliative care.
• Change policies and practice so that the needs of Aboriginal and Torres Strait Islander Peoples in Australia, and Indigenous and culturally diverse peoples across the Oceanic region are addressed, and members of these communities have their end-of-life care wishes and preferences met.

• Change existing structures of opioid and essential medicine policy, delivery and access if these limit evidence-based pain and symptom management, and access in the persons care location of choice.

• Change policies and practices so that the specific palliative care needs of infants, children and young adults are recognised and met.
Palliative care needs to address end of life discrimination experienced by LGBTIQ+ people

Focus needed in palliative care on needs of LGBTIQ+ community. Image: Sharon McCutcheon via Unsplash

Palliative care in Australia needs to respect and meet the needs of many diverse communities, including LGBTIQ+ people who still face discrimination and ignorance at the end of their lives, the Oceanic Palliative Care Conference 2021 heard.

Croakey journalist Linda Doherty writes below about the findings of three research projects on what LGBTIQ+ people fear and want from palliative care, which were presented to a conference session on diversity in care.

Linda Doherty writes:

Forty years after the HIV/AIDS epidemic brought death to the doorstep of LGBTIQ+ communities, palliative care services today still discriminate against patients’ family of choice and continue to preference their biological families.

“Our family structures are inherently different,” said Joel Murray, Manager of Community Health Program Delivery for ACON, New South Wales’ leading LGBTIQ+ health organisation.

“What’s really important to highlight is that for our communities people are more likely to involve their family of choice rather than their family of origin [in palliative care].”
Murray presented findings from a recent analysis of LGBTIQ+ palliative care needs, barriers and enablers to the recent Oceanic Palliative Care Conference 2021 that will inform an information toolkit to be released this month.

The research was funded by NSW Health and involved a partnership of ACON, Carers NSW, Palliative Care NSW, Positive Life NSW, and Seniors Rights Service.

The ACON research findings were consistent with two other research projects outlined at the conference last month, which revealed high rates of discrimination or “anticipatory fear” of discrimination that limited access to palliative care for people in the LGBTIQ+ community due to the experiences of partners, friends and families, dating back to the HIV/AIDS epidemic.

Murray said the research showed there was a strong desire for workforce education and training, inclusive policies and procedures and services that were “respectful, compassionate and person-centred”.

Hannah Morgan, National Palliative Care Project coordinator for the peak body LGBTIQ+ Health Australia, told the conference there were high rates of healthcare discrimination for LGBTIQ+ people in Australia and internationally.

At most risk were LGBTIQ+ people “who sit at the intersection of multiple identities”, such as people with disability, Aboriginal and Torres Strait Islander people and culturally and linguistically diverse (CALD) people, who “may have even more specific palliative care needs”.

The conference heard that barriers to palliative care for sexuality and gender diverse people included: a lack of recognition of chosen family, partners, carers and next of kin (including for financial decision-making and bereavement support); discrimination and stigma; social isolation and loneliness; fear of sub-standard care from faith-based palliative care providers; disrespect for bodily autonomy, fears of being mis-gendered and failure by staff to use preferred pronouns.
This often meant LGBTIQ+ people delayed or avoided palliative care, did not disclose their sexuality for fear of discrimination, and reported “fatigue” when having to constantly educate healthcare professionals about their needs.

When asked in the National Palliative Care Project survey what do you need to feel safe, respected and supported in palliative care, one respondent said:

“Queer literate clinicians for when I can’t be f****d explaining my life anymore because I’m dying.”

Palliative care services needed to consider cultural competency and safety because “there is this distrust in healthcare services, which is incredibly valid”, Morgan said.

She said one of the strongest findings of the national survey was the high levels of concern about religious and faith-based palliative care providers, with one healthcare professional commenting: “I work in the field of education for healthcare professionals and I am not confident that their training covers their personal/moral/religious biases in order to provide what an LGBTIQ+ patient wants or needs.”

This concern about sub-standard care, a lack of cultural competency and bias due to religious beliefs about sexuality or gender diverse people was also raised in the two other research projects.

The national survey – of LGBTIQ+ people and healthcare staff – is part of a three-year project that will develop e-modules to build the capacity of the palliative care workforce to respond to the needs of LGBTIQ+ people in a culturally inclusive way.
In another research project, Nick Roberts, NSW Health senior policy officer in Community Care and Priority Populations, told the conference his collaboration with the University of New South Wales aimed to inform policy to better meet the palliative care needs of diverse LGBTIQ+ communities.

He said the palliative care needs of LGBTIQ+ communities were expected to increase since older lesbians and homosexual men were at higher risk of some cancers than the general population, transgender and gender-diverse people were at increased risk of cardiovascular disease and diabetes, and people with HIV were living longer from the peak of the epidemic but were ageing.

Consistent findings from his research of “what worked well” in palliative care included dignity and respect for the chosen family and partner, correct gendering, using a person’s correct name and pronoun, and “quite moving accounts of the difference it made when a partner could stay in the room” with a patient at the end of life.
Roberts said the findings of the research, which is yet to be published, confirm the 2015 position statement of the National LGBTI Health Alliance and Palliative Care Australia that: “Palliative care for LGBTI people with life-limiting conditions should be accessible, inclusive and affirm their right to dignity and respect”.

Caring at end of life in western Sydney
Croakey’s Allison Barrett also livetweeted an additional ‘Diverse Needs Groups’ session at #21OPCC.

First presenter is Rosemary Leonard, talking about ‘In the end, what matters? Understanding the end of life needs of Aboriginal and some CALD communities living in Western Sydney’.

Collection and reporting of data in these communities are inconsistent. ‘Western Sydney caring at end-of-life team’ started a project to listen to Aboriginal people and Arabic, Hindi and Mandarin speaking communities about their needs.

Wanted to explore how these communities experience death, dying and caring, and what supports and services they use and find helpful.

Research conducted by community consultation, online survey, focus groups, photovoice interviews and face to face interviews.

Community advisors included chaplains, death doulas, funeral directors, pastoral care volunteers, Aboriginal community development workers.
Palliative care needs to address end of life discrimination experienced by LGBTIQ+ people

Key findings – “we need more Nicoles!” She provided key communication, advocacy about cultural needs, provides education and guidance about more appropriate practices. She works across silos, helping people identify the services they need.

Culturally specific supportive and palliative care workers connect community. It’s a very large role – a collaborative team approach may be appropriate to share the workload.

Additional resources identified for CALD communities include training and education in bilingual community educators.

Volunteers are greatly valued.

“One of the things that just came out all the time was the importance of trust, respect and relationships” – Rosemary.

Multicultural health services and volunteer programs need to be extended to support Aboriginal and CALD communities through their end-of-life journey.
Additional resources needed for CALD communities

- Training and education of existing bi-lingual community educators in palliative care and EOL to explain available services in culturally appropriate ways
- Palliative care co-ordinator to maintain networks, liaise with health professionals and manage accessible referral pathways for the main cultural groups

Making the most of volunteers

- Know about diverse roles of health workers
- Integrated into the hospital team
- A volunteer coordinator at each hospital for training and support
- Recruiting volunteers from diverse cultural backgrounds
- Volunteers with CALD training at all hospitals
- A register of on-call volunteers by language
- Register of CALD community support people and services (e.g. not-for-profit groups & religious leaders)

Improving palliative care and EOL spaces

- Culturally appropriate art and symbolic decoration to make people feel welcome
- A unit with its own entrance to easily come and go with access to outside areas (e.g. for yarning or ceremonial circles)
- Well signposted prayer and meditation rooms
- A kitchen for preparing appropriate food
- Private rooms to decorate, play own music, chant, say prayers, etc
- Viewing rooms to allow time for family and friends to visit the deceased
- Awareness that a large number of visitors might need to be accommodated

You can track Croakey’s coverage of the Conference here.

Palliative care needs to address end of life discrimination experienced by LGBTIQ+ people

#21OPCC
Palliative care for asylum seekers

The conference also heard about the palliative care issues for a Turkish asylum seeker with terminal cancer in a presentation from Emeritus Professor Margaret O’Connor, Clinical Research Consultant – Monash University Nursing and Midwifery and Melbourne City Mission Palliative Care.

Aykan’s story

- Aykan arrived by boat in 2013 from Turkey. Family hoped to join him.
- "qualified" as an asylum seeker, but no visa = "illegal"
- "bridging visa" while refugee status determined. Small government benefit & other assistance
- lived with others in insecure rental accommodation, all with uncertain futures
- Aykan unwell - advanced metastatic bowel cancer. Struggled to meet out-of-pocket expenses
- community palliative care team supporting Aykan’s symptom support needs, nursing, counselling, spiritual support, financial aid for medication
Aykan sometimes went without food to pay for pain medication, then without pain medication.

He was constantly distracted/fearful re outcome of his refugee application, and then distress re not being able to see his family again.

What a cruel world and tragic story.

#21OPCC

Aykan’s story cont’d

- asylum refusal - deportation and loss of government's financial support. Lawyers assist appeal
- Aykan resigned that he will never see wife and children, now in Germany seeking refugee protection
- deportation overturned due to terminal condition, admission to a nearby palliative care unit where he died
- close involvement of members of his community
- entitled to be cremated in Australia; Alevis enabled memorial service, then repatriation of body
- the palliative care service wrote to his wife, expressing condolences

Aykan’s story tells us much about the complex toll on asylum seekers #21OPCC

learning to care for an asylum seeker.

- enormity of needs and complexity of care of asylum seekers
- those seeking asylum - many social and health challenges, with life disconnected from familiar culture
- poor health outcomes - mental health, infectious disease, chronic illness, need specialised, long-term services
- a multi-disciplinary team approach - careful thought and time for liaison and advocacy, to work closely with other agencies
- separation from family, filling one’s time, insecurity of an asylum claim - heightened anxiety and uncertainty; need to be addressed by the supporting services

You can track Croakey’s coverage of the Conference here.
Palliative care needs to address end of life discrimination experienced by LGBTIQ+ people

#21OPCC

Marie McInerney
@marleemcinerney

You can track Croakey’s coverage of the Conference here.

It’s better for asylum seekers to be living in community than in detention but the nature of our cruel bridging visas, no work eg, means they often live in poverty and isolation - #21OPCC

**lessons learned**

- living in the community preferable
- most asylum seekers - situations of trauma, need a ‘normal’ life, fear return to country of origin
- depression, anxiety and psychological distress common
- no one service can provide all supports
- significant staff time to coordinate care - interpreter, trust in organisations, differing cultural and religious expectations
- time for trusted professional relationships eg sharing records
- digital technology to coordinate care AND vital for family cultural literacy may be taboo - consult community members

Marie McInerney
@marleemcinerney

Short, sharp, raw insights into the life of asylum seekers in Australia, including the end of their lives #21OPCC

**conclusion**

- dearth of literature / research into palliative care for asylum seekers in Australia
- careful holistic care, in accommodating comprehensive, individualised care for a person seeking asylum who is facing the end of their life
- supports across a number of agencies
- evidence base to the care required of this population

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**#21OPCC**

"Conference News Service"
Palliative care needs to address end of life discrimination experienced by LGBTIQ+ people

#21OPCC analytics

The conference saw great interaction via Twitter, highlighted by the data collected via the #21OPCC hashtag by Symplur.

The #21OPCC Influencers

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<th>Top 10 Influential</th>
<th>Prolific Tweeters</th>
<th>Highest Impressions</th>
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The Numbers

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Twitter data from the #21OPCC hashtag from Mon, September 6th 2021, 12:00PM to Tue, October 5th 2021, 10:00PM (Australia/Sydney) - Symplur

Croakey Conference News Service

- Reporting by Linda Doherty and Cate Carrigan
- Live tweeting by Alison Barrett
- Editing by Marie McInerney
- Layout and design by Mitchell Ward

#21OPCC

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