Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)

BEREAVEMENT DURING COVID-19

NATIONAL COVID-19 BEREAVEMENT PROJECT

UTS: IMPACCT

MESSAGE FROM PROJECT LEAD

Welcome to Issue 3 of the National COVID-19 Bereavement Project Newsletter. It has been a busy start to 2022 and we are excited to share our progress with you.

I am pleased to report that March 2022 saw a milestone in our study as our survey closed with over 2,300 responses. We will continue recruiting to our timelines of 6, 9, 13 and 15 months post-death and we already have had a strong response rate of 67%.

We have completed 100 interviews with people who were bereaved in different circumstances and settings such as in acute hospitals, residential aged care facilities and palliative care. We are beginning to form a picture of the experiences of those who were bereaved during the pandemic.

A quote from a person we interviewed seems to capture the experience of so many of our participants:

> *"It's so hard to separate the issues from grief versus the issues from the pandemic, because it's all about loss. The loss of freedom and the loss of vision of the future, the loss of positivity, it's all about loss. So pandemic grief versus death grief is all so intertwined and it's hard to untangle from what is what." - Participant 1190*

We are now entering the next stage of our study to understand the experience of Aboriginal and Torres Strait Islander Health Workers and Multi-cultural Health Workers of supporting bereaved clients during the pandemic. Their views are sought as they have-multi-faceted roles (being a community member as well as a conduit between health services and their Community).

We secured an extension to our Project and we will now finish in October 2022 following a National Workshop to consult with key stakeholders, partners and consumers to co-design our National Bereavement Action Plan.

I have also included a beautiful piece published by a bereaved health professional which I feel captures so poignantly many of the issues we have found in our interviews.

We hope you enjoy reading this Newsletter and thank you again for your continued support of the Project. Please do not hesitate to get in touch with myself or the team, should you have any questions or comments.

Kind regards,
Professor Liz Lobb

IN THIS ISSUE

A snapshot of people who completed our survey

At the close of 2021, over 1300 people had completed our survey. Our second Facebook campaign attracted a further 691 people. The success of the 2021 and 2022 campaign has resulted in over 2300 surveys to date, exceeding our target of 2000 bereaved Australians. Thank you to those who participated, and those who helped us reach this target.

Of 1254 surveys analysed to date:

The average age was 57 years, with a range of 19 to 90 years of age

The majority were female and lived in Major Cities (66%) or Inner or Outer Regional Australia (33%)

The average time since the death and survey completion was 9 months

Almost half experienced the death of a parent, with cancer or chronic health conditions being the main cause of death

The major impact of public health restrictions on the death were restrictions on funerals; reduced contact with family and friends; and being unable to visit or be present at time of death

The majority of people sought support from family and friends during their grief

"Covid impacted on me personally as one in a series of significant events. The drought followed by the fires was bad enough. We thought. Then came Covid lockdown and during that my husband became ill and died suddenly. All my family lives interstate or at significant distance and lockdown prevented them travelling to me for many months. I grieved alone through winter. The internet was my life-line. Literally. And COVID- 19 has not gone away. I live in fear of another long lockdown without support. It haunts me." Participant 148

"Amongst all the lockdowns it was very isolating at times. Too much time to ruminate on things and not enough contact or opportunity to talk face to face with people. I missed the physical contact, hugs of support from family and friends." Participant 721

"Not being present prior to death to say goodbye, not being at the funeral, had made it very difficult for me to accept the loss." Participant 2114

Support needs of Culturally and Linguistically Diverse and Aboriginal & Torres Strait Islander communities

What are the bereavement support needs of people who identify as Aboriginal & Torres Strait Islander; or from Culturally and Linguistically Diverse communities?

The impact of COVID-19 on Aboriginal & Torres Strait Islander Communities (Follent et. al., 2021)

The COVID-19 pandemic presents a public health risk for Aboriginal & Torres Strait Islander peoples and communities. If death occurs inter-state, travel may be restricted and Aboriginal people may miss out on cultural connections, community events, and visiting extended family.

Indirect impacts of COVID:

- Community supporting the community: Aboriginal community controlled health services are implementing culturally appropriate resources
- "Our mob aren't able to connect for sorry business and funerals, marriages and births. The provision of our health care, along with the provision of our social and emotional wellbeing, has changed. And connectivity is the main ingredient for our mob to stay healthy. This is the biggest barrier."

The impact of COVID-19 on Culturally and Linguistically Diverse communities (Voola, 2021)

The experience of Culturally and Linguistically Diverse people during the pandemic may be unique from other Australians. Many have come from conflict in their own country of origin and are experiencing distress about what is happening with the COVID-19 pandemic in their homeland. Western Sydney MRC conducted a survey of community members in South West Sydney during the Delta outbreak (July 2021).

- 25% said they had no choice but to travel due to health reasons (i.e. regular health or doctor's appointments)
- 24% expressed a desire to get health communication for the community from local community organisations, 23% wanted this information from their GP
- Over half (53%) felt that communication would be delivered better in a one on one with Western Sydney MRC

Follent, D., Paulson, C., Orcher, P., O'Neill, B., Lee, D., Briscoe, K., & Dimopoulos-Bick, T. L. (2021). The indirect impacts of COVID-19 on Aboriginal communities across New South Wales. The Medical Journal of Australia, 214(5), 199.
Voola, A. P. (2021). Pulse of South West Sydney CALD communities: Amplifying voices during COVID-19. Research Report, Western Sydney Migrant Resource Centre, Liverpool, NSW, Australia.

Support needs of Culturally and Linguistically Diverse and Aboriginal & Torres Strait Islander communities

Strategies to promote mental health and well-being of Aboriginal & Torres Strait Islander peoples during the pandemic (Dudgeon et. al., 2021)

In 2020, a working party of 30 Aboriginal & Torres Strait Islander elders and allies gathered and proposed 5 key mental health recovery strategies to promote ATSI health and healing during the pandemic.

1. ATSI elders and community organisations must be heard and supported to lead the pandemic crisis and recovery for their peoples and communities
2. Culturally responsive mental health and wellbeing services and workforces must be established and supported
3. Risk factors associated with social determinants of health must be addressed, and protective factors promoted
4. Equitable and sustainable digital infrastructure and telehealth services must be provided to ATSI peoples across Australia
5. A comprehensive COVID-19 database and evaluation plan must be built, which upholds Indigenous data sovereignty

Self-reported well-being and health-related quality of life of Aboriginal & Torres Strait Islander peoples during the pandemic (Gall et. al., 2022)

Although Aboriginal and Torres Strait Islander COVID cases have been relatively low during the pandemic, the toll on mental well-being needs to be assessed. A longitudinal study collected data from ATSI participants before the pandemic, after the first wave, and during the first extended lockdown in Victoria.

- 55% of participants had a mental health comorbidity;
- Aboriginal and Torres Strait Islander responders with mental health comorbidity were at a greater risk of reduced health related quality of life over time, at a clinically meaningful level;
- Stolen generations survivors experienced negative mental health impacts of lockdowns;
- Having access to Country, communities and families is important, so it is not surprising that there was a decrease in quality of life during COVID.

Dudgeon, P., Alexi, J., Derry, K., Brideson, T., Calma, T., Darwin, L., Gray, P., Hirvonen, T., McPhee, R., Milroy, H., Milroy, J., Murray, D., & Sutherland, S. (2021). Mental health and well-being of Aboriginal and Torres Strait Islander peoples in Australia during COVID-19. The Australian journal of social issues, 56(4), 485–502. https://doi.org/10.1002/ajs4.185

Gall, A., Diaz, A., Garvey, G., Anderson, K., Lindsay, D., & Howard, K. (2021). Self-reported wellbeing and health-related quality of life of Aboriginal and Torres Strait Islander people pre and post the first wave of the COVID-19 2020 pandemic. Australian and New Zealand Journal of Public Health, 1-7.

What is Study 4?

Study 4: “Identifying the mental health effects on and support needs of people bereaved during and following COVID-19: Mapping the experience of CALD communities”

The experience of Culturally and Linguistically Diverse people during the pandemic may differ as many have come from conflict in their country of origin and are experiencing distress about what is happening with the COVID-19 pandemic in their homeland. The Multicultural Health Communication Service (NSW) are partnering with us to provide support and linkage with Multicultural support workers; cultural support workers and bi-lingual community workers who will be invited to participate in interviews as eligible representatives of different communities.

Study 4: "Identifying the mental health effects and support needs of Aboriginal and Torres Strait Islander people bereaved during COVID-19: A qualitative study of the views of Aboriginal Health Workers as members and representatives of their communities in NSW"

This study will focus on Aboriginal Health Workers within the South Eastern Sydney Local Health District (SESLHD) in New South Wales to identify the challenges Aboriginal people are facing during this pandemic, and potential solutions.

This qualitative study will be guided by a small Reference Group comprised of volunteer Elders and/or trusted community members who will be consulted at each stage of this research including planning and oversight of methods, interpretation of de-identified data, and feeding back findings to the community.

Investigators:
Bianca Warner: Aboriginal Palliative Care Co-ordinator - South East Sydney Local Health District (SESLHD);
Margaret Broadbent: SESLHD Deputy Manager – Aboriginal Health Unit;
Jessica Miller: Aboriginal Health Worker - SESLHD chronic care;
Samantha Gifford: SESLHD Aboriginal Hospital Liaison - St George & Sutherland Hospitals;
Elizabeth Lobb: Professor of Palliative Care - Calvary Health Care Kogarah; and
Michelle DiGiacomo: Associate Professor - IMPACCT, University of Technology

Reference Group members:
Auntie Annette Webb
Auntie Diana Schreiber
Ann Cribb
Cheryl Porter-Pedras

Update on study 4 interviews

- To date, 5 interviews with Multicultural Health Workers have been completed. Recruitment of Multicultural Health Workers is ongoing.
  - If you are a Multicultural Health Worker, and wish to receive more information about participating, please email Dr. Serra Ivynian (serra.ivynian@uts.edu.au)
- We are awaiting ethics approval to commence interviews and focus groups with Aboriginal & Torres Strait Islander Health Workers. We expect to commence recruitment within the next two months.

"How he died" - Mary Bryant

Last week I heard someone say, "how he died". I looked up, the words touched me deeply. They didn't pierce me like an arrow, it felt more like a splat on my shirt. The conversation moved on and I could hear myself refusing to leave. I could hear myself saying, "how he died, how he died mattered", "yes it mattered to me", "it matters".

You see my Dad died last year. He died like many others, in a nursing home. He wasn't alone. We were allowed to spend the last twenty-four hours with him. Well, that's the story I told myself. I told myself "He wasn't alone". The first question anyone asked me when he died was "did you get to be with him?" I could answer that I did, and the chorus responded with relief and sentences like "I'm glad, what a relief, that's great."

The truth is it wasn't great, and I am not sure I was with him. Dying doesn't happen in a day even if we die in a day. Goodbyes take longer than that and if we don't get to say goodbye that day, we will keep saying goodbye for days, weeks and years after the person we loved died.

When I was able to see Dad after four months of being exiled, I could barely recognise him. We hadn't facetimed or had windows of love because Dad would get distressed and confused when he couldn't make sense of sounds. His brain had deteriorated so much that he couldn't really perceive. Four months is a long time not to see someone who is slowly leaving this world.

I knew my Dad, I knew his expressions. I knew how his forehead crumpled when he was in pain and how he would sing when he was happy. Dad knew me, even though he lived with Alzheimer's, he would rub my hand when I visited, blow me kisses and tell me I was beautiful. He didn't know my name and he couldn't see the spoon approaching his lips until it touched his mouth, but he knew me.

How he died mattered, it mattered to me. Dad died alone, his dying wasn't one day. In fact, I have a feeling he had left the room well before I entered it, in the last twenty-four hours of his life. He was not aware or conscious or present. His body was caught in the labour pains of his own rebirth and death. I didn't get to say goodbye. I didn't get to be with him even though I was with him in the room, he wasn't with me.

Somehow this part of the story is being lost. The experience of the pandemic and restrictions re COVID-19 are asking us to give up the hope of a good death. The hope that we could journey together. Families are being separated from each other in goodbyes and no one is noticing the effect that has. The words that weren't said, the comfort that wasn't given, the time that wasn't shared. I had a one-sided goodbye, a half goodbye.

"How he died" - Mary Bryant

I am a bereavement counsellor and manage bereavement counselling at a major Sydney hospital. I hear brilliant, brave people share their stories every day, of how they experienced how he died. We know the way we die matters. We know it matters for the person who is dying and the people who love or care for them. Yet somehow through this time we are asked to forget it matters because of the pandemic.

We are supposed to pretend and be grateful for the two or twenty-four hours we spent with them. If we can't be there, then the pressure is to be resilient (I hate the word) or be grateful they didn't suffer, or it was quick, or a stranger stood by them.

Many years ago, I was called to the scene of a road accident. Two children had been hurt. I stood by the kerb with strangers concerned for the well-being of the children that lay in the middle of road. The children were circled by emergency staff. It didn't take long for the story to emerge from the crowd of onlookers. The children had been hit by a car as they crossed the road. One child was fine, the other had a head injury. Five minutes later the story grew, one child was being air-lifted by a helicopter to the hospital. Then suddenly the ambulance drove away and the Doctors attending the scene joined me at the kerb. They explained both children were fine, they had no significant injuries, and they were going to hospital for observation.

I wrote to the staff in the hospital that day and explained the two key words in grief story telling /sharing are truth and inclusion. I explained when we don't get to hear the truth or be included, we imagine the worst. I encouraged staff to tell patients and their carers the truth of what is happening. The truth about their diagnosis and treatment and trust they will manage, they will cope, even if that includes the word dying. The Doctors at the scene that day knew the children were fine, while the people waiting on the roadside imagined the worst. They didn't have access to the truth and weren't included and they created a story and it was not the truth.

When our loved ones die without us with them, near them or by them, we imagine the worst or like me, we don't imagine at all because it's as if those months were lost in time. Platitudes and invitations to be positive or look on the bright side, are not what we need. Reminders of the need for resilience or expectations that we should be grateful or accepting of health restrictions ask us to bury our grief, forget our goodbyes and pretend.

All any of us need is the opportunity to share without judgment or feedback, how he died. To be heard, to share our pain, to feel the loss. I wanted to see Dad in the weeks leading to his death. I wanted to feed him and notice his swallowing change. I wanted to wipe his face with a wet cloth and rub his sweet, confused brow. I wanted to feel his soft smooth fingers rub mine, ever so faintly, as I sat humming Amazing Grace. I want those days back, I know I can't have them. I just want to be able to say, I wish I could.

@MaryBryant

OUR TEAM

UTS RESEARCH TEAM

Dr. Serra Ivynian - Project Manager

Dr. Serra Ivynian is a Research Fellow at IMPACCT and the project manager for this study. Her PhD research investigated care-seeking behaviour in patients with heart failure, with inferences for patient-provider communication, improving health literacy and coping responses for people with chronic illness.

She has worked on national evaluation projects to help improve palliative care service delivery across Australia, with a focus on supporting informal carers of palliative patients being cared for at home. Her current research focuses on understanding the information, practical and support needs of carers at all stages, including post-bereavement, using quantitative and qualitative methods.

Kimberley Jones - Research Assistant

Kim has a strong research background in paediatric psycho-oncology and neuropsychology. Kim has also worked clinically, in support roles in Out of Home Care settings, and in private psychology practice settings. Her research interests are in mental health, CALD and ATSI groups, and public health.

Sara-Jane Roberts - Research Assistant

Sara has a research background in behavioural science, human development and paediatric palliative care. Sara's research interests focus on improving the quality of life and psychosocial wellbeing of vulnerable populations, which was shaped through her research endeavours within end-of-life care.

PROJECT PARTNERS

phn SOUTH WESTERN SYDNEY An Australian Government Initiative

Carers NSW Australia

AUSTRALIAN FUNERAL DIRECTORS ASSOCIATION

Flinders UNIVERSITY

phn CENTRAL AND EASTERN SYDNEY An Australian Government Initiative

Calvary

THE GROUNDSWELL PROJECT

NSW GOVERNMENT Multicultural Health Communication Service

australian centre for grief and bereavement

Meaningful Ageing

Maridulu Budyari Gumal Working together for good health and wellbeing

Sydney Partnership for Health, Education, Research and Enterprise (SPHERE)

CONTACT US

We greatly appreciate your support in this important study. We will send these newsletters out quarterly.

For more information, check out our website:

www.lossandgriefduringcovid19.com

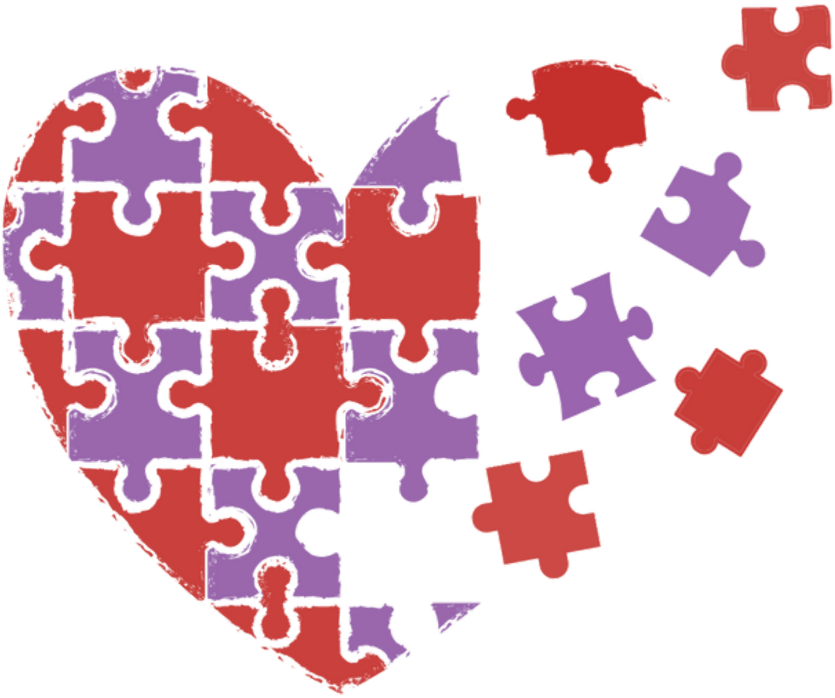
For questions or comments, email us at:

bereavementincovid19@uts.edu.au

For specific questions, get in touch with our project manager:

Dr. Serra Ivynian

serra.ivynian@uts.edu.au



BEREAVEMENT
DURING COVID-19