

ACT End of Life and Palliative Care Research Collaborative – Members Research Activity

Update September 2021



Current Research Studies

Research currently underway	Researcher	Status
Community of Practice for Nurses to improve dying in hospitals	Maureen O'Brien	Study commenced; data collected. Project on hold
Experiences of EOL care at TCH from the perspective of bereaved caregivers	Liz Layard Janie Busby Grant, Michael Chapman, Abbey, Elly Law, Imogen Mitchell Kirsten Ranse, Brett Scholz	Writing up
End of Life communication in the ICU at TCH.	Liza Goncharov, Di Slade, Imogen Mitchell, Michael Chapman, Brett Scholz	Writing up
Patient and Clinician Preferences for the Palliative Care Built Environment in Hospital Settings	Emily Sisson	Completed. Final report provided to organisation
Lactation and Milk Donation After Infant Death	Katherine Carroll, Catherine Waldby, Debbie Noble-Carr	Writing up
Palliative Care Needs Rounds telehealth in a pandemic	Juliane Samara, Dr Raymond Li, Wendy Kroon, Barbara Harvie, Robyne Hingeley and Nikki Johnston OAM	Completed
Palliative Care Needs Rounds Quasi experimental mixed method pilot	Prof Liz Forbat, Dr Michael Chapman, Clare Lovell, Dr Raymond Liu, Nikki Johnston OAM	Completed
INSPIRED Trial	Prof Liz Forbat, DR Wai-Man Liu, Jane Koerner, Lawrence Lam, Juliane Samara, Dr Michael Chapman and Nikki Johnston OAM	Completed
Palliative Care Needs Rounds Rural study	DR Sue Rainsford, Dr Raymond Liu, Nikki Johnston OAM, Dr Nick Glasgow	Completed
Shared Decision Making in the Grey Zone of Peri-viability	Katherine Carroll	Writing up
Exploring motivations for, and experiences of, ACP amongst people with life limiting illness.in New Zealand	Maureen O'Brien	Study completed
Education on Einstallle communication at the end of life	Zsuzsoka Kecskes	Study commenced

Research currently underway	Researcher	Status
Understand Palliative Care tools	Ekavi Georgousopoulou	Planning stage
BEAMs trial - COPD and breathlessness	Juliane Samara	Study commenced
An exploration of pain assessment in unresponsive patients at end-of-life	Tricia O'Connor (PhD study)	Planning stage
Consumer Leadership in Palliative Care	Brett Scholz	Study commenced
What does End of Life care look like for patients after a Medical Emergency Team (MET) consultation in the acute care setting? A clinical record audit	Jasmine Bujalski/Beelah Bleakley/Kasia Bail/Holly Northam	Analysis stage
Evaluation of a digital system in residential aged care	Kasia Bail	<ul style="list-style-type: none"> • Final Report – submitted to funders • Systematic review – final drafting Qualitative analysis – submitted • Mixed Methods analysis – final drafting
Improving the care of patients with Behavioural and Psychological symptoms of Dementia (BPSD) in an acute care setting	Kasia Bail, Dona Dolphus, Maya Zwikael, Rhonda Maher, Sarah Cope	Study commenced
Aged Care Transition To Practice Program – new graduate program with gerontological competencies in residential aged care	Kasia Bail, Victoria Traynor, Karen Strickland, Diane Gibson	Study commenced
Psychosocial effect of tube feeding on palliative head and neck cancer patients and their carers	Georgie Britton	<ul style="list-style-type: none"> • Narrative review - write up stage • Systematic review - planning stage • Interviews with patients & carers - awaiting ethics amendments • Focus groups with health professional - planning stage
What do Aboriginal and Torres Strait Islander End of Life pathways look like in the ACT?	Joyce Graham (Lead)	Study commenced
Impact/s of disasters (e.g., fires, COVID-19, floods etc). on end-of-life care provision	Marguerite Kelly	<ul style="list-style-type: none"> • Systematic review – published • Interviews with service providers – data analyses stage • Interviews with service users – data analyses stage
End of life experiences in ICU	Victoria Ims, Bronwyn Avard, Michael Chapman	Study commenced
Medical attitudes towards assisted dying in the ACT	Serena Meverson, Alison Davis, Michael Chapman	Study commenced

Research currently underway	Researcher	Status
Melatonin for delirium prophylaxis for people with advanced cancer (Cancer Symptom Trials)	Michael Chapman	Study closed
A pilot project of a decision facilitation process informed by systems theory for people with dementia	Michael Chapman, Paul Komesaroff, Liz Forbat, Jenny Philip, Brett Scholz, Emma Sharp	Grant funding obtained (PPF). Co-design process under way
Palliative Care in Prisons (ImpACCT): National study	Local lead Michael Chapman	Project progressing through phase one
Trans-Tasman perspectives on telehealth for palliative care	Aileen Collier (PI), Michael Chapman local investigator	Funding through Health Research Council of New Zealand (Auckland)2020-01-01 to 2021-01-01 Grant GRANT_NUMBER: hrc_1805b60b4f Project underway, Data accrual
Creating partnership in isupport program to optimise carers' impact on dementia care grant	Prof Lily Xiao, Flinders (PI). Michael Chapman local investigator	National Health and Medical Research Council (ACT, ACT)2021 to 2025 Grant GRANT_NUMBER: APP MRF2008321
Exercise for fatigue for patients with advanced cancer and palliative needs	Kellie Toohey, Liz Layard, Michael Chapman, Gemma Ingham, Kat Urban	Planning stage
End of Life Care Needs for people detained in a prison: the voice of those detained	Rory Maguire, Toni Ashmore, Brett Scholz,	Planning stage
How can quality end of life care be delivered in acute hospital settings	Toni Ashmore, Imogen Mitchell, Kathy Eagar, Brett Scholz, Diana Slade	Planning stage
Delphi Study: Research Priorities for End of Life and Palliative Care in the ACT/ SNSW	Karen Strickland, Imogen Mitchell, Toni Ashmore, Michael Chapman, Nick Glasgow, Jacky Clancy	Writing up stage
Qualitative evaluation of clinical supervision for nursing staff in palliative care	Liz Layard, Michael Chapman and Jason Mills	Planning stage
Coproduced project about consumers' needs in the palliative care sector	Brett Scholz, Sydney Dy, Alan Bevan, Matt Austin, Ekavi Georgousopoulou, Liz Curran, Vinh Lu, Imogen Mitchell	Project funded to commence in 2020, pushed back to 2021
Experience of supportive care for people with primary brain cancer – an integrative review	James Li, et al	Study commenced
Melatonin for delirium prophylaxis for people with advanced cancer (Cancer Symptom Trials)	Michael Chapman	Recruitment complete
Strengthening the delivery of palliative care in an Australian hospital through nursing leadership: a mixed methods action research study	Kate Reed, Claudia Virdun, Prof Jane Phillips, Dr Nicole Heneka, Cheryl Rowsell and Dr Michael Chapman	Recruitment about to commence

Research currently underway	Researcher	Status
The Rapid program: a prospective, national, quality improvement program investigating the use of non-pharmacological and pharmacological interventions frequently used in end of life care	Kate Reed as one of a group of Chief Investigators led by David Currow for NHMRC grant	Awaiting outcome of application
Benefits of non-clinical respite for people with a life-limiting illness living at home	Palliative Care ACT, UNSW	Study commenced
A Foucauldian Analysis of Nineteenth-Century Obituaries and Coronial Inquests from the Stamford Mercury (England, 1801 – 1841)	Thy O'Donell (supervisor Baptiste Brossard)	Study completed, awaiting results
Reliving trauma near death: a systematic review	Nikki Johnston	Study commenced.
LifeCircle ACT Pilot and Evaluation of Digital Platform Providing Support for Carers (now rebranded The Violet Initiative)	Rose Dillon	Completed. Final report provided to organisation
ACT Pilot to test clinical referrals/traction/impact of the LifeCircle solution (now rebranded The Violet Initiative)	Melissa Reader	Completed. Final report provided to organisation
People transitioning from hospital to residential aged care – exploring barriers	Kasia Bail, Daisy Azmi	Final report – submitted to organisation

Publications in the last 5 years

Date	Author	Publication	Journal	Link
2021	Mitchell I, Lacey J, Anstey M, Corbett C, Douglas C, Drummond C, Hensley M, Mills A, Scott C, Slee JA, Weil J, Scholz B, Burke B, D'Este C.	Understanding dying in Australian Hospitals.	Australian Health Review. Online June 2021. Q2	
2021	Noble-Carr, D., Carroll, K & Waldby, C.	Mapping hospital-based lactation care provided to bereaved mothers: a basis for quality improvement.	Breastfeeding Medicine.	https://www.liebertpub.com/doi/abs/10.1089/bfm.2021.0089
2021	Kaemingk, B., Carroll, K., Thorvilson, M., Schaepe, K., Collura, C.	“Uncertainty at the Limits of Viability: A Qualitative Study of Neonatologists' Antenatal Consultations” Pediatrics	Pediatrics	https://pediatrics.aappublications.org/content/147/4/e20201865?download=true
2021	Samara, J	Palliative Care Needs Rounds: influencing policy, funding and practice	CareSearch Blog	Palliative-care-needs-rounds-influencing-policy-funding-and-practice (caresearch.com.au)

Date	Author	Publication	Journal	Link
2021	Strickland, K., Bail, K., Cope, S., Turner, M., & Moss, C	Supported decision-making to assist older persons experiencing elder abuse: An integrative review	Collegian.	https://bit.ly/3umxl6v
2021	Jane Koerner, Nikki Johnston, Juliane Samara, Wai-Man Liu, Michael Chapman & Liz Forbat	Context and mechanisms that enable implementation of specialist palliative care Needs Rounds in care homes: results from a qualitative interview study	BMC Palliative Care	DOI: 10.1186/s12904-021-00812-4
2021	Kelly, M. Mitchell, I, Walker, I, Mears, J, Scholz, B ,	End of Life care in natural disasters including epidemics and pandemics: a systematic review	BMJ Supportive and Palliative Care.	http://dx.doi.org/10.1136/bmjspcare-2021-002973
2021	Leonard, R., Noonan, K., Horsfall, D., Kelly, M., Rosenberg, J., Grindrod, A, Rumbold, B, Rahn, A.	Developing a Death Literacy Index.	Death Studies	https://www.tandfonline.com/doi/full/10.1080/07481187.2021.1894268
2021	Samara, J., Liu, W-M., Kroon, W., Harvie, B., Hingeley, R., Johnston, N.	Telehealth Palliative Care Needs Rounds during a pandemic.	The Journal for Nurse Practitioners.	https://doi.org/10.1016/j.nurpra.2020.12.009
2020	Scholz, B., Goncharov, I., Emmerich, N., Lu, V.N., Chapman, M., Clark, S., Wilson, T., Slade, D., Mitchell, I.A	Clinicians' accounts of communication with patients in end-of-life care contexts: A systematic review	Patient Education and Counseling	https://doi.org/10.1016/j.pec.2020.06.033
2020	Rainsford, S., Liu, W-M., Johnston, N., Glasgow, N.	The impact of introducing palliative care needs rounds into rural residential aged care: a quasi-experimental study. 2020;28(5):480-489.	Australian Journal of Rural Health.	https://doi.org/10.1111/ajr.12654
2020	Lara Sweeney, Katherine Carroll, Debbie Noble-Carr, Catherine Waldby	Lactation after infant death: an analysis of Australian healthcare agencies' online health information	BMJ	https://doi.org/10.1080/14461242.2019.1708206
2020	Katherine Carroll, Debbie Noble-Carr, Lara Sweeney, Catherine Waldby	The "Lactation After Infant Death (AID) Framework": A Guide for Online Health Information Provision About Lactation After Stillbirth and Infant Death	Journal of Human Lactation	Open Access: https://journals.sagepub.com/doi/10.1177/0890334420926946
2020	Liz Forbat , Wai-Man Liu, Jane Koerner, Lawrence Lam, Juliane Samara, Michael Chapman and Nikki Johnston	Reducing time in acute hospitals: A stepped-wedge randomised control trial of a specialist palliative care intervention in residential care homes	Palliative Medicine	https://doi.org/10.1177/0269216319891077

Date	Author	Publication	Journal	Link
2020	Mills J, Li C, Fullerton S, Chapman M, Jap J, Sinclair C, Collins A, Campbell E	Staying connected and informed: Online resources and virtual communities of practice supporting palliative care during the novel coronavirus pandemic.	Progress in Palliative Care. 2020	https://doi.org/10.1080/09699260.2020.1759876
2020	Komesaroff, P.A., Chapman, M., Kerridge, I. et al.	Lead Essay—Inside the Pandemic.	Bioethical Inquiry (2020).	https://doi.org/10.1007/s11673-020-10037-4
2020	Frank M.P. van Haren, Angus Carter, Elena Cavazzoni, Michael Chapman, Rohit L. D'Costa, Sarah L. Jones, Andrew McGee, Stewart Moodie, Leo Nunnink, Michael O'Leary, Helen Opdam, Sam Radford, Andrew J. Turner, Dominique Martin.	Conflicts of interest in the context of end of life care for potential organ donors in Australia	Journal of Critical Care 59: 2020, 166-171,	https://doi.org/10.1016/j.jcrc.2020.06.016
2020	Leonard, R., Noonan, K., Horsfall, D., Psychogios, H., Kelly, M., Rosenberg, J., Rumbold, B., Grindrod, A., Read, N., and Rahn, A.	Death Literacy Index: A Report on its Development and Implementation. Sydney: Western Sydney University		https://doi.org/10.26183/5eb8d3adb20b0
2019	Forbat L, Johnston N, Mitchell I.	Defining 'specialist palliative care': findings from a Delphi study of clinicians	Australian Health Review	http://www.publish.csiro.au/ah#OnlineEarly or http://www.publish.csiro.au/AH/AH18198
2019	Liu W, Korner J, Lam L, Johnson N, Samara J, Chapman M, Forbat L	Improved Quality of Death and Dying in Care Homes: A Palliative Care Stepped Wedge Randomised Control Trial in Australia	Journal of American Geriatrics Society	https://doi.org/10.1111/jgs.16192
2019	Chapman M, Philip J, Komesaroff P.	Learning from the cultural challenge of dementia.	Journal of Bioethical Inquiry.	https://doi.org/10.1007/s11673-019-09916-2
2019	Chapman M, Philip J, Komesaroff P.	The ecology of dementia: A manifesto.	Journal of Bioethical Inquiry; 2019 16, pages209–216	https://doi.org/10.1007/s11673-019-09910-8
2019	Chapman M, Philip J, Garner S, Komesaroff P.	Fragile Objects: A visual essay.	Journal of Bioethical Inquiry.	https://doi.org/10.1007/s11673-019-09911-7
2019	Siddarth Nayar, Sivaraj Rajadorai, Thomas Robertson, Ashwin Swaminathan	Clinical and pathological correlation in an uncommon motor neurone disease presenting with Type II respiratory failure.	Case Reports in Internal Medicine	https://doi.org/10.5430/crim.v6n1p22
2019	Scholz B, Bevan A, Georgousopoulou E, Collier A, Mitchell I.	Consumer and Carer Leadership in Palliative Care Academia and Practice. A systematic review with narrative synthesis.	Palliative Medicine	https://www.ncbi.nlm.nih.gov/pubmed/31199194

Date	Author	Publication	Journal	Link
2019	Kate Reed	Sustainable access to appropriate opioids for palliative care patients in Australia-preventing the need for crisis management	Journal of Pain and Palliative Care Pharmacotherapy	https://doi.org/10.1080/15360288.2019.1650869
2019	Carroll, K	'Suppress or Express? Milk Donation After Infant Death' in C. Beyer and A. Robertson (Eds.)	Mothers Without Their Children. Demeter Press	https://demeterpress.org/books/mothers-without-their-children/
2018	Carroll, K.	'Approaching Bereavement with Heartfelt Positivity'. In T. Loughran, & D. Mannay (Eds.)	Emotion and the researcher: Sites, subjectivities and relationships (Vol. x). Studies in Qualitative Methodology. Bingley: Emerald. Pp. 97-112	https://www.emerald.com/insight/content/doi/10.1108/S1042-319220180000016007/full/html?skipTracking=true
2018	Noonan, K., Horsfall, D, and Kelly, M.	Beyond Taboos? Australians' capacity to care for each other through death, dying and loss. Research Report. The GroundSwell Project. Sydney		
2017	Forbat, L., Chapman, M., Lovell, C., Liu, W., Johnston, N.	Improving specialist palliative care in residential care for older people: a checklist to guide practice. 2018;8(3):347-353.	British Medical Journal Supportive and Palliative Care.	https://doi.org/10.1136/bmjspcare-2017-001332 .
2016	Johnston, N., Lovell, C., Liu, W., Chapman, M., Forbat, L	Normalising and planning for death in residential care: Findings from a qualitative focus group study of a specialist palliative care intervention.	British Medical Journal Supportive and Palliative Care.	http://spcare.bmj.com/content/early/2016/08/03/bmjspcare-2016-001127.short?rss=1
	Debbie Noble-Carr	Vulnerable children's perceptions and experiences of loss	publish in the future	
	Maureen O'Brien	'Understanding the experience of advance care planning processes for people living with Parkinson's disease'	publish in the future	
	Kathryn Dwan	Consumer experiences and expectations of home-based palliative care	publish in the future	
	Kasia Bail, Karen Strickland	Supported decision making in older people	publish in the future	
	Paresh Dawda, Nicole McDerby	Opioid stewardship in Australian residential aged care facilities: a collaborative approach to quality opioid medication use.	publish in the future	

Presentations in the last 12 months

Year	Presenter	Presentation Title	Conference /Workshop and date
2021	Thy O'Donell	A Foucauldian Analysis of Nineteenth-Century Obituaries and Coronial Inquests from the Stamford Mercury (1801-1842)	ACUR@ANU – 17 September 2021
2021	Juliane Samara	Palliative care needs rounds in residential care settings: changing government policy and funding in Australia	OPCC 7 – 10 September 2021
2021	James Connor, Louise Mayo	Piloting 'Leo's Place' – a world's first, non-clinical, palliative care respite house	OPCC 7 – 10 September 2021
2021	Tricia O'Connor	Holistic care needs of the imminently dying: a systematic review	CHARM 27 – 30 July 2021
2021	Marguerite Kelly	Impacts of natural disasters including epidemics on end-of-life care: findings from a systematic review	CHARM 27 – 30 July 2021
2021	Yansong Huang	So, what does dying look like in Canberra Health Services?	CHARM 27 – 30 July 2021
2021	Paresh Dawda, Nicole McDerby	Opioid stewardship in Australian residential aged care facilities: a collaborative approach to quality opioid medication use https://www.nps.org.au/nms2021	National Medicines Symposium 2021