



Calvary

Palliative and End of Life Care
Research Institute

Research **SNAPSHOT**

DECEMBER 2017

Translating evidence into action to improve outcomes for palliative care patients and their carers

Palliative care patients and their families deserve the best possible care that we can give them.

This commitment to delivering the best possible care underpins the establishment of the Calvary Palliative and End of Life Care Research Institute. Projects being undertaken at the Institute address the whole arc of the palliative care experience for both patients and their families and friends.

In order to offer the highest quality and safest palliative care we are committed to evidence-based approaches in everything we do. Collaborations play a vital role in undertaking research and then translating the results into practice.

The Calvary palliative care network in the Institute cares for over 1,200 patients every year. In keeping with the holistic mission of palliative care we undertake research projects to improve their physical symptoms as well as their psycho-social and spiritual experience. Research undertaken by the Institute has real-world focus addressing issues and concerns in all the different settings that our patients and their families find themselves. Patients' experiences and outcomes are our central concern and we involve them in planning and undertaking our research.



Institute Chair Professor Liz Lobb comes to the role with 21 years experience in psycho-oncology and palliative care research. She has established national and international research collaborations and pursued independent multi-disciplinary clinical collaborations in oncology, haematology, cancer genetics and palliative care. She was given the Palliative Care NSW Award for her contribution to palliative care research in 2010.

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A Collaborative Network Grant (CRN) from the Australian Government through the University of Notre Dame to Professor Liz Lobb (Calvary Kogarah) and Professor Jane Phillips (University of Technology) provided funding to appoint two research academics and four PhD students. The studies they initiated have resulted in a number of high quality journal publications, invited conference presentations and awards. Through the CRN, there has been a strong relationship with clinical partners such as medical consultants and allied health professionals which has brought together the research and clinical work and facilitated translational outcomes. These project have

been in collaboration with Curtin University, the Garvan Institute, St Vincent's Hospital, Calvary Health Care Kogarah, Greenwich Hospital and a number of other health services in NSW. The project has six main focuses:



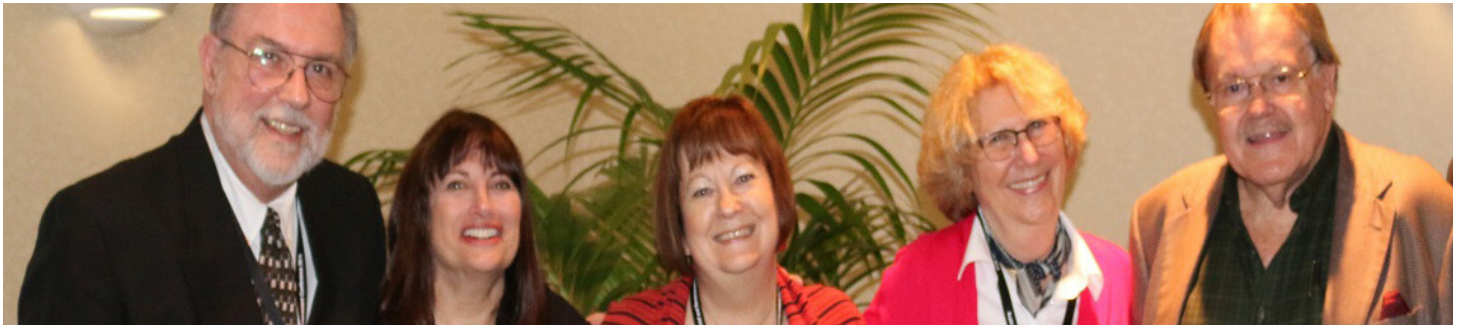
The PERSICOPE Project - to explore clinicians' perceptions and patient impact of medication errors with opioids in adult specialist palliative care inpatient services and identify strategies to support safe opioid delivery processes in palliative care. This project was awarded the Ian O'Rourke Scholarship in Patient Safety, which facilitated collaboration with the Institute for Safe Medication Practices (ISMP) in the US.



The DigiTech Pain Project- to evaluate the role of digital health technologies in facilitating older people's pain self-management capabilities. Studies within this project have been orally presented in two conferences: Palliative Care Nurses Australia Conference (2016), and Sigma Theta Tau International Conference (2016).

The Mapping Grief Study - The experiences of care, grief and adjustment for bereaved family members. This study aims to investigate grief after expected and unexpected death involving longitudinal studies with participants

at multiple sites. This study was awarded 3 oral presentations at the International Grief & Bereavement in Contemporary Society Conference in Lisbon in July 2017; and an oral presentation at the National Palliative Care Conference in Adelaide in September 2017



The Sleep in Caregivers Project - to improve the sleep of caregivers of community palliative care patients. This PhD study was a poster presentation at the Sleep Down Under Conference in Adelaide in October 2016.

The VOICE Study - to investigate the role of family meetings in palliative care. A pilot for this study was an invited presentation at the Catholic Health Research Forum in Sydney in June 2017 and the Asia Pacific Hospice Conference in Singapore in July 2017.

Ambulance Care Plans - A study of the impact of Ambulance Palliative Care Plans on patterns of care, treatment and hospitalisation, and on palliative care patients' and caregivers' experiences of crisis.

This study aims to explore long term outcomes of Ambulance Care Plans on palliative care services. This study, in collaboration with Ambulance Services NSW has tracked 100 patients thorough the acute care health system noting their access to Ambulance Care Plans and hospital admissions. A health economist from Griffith University is collaborating on the study.



Integrating specialist palliative care into residential care for older people: a stepped wedge trial (INSPIRED trial)

This study is implementing and evaluating a new model of care integrating specialist palliative care into aged care. We are using a stepped wedge randomised control trial design to implement the new model with 12 facilities (over 1200 residents) in care homes in the ACT. The primary outcome is reducing time spent in acute care, with secondary outcomes focused on improving staff knowledge and confidence in palliative care, better controlled symptoms of people at end of life, increasing people's ability to die in their preferred place. The study is highly likely to lead to a change in practice across the Territory. There is already uptake of the model interstate. This work has been presented at a Commonwealth Ministerial Think Tank with Ken Wyatt.

Preventable presentations at Emergency Departments by patients receiving specialist out-patient palliative care in the Australian Capital Territory

This study in the Australian Capital Territory aims to investigate why palliative care patients present to Emergency Departments (EDs) and how this might be avoided. Multiple ED visits can

be considered markers of sub-optimal care and can cause distress to patients and carers. Studies of nursing home residents' use of EDs report high rates of admission, despite easy access to medical care, notably for pneumonia and urinary tract infections. This study seeks to understand why patients in receipt of specialist palliative care out-patient (SPC) services attend the ED and to develop alternate care pathways. This is a mixed method study, with retrospective case-note audit of medical records combined with prospective qualitative data from clinician and patients. The study is highly likely to lead to a change in practice across the Territory in reducing preventable presentations to the ED



A re-assessment of meaning-making in patients with early-diagnosed



incurable cancer

Patients diagnosed with incurable cancer may experience significant existential distress, including challenges to spiritual beliefs, denial, grief over multiple losses, and difficulty planning life in the context of uncertainty about the future. This study sought to understand how patients made sense of their diagnosis, and to describe the relationship between religion/spirituality, meaning-making and coping for this patient population. In this study 27 patients were recruited from the oncology and palliative care service at three metropolitan hospitals.

A semi-structured face-to-face interview was conducted and the interviews were audio-taped and transcribed verbatim. Participants did not express a need to make sense of their diagnosis, but derived meaning from their heightened awareness of the importance of connection to their everyday life activities. Many did not ascribe to a particular religious belief; rather, they relied on a personal spirituality or philosophy to cope. There was an acceptance of the future, in the context of living in the present, and many reported a good quality of life. Importance was placed on their doctor keeping up with technology, giving advice and guidance, being honest, and being confident and positive.

We concluded that participants in this study had early incurable cancer but finding meaning, and making sense of their current situation, was not a priority. Of importance was maintaining connections to family and to the wider community. Our patients relied on their clinician to manage

disease progression, maintain hope and remain positive as a strategy for coping with uncertainty when facing incurable disease.

Living with advanced cancer and an uncertain disease trajectory: An emerging patient population in palliative care?

This study explored how patients diagnosed with advanced cancer cope with an uncertain disease trajectory. Twenty seven patients with advanced cancer and with a prognosis of 12 months or more were recruited from the medical/radiation oncology and palliative care service at three metropolitan hospitals. We conducted semi-structured face-to-face interview which were audio-taped and transcribed verbatim. The results indicate that patients cope by avoidance, remaining positive, maintaining as normal a life as possible, minimizing the impact of the disease on their daily lives; comparing themselves favorably to others in a similar situation; and focusing on the outcome of treatment to control disease progression. Most did not wish to discuss prognosis or have detailed information on disease progression. Participants in this study represent an emerging cancer patient population who are receiving palliative therapies. Whilst they have incurable cancer, they self-report as clinically well, they describe a good quality of life and the trajectory of their disease, while unpredictable may extend over many months to years. Our study suggests that a flexible model of care is needed to support the needs of people who may still be receiving some form of chemotherapy and/or radiotherapy, and remain well. This model may need to take more of an intermittent approach, that is, as required for specific symptom management, rather than patients being linked continuously to a palliative care service for long periods of time.



Identifying barriers to access to palliative care services at Calvary Health Care Kogarah by CALD communities

At Calvary Health Care Kogarah China, Greece, Italy and Macedonia are the top 4 countries of birth for our CALD patient population. However, we do not have a clear picture of this client group. This study aimed to understand the perceived barriers to access to palliative care by CALD patients and their families. Four focus groups were held with palliative care in-patient and community nursing staff and allied health staff. The following themes were identified: language around the disease; building trust; family members living overseas; expectations of families and communities; the role of families in decision-making, managing care, discussing diagnosis and prognosis and the appropriateness of interpreter usage. Language around the disease, in particular use of the word cancer, was noted to be a challenge especially when family members wanted to protect the patient and not have diagnosis or prognosis discussed. The importance of building trust and rapport and of establishing a relationship before any real communication could occur was highlighted. This was couched in the knowledge that many cultural groups have come from

repressive regimes and trust in institutions or authority was lacking. Discussions with family members who lived overseas on whether to come to the bedside were difficult especially when the diagnosis or prognosis had not been communicated. Staff commented on the family's strong expectations of care, but also of the community's expectation. This was especially noted in terms of providing care, be it in the home, in hospital, or having the patient transferred to a nursing home. Families felt keenly the censure of family and community if expectations around care were not fulfilled. Participants also highlighted that interpreter use was more nuanced than lack of access and related to the issue of family/group decision making in some cultures rather than individual autonomy. Focus groups with staff provided a nuanced insight to communication issues. Participants prefaced their comments that dying is difficult for everyone, regardless of culture. They highlighted not only the importance of communication, but the difficulty when information could not be obtained which was considered important to patient and family care and support.

Upfront Family Meetings for In-patient Palliative Care Services



Family meetings in palliative care can enhance communication with family members and identify unmet needs. However, the patient's voice is rarely heard. This quality improvement project investigated a patient-centered family meeting, which is a different approach to palliative care family meetings, to determine its feasibility and acceptability for patients, family and the palliative care team. Newly admitted patients to Calvary Health Care Kogarah's specialist palliative care unit were invited to ask anyone they wished to join them in a meeting with the palliative care team and to identify issues they wished to discuss. Consenting inpatients were interviewed shortly after admission; participated in a family meeting and re-interviewed 2-3 days after the meeting. Family members provided feedback at the end of the meeting.

A focus group was held with staff for feedback on this new approach for family meetings. Meetings were observed, documented and thematically analysed. Thirty one newly admitted patients were approached to participate in a family meeting. 84% had family meetings and the majority (96%) was attended by the patient. Thematic analysis revealed 69% of patient-centered meetings raised end-of-life concerns and 54% were "family-focused". The study concluded that patient-centered family meetings in palliative care were shown to be feasible and acceptable for staff, patients and family members. Many patients and families spontaneously shared end-of-life concerns.



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