



Palliative Care NSW  
Biennial State Conference 2016  
**13-15 October, Broken Hill**

# Book of Abstracts

Oral Presentation Abstracts

Poster Abstracts

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# Oral Presentations

## Friday - Abstracts 1 – Morning concurrent sessions

### **Listen, Acknowledge, Respond: addressing the mental health treatment gap.**

[Friday 11:00, Abstracts 1]

**Julianne Whyte**, CEO Amaranth Foundation, 23 Riesling Street, Corowa, 2646, 0408 388 533,  
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Sadness, social withdrawal, depression, loss of hope; if a healthy person experiences any of these feelings, the health care system has well established processes and services to treat them. Why then do we accept this as 'normal' and 'to be expected' for those facing their last days. Our research shows mental illness in the terminally ill is underdiagnosed and undertreated – it's a "Treatment Gap".

Our previous research trialled a trans-disciplinary social work approach to palliative care that integrated mental health screening and treatment. The impact on clinical and emotional outcomes for patients, their family and caregivers was then evaluated using qualitative, informal, semi-structured interviews with patients, carers, family members and service providers. The trial found symptom management typically takes precedence in palliative care, with MH referrals occurring late in the disease trajectory when they are acute or crisis driven, missing an opportunity to enhance quality of life while there was still life to be lived. Participants reported they valued the psychosocial support provided, their distress had been greatly reduced, and their coping in the bereavement period enhanced.

While research shows the mental wellbeing of palliative care patients significantly impacts their quality of life while dying, addressing these needs takes specialist skills: the "pat on the back" approach is not enough and healthcare workers admit they need more guidance. These findings also informed the current Commonwealth-funded Listen Acknowledge Respond project which will upskill healthcare professionals to screen, assess and treat MH in the last 400 days of life, and measure the impact of this.

Through sharing research outcomes (both completed and research in progress) and the stories of patients, their family and caregivers, this presentation will demonstrate that trans-disciplinary teams with specialist knowledge in adapting traditional mental health interventions provide better holistic care and deliver better outcomes for patients and their family and caregivers.

### **“Dying is difficult in any language”: The views of palliative care nurses on barriers to access to palliative care for patients from Culturally and Linguistically Diverse (CALD) backgrounds.** [Friday 11:20, Abstracts 1]

**Lobb, EA**, Calvary Health Care Kogarah, School of Medicine, the University of Notre Dame Sydney, Cunningham Centre for Palliative Care, Darlinghurst, Sydney.

Other authors: Jerzmanowska N; Ellis J; Green M

Background: At Calvary Health Care Kogarah (CHCK) 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.

Aims: This study aimed to understand the perceived barriers to access to palliative care by CALD patients and their families.

Methods: Four focus groups were held with palliative care in-patient and community nursing staff and allied health staff (n = 29).

Results: 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 building 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.

Conclusion: 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.

### **A Changing Landscape? - A Snapshot of Palliative Care Advanced Trainees and Intentions toward rural practice in Australia. [Friday 11:40, Abstracts 1]**

**Dr Alison Blight**, Advanced Trainee in Palliative Medicine & Provisional Fellow in Pain Medicine, Newcastle NSW

Other authors: Dr Richard Lawrence

This study used an online survey between November 2015 to February 2016 to explore factors that may influence intention towards future "Rural" practice amongst Australian Advanced Trainees (ATs) in Palliative Medicine. Using the ANZSPM member database, individual email invitations were sent in November 2015 and January 2016. 25 of approximately 88 ATs responded (28.5%).

Two thirds of the respondents were female, and 52% had entered training via the GP pathway. 64% were in their 3<sup>rd</sup> (or more) year of training, and 20% aged older than 45 years.

Of all respondents, 56% reported having lived in rural Australia, 24% had undertaken rural placements in Palliative Care, and 32% had visited rural areas with Palliative Care Outreach services. Hence 44% of respondents had some rural palliative care training experience.

In 2001 the Australian Government introduced the Rural Medical Bonded Scholarship (MRBS) for medical students as a strategy to address medical shortages in rural Australia. Scholarship holders are required to commence rural practice within 1 year of obtaining Fellowship, and remain in rural practice for up to 6 years. 2 trainees (8%) acknowledged being under this scheme.

On intentions towards rural practice of Palliative Care within 5 years of gaining Fellowship, 64% of respondents indicated "No", 12% indicated they intended "Yes" to work rurally (including MRBS holders) and a further 24% were "Undecided", inferring that up to 36% of candidates in this cohort would consider practicing Palliative Medicine in a rural area in the future (i.e. "Yes" + "Undecided").

"No" intentioned and "Undecided" respondents were invited to give reasons. From these 22 respondents, 59% gave some indication of specific perceived barriers, including partner, family, individual or professional/work related concerns.

This study suggests that up to a third of ATs in Palliative Care would consider rural practice in the future, and that rural palliative care training experience (particularly Outreach visits) may influence

intentions towards rural practice. Barriers identified included family, individual and professional concerns. The study also demonstrates an effect of the MRBS scheme on the future rural palliative care workforce.

## **Carter v.Canada: Perspectives on Physician Assisted Dying. [Friday 12:00, Abstracts 1]**

**Linda Ora**, Palliative Care Clinical Nurse Consultant, Nepean Blue Mountains Local Health District, [linda.ora@health.nsw.gov.au](mailto:linda.ora@health.nsw.gov.au), 0412 263 726

In a momentous decision released in February 2015, the Supreme Court of Canada ruled that the Canadian Criminal Code prohibitions on voluntary euthanasia and assisted suicide violate the Canadian Charter of Rights and Freedoms. As a result, physician-assisted death has now become available in Canada.

While this could be one of the most important decisions ever rendered in Canadian history, very little is known about the Carter decision in Australia. As leading nations in palliative care research, integrated care and best practice models, it is important that Australians working in palliative care reflect on the legalisation of physician assisted death in Canada - a decision which will irrevocably change the landscape of dying.<sup>1</sup>

The aim of this presentation is to highlight the Carter decision and to consider the implications for care of the dying; and to engage the audience in a balanced discussion on practical and ethical perspectives on the issue of a physician assisted death. The information to be presented has been constructed through the author's recent observation and participation at various health and palliative care forums in Canada; and through the exploration of the documented commentary of academics, physicians and ethicists on the topic.

This presentation clearly aligns with the Palliative Care NSW State Conference theme of Transforming the Landscape of Dying and aims to:

- Outline the Supreme Court decision and the main aspects of the newly developed legislation supporting physician assisted dying in Canada;
- Explore some of the expert commentary regarding the main arguments for and against physician assisted dying;
- Detail the proposed safeguards to protect vulnerable individuals; and
- Highlight the official position of the Canadian palliative care peak bodies on the issue.

This presentation was recently delivered at the 27th Annual Nepean Blue Mountains Supportive and Palliative Care Conference and received excellent feedback. While the focus of the presentation is on the Canadian context, the conversation about physician assisted dying will increase awareness, understanding, and convey the complexity of the issue for the Australian audience.

[1] [Sommerville, M. \(2016\) Ethics Colloquium, Carter vs Canada: Physician Assisted Suicide in Canada Today - Part 2 Viewed 23 March, 2016](#)

## Friday - Abstracts 2 – Morning concurrent sessions

### **Carer experiences of palliative care: informing and transforming practice through an exploration of carer narratives. [Friday 11:00, Abstracts 2]**

**Kristin Bindley** (Bereavement Counsellor), Mt Druitt Supportive and Palliative Care Unit, Supportive and Palliative Medicine, Western Sydney Local Health District

Other authors: Suzanne Coller, Trish Dalgleish, Pamela Kalkandis, Anne May, Wendy Pavlek

Following participation in the National Standards Accreditation Program in 2011 and 2013, our interdisciplinary team reflected on findings from two quantitative survey processes undertaken using the Family Evaluation of Palliative Care. Discussion considered approaches to future evaluation that would yield richer detail about the experiences of bereaved carers of people with a life limiting illness; from their first contact with our palliative care service, throughout the illness trajectory to the time of death and into bereavement.

With a desire to engage bereaved carers directly in service evaluation and to learn from their unique narratives, our team commenced a qualitative study (analysis phase in progress at time of submission). Influenced by principles of narrative methodology, the study sought to interview bereaved carers using an open-ended, in depth interview framework designed to facilitate holistic exploration of the physical, social, emotional, psychological and spiritual dimensions of the carer's experience of palliative care. Thirteen bereaved carers were recruited three to six months following the death of a palliative care patient known to Mt Druitt Supportive and Palliative Care Unit. An undergraduate Social Work Honours student interviewed participants, with co-supervision from two members of the research team. The process of data immersion involved members of the research team transcribing and coding interview transcripts collaboratively.

This paper will report on the thematic analysis of the interview transcripts, undertaken with the aid of thematic networks as an analytic tool (Attride-Stirling, 2001, Braun and Clarke, 2008). Approaches to the effective dissemination of findings intended to inform practice will be discussed. Underpinned by specific ethical considerations relevant to bereavement research (Bentley and O'Connor, 2015, Beck and Konnert, 2007, Buckle et al, 2010, Sekelja, 2009), this study values the experiences of bereaved carers and endeavours to honour the potential for their voices to transform care.

### **Are Rural and Remote Patients, Families and Caregivers Needs in Life-Limiting Illness Different from those of Urban Dwellers? A Narrative Synthesis of the Evidence. [Friday 11:20, Abstracts 2]**

**Dr Sue Kirby** [sue.kirby@health.nsw.gov.au](mailto:sue.kirby@health.nsw.gov.au); Senior Research Fellow; Broken Hill University Department of Rural Health, the University of Sydney; 08 8080 1287.

Other authors: Veronica Barlow, Dr Emily Saurman, Prof David Lyle, Ass Prof Megan Passey, Prof David Currow.

Objective: This review aimed to assess the evidence to answer the question whether palliative end-of-life care needs of patients and caregivers in rural and remote communities differs from those of urban dwellers.

Design: Peer-reviewed papers from 1996 to the present dealing with the experience of rural and remote patients and caregivers at the end-of-life compared to that of urban people were extracted for narrative synthesis.

Main outcome measure: The experience of patients and caregivers at the end-of-life in rural and remote locations compared to those of urban dwellers.

Result: The 8 papers included showed that palliative needs rural and remote residents are related to context. Diagnosis and treatment are less well managed in rural areas. Rural differences include:

people are more accepting of death and less likely to intervene to delay death; caregivers tend to be younger and include friends as well as family and local support networks are important.

Conclusion: Rural and remote end-of-life needs are shaped by reduced access and availability of services which has a negative influence on outcomes. This is counterbalanced by an acceptance of death and local support networks. Well-designed longitudinal studies with samples comprised of rural and urban residents for comparison, are required to monitor how end-of-life need might change with the approach of death. Clinicians, health services and policy makers need a better understanding of rural attitudes and of how rural community networks mobilise to support end-of-life care in their rural and remote communities.

### **Sleep disturbances in caregivers of patients with advanced cancer: A systematic review. [Friday 11:40, Abstracts 2]**

Ms **Kirstin F Maltby**, University of Notre Dame Australia, 160 Oxford St, Darlinghurst 2010, Australia. [Kirstin.maltby1@my.nd.edu.au](mailto:Kirstin.maltby1@my.nd.edu.au), 0433778438

Other authors: A/Prof Christine Sanderson; Prof Elizabeth A Lobb; Prof Jane L Phillips.

Background: Sleep disturbances are a common issue found in many caregiving groups.

Aim: To determine the sleep patterns of caregivers of patients with advanced cancer.

Design: A systematic review of studies reporting empirical sleep data was undertaken in 2015 in accordance with the PRISMA Statement.

Data Sources: A total of eight electronic databases were searched with no date restrictions imposed. Bibliographies of included studies were searched. Search terms included: sleep, insomnia, sleep disturbance, circadian rhythm, caregiver, carer, advanced cancer, palliative cancer, and MESH suggestions. Inclusion criteria required studies to be in English and report primary qualitative and/or quantitative research that examined sleep in caregivers of patients with advanced cancer. Unpublished studies, conference papers and dissertations were excluded.

Results: Overall ten studies met the inclusion criteria and were included in the review. Two major findings emerged from the data synthesis. First, at least 72% of caregivers reported moderate-severe sleep disturbance as measured through the Pittsburgh Sleep Quality Index. Second, objective measure of caregivers sleep identified that some caregivers experienced up to a 44% reduction in their total sleep time compared to the recommended 8 hours.

Conclusions: A majority of caregivers of patients with advanced cancer sleep have moderate-severe sleep disturbances with reductions in total sleep time. Additional studies need to explore the predisposing and perpetuating factors of these sleep disturbances so as to find ways to optimize sleep.

### **What can we learn from family caregivers about hope during a home death? [Friday 12:00, Abstracts 2]**

**Matra Robertson**, PhD, MSW

Other authors: Rod MacLeod, Wendy Duggleby.

Introduction: In palliative care home deaths are considered as a desirable outcome. Palliative care services focus on relieving the spiritual, psychological and physical suffering of people who are dying and support their family caregivers. One aspect of palliative care little studied, are the potential spiritual, psychological and physical factors that support hope during a home death.

Objectives: To report on preliminary data drawn from a study in progress on family caregivers' experiences of hope during a home death.

Approach: A preliminary analysis of interviews is reviewed emphasising data from family caregiver's interviews. This is presented alongside the spiritual, psychological and physical factors that support hope during a home death and what in health care was reported as averse to hope.

Practice implications: Multidimensional factors that support the hopes of people who are dying and their family caregivers are not well recognized in palliative care. Understanding the experiences of hope during a home death provides direction for interventions in clinical practice that are informed by people who are dying and their family caregivers. We have the assumption that clinical interventions conceptualized by people who are dying and their families, develop a better fit. This study provides a rich source of learning to enlarge our understanding of home death and hope.

## **Friday – Abstracts 3 – Afternoon concurrent sessions**

### **Ambulances and palliative care patients. A study of NSW Ambulance Palliative Care Plans, and their impact on patients' experience of crisis. [Friday 13:30, Abstracts 3]**

Sanderson C, Calvary Health Care Kogarah; School of Medicine, the University of Notre Dame Sydney; Cunningham Centre for Palliative Care, Darlinghurst, Sydney.

Other authors: Comans, T; Lobb, EA; Shiels M; Goodwin B; Loudfoot A; Liauw W; Links M; Davis JM; O'Keefe V.

When an ambulance attends a palliative care patient, paramedics have very little discretion about whether or not to treat or transport the person, even when there is an advance directive in place. Unwanted resuscitation and admissions to hospital sometimes occur as a result.

In response to this problem, NSW Ambulance developed Authorised Care Plans for palliative care patients, so that their wishes about resuscitation and treatment and a specific management plan can be recorded and flagged in the ambulance computer system. These Ambulance Palliative Care Plans (APCPs) are increasingly being regarded as an essential part of an advance care plan for community palliative care patients. Since their initial piloting they have not been evaluated in detail.

A study of the implementation of APCPs by a regional palliative care service is being undertaken in the southern sector of SESLHD, involving Calvary Kogarah and two regional teaching hospitals. It will investigate the process of documenting an APCP from the point of view of both patients and clinicians, the triggers and barriers to setting up these plans, and how they are perceived by patients and their families. Interviews will be done with patients and families after any ambulance call out, to understand the effects of having a plan in place. A health economic analysis will also be undertaken, to identify the potential costs and benefits, and particularly to understand and quantify the potential for avoiding unwanted admissions to emergency departments. Future studies are also planned to understand the impact on NSW Ambulance of greater uptake of these plans, and to understand the needs and concerns of paramedics who in future may become increasingly involved in providing care for palliative care patients in crisis.

## **Implementing the Palliative Care After Hours Helpline to support Palliative Care patients, their carers and families. [Friday 13:50, Abstracts 3]**

Ms **Janelle Painter**, Healthdirect Australia, Level 19, 133 Castlereagh Street, Sydney 2000, [Janelle.Painter@healthdirect.org.au](mailto:Janelle.Painter@healthdirect.org.au) Phone: (02) 9263 9132; 0403 846 033

Other authors: Mary Byrne; Louise Farrell.

The availability of appropriate specialist and primary community services, particularly in rural areas, and after-hours Palliative Care services, often influences whether patients' wishes to be cared for and to die at home can be fulfilled.

The Palliative Care After Hours Helpline (Helpline) is helping strengthen holistic care of people dying in New South Wales (NSW) by providing professional advice and support for people with a life-limiting condition who prefer to be cared for at home as they approach the end of their life and, where appropriate, preventing people from having to go to hospital.

The Helpline is a free NSW Health service for NSW palliative care patients, their carers, families and health professionals. The Helpline provides more choice about care patients can receive at home by connecting them to additional professional advice and support as they approach and reach the end of their lives. This assists health professionals to enable patients to remain at home, and reduces unnecessary after-hours visits and presentations at emergency departments. The service commenced in March 2016 and is available during the evenings, on weekends and public holidays.

The Helpline is designed to be complementary to specialist palliative care and other services provided during the day, and other existing after-hours palliative care arrangements. Continuity of care for the patient is ensured by providing a call summary to the patient's specified principal healthcare provider.

Calls to the Helpline are managed by registered nurses with training in palliative care who respond to callers using palliative care symptom assessment and management protocols. More complex and sensitive matters are managed by palliative care nurse specialists with expert knowledge, skills and experience.

The quality and clinical safety of the service is managed under the Healthdirect Australia Clinical Governance Framework with input from metropolitan, regional and rural palliative care clinicians, NSW Health, and the service provider. The aggregated data from calls received will demonstrate how linking with existing health services: NSW Ambulance and the NSW Paediatric Palliative Care Programme enables patient-centred palliative care and ensures that appropriate professional support and advice is provided and personalised to the caller for all NSW demographics.

## **POMSNAME: A tool to promote quality assessment in palliative care. [Friday 14:10, Abstracts 3]**

**Ms Kerrie Womsley**, Clinical Nurse Consultant Palliative Care, Hoxton Park Community Health Centre, [Kerrie.Womsley@sswahs.nsw.gov.au](mailto:Kerrie.Womsley@sswahs.nsw.gov.au) 02 9827 2222.

Other authors: Dr Ann Dadich; Mr Michael Hodgins; Noemir Gonzalez; Valerie Weller; Cindy Van.

With the introduction of electronic medical records in health services, documentation has never been more scrutinised. This is because accurate and in-depth clinical documentation is deemed vital for consistent quality care. This is particularly important in palliative care where multiple symptoms need to be addressed within a single clinical encounter. To improve the accuracy and comprehensiveness of palliative care documentation in community health, the acronym, POMSNAME, was devised as a memory aide to prompt the assessment of: Pain, Orientation and Oral, Mobility, Social, Nausea and vomiting, Appetite, Medication, and Elimination. Accordingly, the aim of this quality improvement exercise, which remains in progress, is to determine the effectiveness of the POMSNAME acronym to improve palliative care documentation and subsequently guide assessment in a community health centre.

Palliative care case-notes were audited one month before (n=56) and palliative care case-notes were audited one month after (n=48) the acronym was introduced to 13 community health nurses. Case-notes were audited for the documentation of each item before and after one-month.

The results from this audit suggest that reference to 8 of the 9 POMSNAME items in case-notes increased over the one-month period. The documentation of Orientation (23.4%), Mobility (27.7%) and Social issues (39.3%) saw the greatest increase, while Medication (-2.1%) was the only item to decrease.

The improvement of palliative care documentation in 8 of 9 items demonstrates the potential of the POMSNAME acronym as a memory aide. Structuring the documentation in this way guided a holistic assessment, particularly among clinicians with limited palliative care experience. Further research is needed to determine whether and how other domains warrant inclusion, including (but not limited to) respiratory issues, sexual health, and spirituality.

## Friday - Abstracts 4 – Afternoon concurrent sessions

### Transforming the Landscape of Dying – Establishing a new Palliative Care Unit (PCU). [Friday 13:30, Abstracts 4]

**Mary Trotter** CNE Palliative Care, Wauchope District Memorial Hospital,  
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Other authors: Susan Carter; Linda Varady

The Palliative Care service Overview 2008-2009 demographic and epidemiological data identified population trends that were likely to increase the demand for palliative and end-of-life care within the North Coast Area Health Service (NCAHS). In response to the Department of Health Garling review in Nov 2008 and in alignment with NCAHS strategic planning it was proposed to establish 6 dedicated Palliative Care beds within Wauchope District Memorial Hospital (WDMH) to provide a group of services in the continuum of care required for patients experiencing a life-limiting illness within the Hastings Macleay Clinical Network (HMCN).

Initial in-patient palliative care services commenced in 2010 with six beds allocated within the main hospital where the dedicated Palliative Care multidisciplinary team cared for patients in challenging conditions. The need to “Transform the Landscape of Dying” was immediately evident and with support from the team, management, community and local Palliative Care services planning began to remodel the service and accommodate patients requiring palliative care and their families in an appropriate and supportive environment.

Building commenced in late 2012 and the 8 bed specialty sub-acute PCU opened in July 2014.

For patient’s end-of-life preferences and needs to be fulfilled, all members of the interdisciplinary team including the patient, family and carer are required to work together effectively. Enhanced collaboration and teamwork across boundaries was essential in promoting improvement of the patient experience and continuity of care for the palliative patients across the HMCN.

The establishment of firm connections between the PCU team, the Port Macquarie Base Hospital (PMBH) after-hours medical registrars, a variety of allied health and community support services and volunteers ensures a consistent and seamless palliative care service across settings responsive to the needs of patients and their carers.

Consistent improvement in patient outcomes and experience has been demonstrated in Palliative Care Outcome Collaboration (PCOC) data, reduced need for transfer of patients at end-of-life, staff and patient survey data and individual patient stories collected. The evaluation of the unit will continue

with ongoing feedback from regular staff and patient surveys and patient stories collected for our Essentials of Care and Quality Improvement Plans.

### **Good Relationships- Managing the Transition from the ICU to General Ward for End of Life Care. [Friday 13:50, Abstracts 4]**

**Linda Magann** CNC Palliative Care, St George Hospital, [Linda.Magann@health.nsw.gov.au](mailto:Linda.Magann@health.nsw.gov.au), Ph: (02) 9113 1111 page 502

Other authors: Sarah Jones; Abby Peacock–Smith; Simone Moran.

Background: Managing transition from the Intensive Care Unit (ICU) to a ward bed for end of life care is often fraught with challenges. Ensuring the transition is seamless requires withdrawal of inappropriate interventions, prescribing of appropriate medications for ongoing symptom management and ongoing supportive communication for patients and families. At St George Hospital in Sydney in 2014, 40 patients were referred to the Palliative Care team for end of life care from ICU. 21 died in the ICU, 11 in a ward bed and 7 were discharged.

Aim: To develop and implement a tool to operationalise seamless transfer of patients to the wards for end of life care

Methods: Senior nursing staff from ICU and Palliative Care collaborated to develop an Intensive Care Clinical Business Rule to incorporate the End of Life Care Plan (EOLCP) used hospital wide. Parameters of care as set out in the St George EOLCP were used to alter and reflect the complex nature of ICU patients as they transition from active to conservative care

Results: The completed tool has implemented and evaluation has commenced

Discussion: This process relied on the unique relationship between palliative care and ICU staff

Conclusion: Embedding a change in culture within the ICU to include palliative care takes time and effective communication. Better outcomes for patients and their families is the aim and empowering medical and nursing staff in the ICU to confidently provide good end of life care is paramount to achieving this.

### **Creatively transforming care within the acute hospital setting using the arts to connect to self and others. [Friday 14:10, Abstracts 4]**

**Katrina Armour**, Nurse Unit Manager, Royal Prince Alfred Hospital, Camperdown, Palliative Care, Aged Care and Immunology

Other authors: Josephine Ferrar; Judith McMahon; Joan Ryan

BACKGROUND: Nurses working in Palliative Care or exposed to its ethos will be challenged individually and collectively by disparities in the provision of Palliative Care and the landscape of dying within the acute hospital environment. Collocation of hospital based palliative care patients with other specialities on a shared model of care can cause tension across such an interface. Nurses confront suffering routinely whenever or wherever they are caring for dying patients and are often seen as the caretakers of suffering. As such suffering manifests directly on the physical, emotional, psychological and existential dimensions of care that often defies reduction to a clinical pathway or conceptual framework. What then are the challenges of transforming the landscape of dying when nurses are faced with ethical and moral dilemmas of competing goals of care when death perhaps is not the most feared cause of all suffering?

AIM: To recognise the legitimacy of such emotionally and ethically charged work within a shared model of care within acute hospitals; Using the arts as a conduit to reflect.

METHOD: Thematic analysis of qualitative and quantitative data from nursing staff on a newly configured ward accommodating Palliative Care with two other specialities.

**RESULTS:** Nurses reported high levels of workplace frustration, uncertainty and confusion. Responses ranged from anger to feeling helpless and overwhelmed. However, using the arts created a positive sense of wellbeing, happiness and increased connectedness to the person and core values of care. Humour, positivity and a sense of possibility also noted.

**CONCLUSION:** Collocation of hospital based Palliative Care patients provides opportunity for nurses to learn broadly. It is vital in response to an aging population with chronic and complex care needs and the evolution of more collaborative models transforming Palliative Care. This report asserts the importance of reflective practise and creativity in approaching less conventional models of Palliative Care.

## **Abstracts 5 – Friday – Afternoon concurrent sessions**

### **What are the barriers to providing good end of life care for patients from Culturally and Linguistically Diverse (CALD) communities? [Friday 13:30, Abstracts 5]**

**Lobb, EA,** Calvary Health Care Kogarah, School of Medicine, the University of Notre Dame Sydney, Cunningham Centre for Palliative Care, Darlinghurst, Sydney.

Other authors: Jerzmanowska N; Ellis J; Green M

**Background:** While there has been significant development of specialist palliative care services within NSW there is little information available at a patient level that describes how palliative care services impacts on the type and quality of care provided to CALD patients.

**Aims:** This study aimed to describe and understand key elements in the CALD patient's journey in a Specialist Palliative Care Service to: a) explore their clinical experiences; b) identify elements of best practice currently occurring and c) identify opportunities for improvement.

**Methods:** The medical records of 100 consecutive deceased CALD patients were audited over a 12 month period.

**Results:** The major barrier to good palliative care was access to a professional interpreter. Over half (55%) were identified as requiring an interpreter on admission, however, professional interpreting services were utilised for only 9%. Over a third of patients (37%) had family members interpret and 11% used staff. Family members' psycho-social distress in the last 7 days of the patient's life was reported to be higher than patient distress. Almost half (49%) of families were documented as interacting with a social worker and a third of patients. Other barriers to care recorded were language, concern of family members over the patient not eating and bringing in food from home and in some case force-feeding the patient, family reluctance for medication administration, and in some cases the large numbers of visitors. Family reluctance for the patients to be told their diagnosis or prognosis and indeed that they were in a palliative care unit was also noted.

**Conclusion:** This data highlights barriers to good palliative care for patients with a CALD background. The challenges of dealing with a life limiting illness and facing end of life care, the complexity of treatment, navigating services and understanding medical terminology is challenging for most. Of particular significance for CALD patients and families was the added barrier of language. Strategies to minimise these barriers, in particular access to interpreters; education of staff in the use of interpreters and understanding the concerns of this particular patient group is central to providing good end of life care and support.

## **Cancer pain management needs and perspectives of patients from Chinese backgrounds: a systematic review of the Chinese and English literatures.**

[Friday 13:50, Abstracts 5]

Professor Jane Phillips, Centre for Cardiovascular and Chronic Care, Faculty of Health, University of Technology Sydney (UTS), [Jane.Phillips@uts.edu.au](mailto:Jane.Phillips@uts.edu.au), +61 2 9514 4822 or +61 2 9514 4862.

Other authors: Xiangfeng Xu; Tim Lockett; Alex Yueping Wang; Melanie Lovell.

**Background:** More than half of all cancer patients experience unrelieved pain. Cultural beliefs have potential to influence pain-related behaviours and management. People from Chinese background forms one of the largest culturally and linguistically diverse group in Australia. Understanding of Chinese background cancer patients' health perspectives and provide culturally sensitive care is essential to ensure effective pain control.

**Aims:** To explore pain management perspectives and needs of cancer patients from Chinese backgrounds as well as barriers and facilitators for optimal cancer pain management.

**Methods:** A systematic review of peer reviewed articles published in English or Chinese journals (January 1990 to August 2015) about self-reported pain management perspectives of adult cancer patients from Chinese backgrounds.

**Results:** Of 3,904 identified articles, 23 (English n=15 and Chinese n=8) met the inclusion criteria. These articles reported primary data from 19 studies involving cancer patients (n=6,008) from Hong Kong, Taiwan and mainland China. Nearly all patients (83.5% inpatients and 100% outpatients) experienced some level of unrelieved cancer pain. A reluctance reporting pain and/or undertake analgesics were the main sources of unrelieved pain, which was linked to patient (e.g. pain endurance belief), family (e.g. side-effective concerns), health provider (e.g. poor communication), and system (e.g. lack of access to analgesics) related barriers. Very few studies reported the patients' traditional Chinese mediation needs and no studies explored the perspectives of Chinese migrants.

**Discussion/Implications for practice:** The patient related barriers may stem from the beliefs of Taoism/energy, Buddhism and/or Confucianism. Family's pain beliefs have strong influence on the patients' pain control, since the health decisions are made on a family consensus. The cultural beliefs and social concerns often prevent the patients speak out the presence of pain, which has implications for how health professionals engage family members in shared decision-making regarding pain management.

**Conclusion:** While the patient related barriers to pain management are similar in Chinese and Western context, the beliefs underlying these barriers may differ which demands future research to inform culturally sensitive approach and to understand any additional barriers in Chinese migrants.

## **Data drives improvement; Utilising Palliative Care Outcomes Collaboration (PCOC) reports to transform clinical care for patients and families – A case study analysis.** [Friday 14:10, Abstracts 5]

**Gaye Bishop**, PCOC Quality Improvement Facilitator, Palliative Care Outcomes Collaboration | Australian Health Services Research Institute (AHSRI) University of Wollongong

Other authors: Fiorina Mastroianni.

Palliative care services can use PCOC patient outcome reports to review clinical practise and implement strategies for improvement. Data is essential for services to strategically and sustainably transform the clinical care environment. The PCOC assessment framework uses both clinician and patient rated validated assessment tools to assess and manage care. This presentation will use case studies to show how services can use a cycle of continuous assessment reporting and improvement to transform the palliative and end of life care that is provided to patients and families.

The PCOC assessment framework, audit and feedback quality cycle is designed to support palliative care services to measure patient-defined outcomes and to continually strive to improve the care that is offered. "There is a need to ensure that every service is delivering the best possible care to the people who most need that care." Currow et al (2014).

This presentation will demonstrate how services improved outcomes for patients and families by using the PCOC assessment framework to better manage urgent and complex needs. In one case study the service changed response protocols for patients in the unstable phase. This resulted in significant improvements in clinical care, with the service achieving the benchmark for time in unstable phase within 12 months.

A second case study will showcase a service that has overcome a number of challenges to transform the care that is provided in a mixed medical ward within an acute setting. PCOC data and audits were used to implement improved education and assessment strategies which resulted in this service meeting 11/14 benchmarks within two years. These improvement strategies have led to significant and sustained improvement to achieve the benchmark for moderate to severe pain (60%) from 45.2% to 65.9% in the clinician rated tool and improvement from 48.8% to 54.2% in the patient rated tool.

Quality improvement strategies will be included in the discussion and delegates will learn to identify, discuss and reflect on common report findings and outcomes that can be used to drive palliative care improvements and change clinical practise to improve patient care.

## **Saturday – Abstracts 6 – Morning concurrent sessions**

### **The unmet palliative care needs of residents in residential aged care facilities: What a scoping study can tell us about future needs. [Saturday 11:00, Abstracts 6]**

Backhouse, C, Calvary Health Care Kogarah

Other authors: Lobb, EA; Davis, JM; Oehme, J.

**Background:** The majority of Australians living permanently in RACF's are over 85 years, have one or more life threatening conditions, high levels of care needs and are likely to die within months of their admission. Calvary Health Care Kogarah (CHCK) provide a consultative palliative service to the Residential Aged Care Facilities (RACFs) in South Eastern Sydney Local Health District (SESLHD) and are aware that the service does not adequately meet their clients' palliative care needs.

**Aims:** A scoping study was conducted over the period March – June 2016. The aim was to: a) identify gaps in the provision of RACF palliative care services; b) examine patterns of care and referral; c) explore the criteria used by RACFs to identify deteriorating residents; d) and explore general practitioner (GP) response to palliative needs. **Methods:** 60 RACFs were identified and interviews conducted with staff in 47 facilities (78%) either by phone or email.

**Results:** Preliminary data indicates that RACFs identified the main barriers to the provision of palliative care as the inability of Community Palliative Care Team to respond in a timely manner (n=19), a lack of knowledge of palliative care by GP's and a reluctance by them to refer to Specialist Palliative Care services (SPCS) (n=18), and family reluctance to accept a palliative approach to care (n=14). Most facilities interviewed did not use a validated method of detecting the deteriorating client. Many had inaccurate concepts of a "palliative approach" or specialist palliative care. Most felt that "very few" of their residents were on a "palliative approach" although statistics show that 'the majority of Australians living in RACF's are likely to die within months of their admission.

**Conclusions:** These results suggest the need to transform clinical care of the elderly by improving palliative communication with and education of GP's, staff and families. This will build capacity within facilities to manage palliative residents in an efficient and effective manner that has the dying person

comfortable throughout the course of the dying process as well as limiting admissions to emergency departments and improving confidence in care for both clients and families.

**Implementing facilitated case conferencing for people living in aged care with advanced dementia – benefits, barriers and facilitators. [Saturday 11:20, Abstracts 6]**

Dr Tim Lockett, Faculty of Health | University of Technology Sydney, Level 7, 235 Jones St, Ultimo NSW 2007 (PO Box 123), T +61 2 9514 4861 E [tim.lockett@uts.edu.au](mailto:tim.lockett@uts.edu.au)

Other authors: Prof Meera Agar; Dr Georgina Luscombe; Prof Jane Phillips; Prof Elizabeth Beattie; Prof Dimity Pond; Prof Geoffrey Mitchell; Prof Patricia M Davidson; Ms Janet Cook; Ms Deborah Brooks; Dr Jennifer Houltram; A/Prof Stephen Goodall; Prof Lynnette Chenoweth.

Methods: This study was a qualitative sub-study of a cluster randomized controlled trial called the IDEAL Project. In each of 10 intervention facilities, registered nurses worked as Palliative Care Planning Coordinators (PCPCs) two days a week for 18 months. They facilitated family case conferences and trained nursing home staff in person-centred palliative care. Perceptions of FCC as a “whole package” and the PCPC role in particular were evaluated using semi-structured interviews with PCPCs, facility staff and physicians. Analysis used a thematic framework approach with two researchers coding independently and then agreeing codes and themes.

Results: Interviews were conducted with 11 PCPCs, 18 nurses, 8 allied health staff and 3 physicians. Perceived benefits of FCC included better communication between staff and families, multi-disciplinary involvement in care planning, improved staff knowledge and attitudes, and improved palliative care resources. Barriers in various facilities included resistance from management, staff and GPs, time pressures and staffing levels, and PCPC/staff lack of confidence. Facilitators included positive family feedback and funded time and training for the PCPC role.

Conclusion: The success of FCC varied according to support from management and staff, and whether facilities had a culture of collaboration and quality improvement. The Australian aged care sector’s current policy environment and business model mean that, in most facilities, case conferencing is unlikely to receive the levels of nursing qualification, training and time needed to optimise benefits. Future studies should document resident and family perceptions of case conferencing, as consumer advocacy will be an important driver for improvement.

**Transforming Clinical Care: One year of After Death Audits in a Residential Aged Care Facility (RAC). [Saturday 11:40, Abstracts 6]**

Larissa B McIntyre FACN & Rita C Taylor RN

BaptistCare Orana Centre, 193-201 Brisbane Water Drive, Point Clare NSW 2250, (B) 4337 5425 (M) 0438 416 006, (e) [lmcintyre@bcs.org.au](mailto:lmcintyre@bcs.org.au)

AIM: Our facility was the pilot site for the trial the After Death Audit tool <sup>(1)</sup> for a 12-month period. This was an objective of the organisation’s Palliative Care Strategic Plan 2014. This enabled us to measure our end of life care delivery and to address any shortfalls identified by the audit.

BACKGROUND: BaptistCare has been providing aged care (residential & home based) & community services across NSW & ACT for more than 70 years. It currently operates 17 residential facilities with approximately 1800 beds.

Recognising that palliative care and end –of – life (EOL) care is core business for RAC; BaptistCare began to ask how palliative care services could be better delivered across all their RAC sites to ensure a consistent & high quality delivery of care in keeping with the evidenced – based approach of the *Palliative Approach Toolkit (2012)*.

A multifaceted approach was taken to develop the strategy beginning with the identification of the principles of practice, research to inform the scope utilising current state & national documents, a

comprehensive audit undertaken across all BaptistCare RAC. The BaptistCare Palliative Strategic Plan was released in 2014 and part of the plan included incorporating the After Death Tool into RAC clinical practice.

OUTCOME: At the time of writing, audits had been undertaken on all deaths in the facility. During this time the original audit tool was reviewed to include additional information to capture length of stay; as this has been identified to be significant change in residential care over the last 5 - years. Further information regarding the type of admission was also included to differentiate between Respite or Permanent; this data highlights those people who choose to use RAC for their EOL care as opposed to remaining in the acute care sector or dying in "their own home". This data opens up the need for robust discussion for a Palliative Care payment for RAC.

REFERENCES: National Palliative Care Program. (2013). *Residential Aged Care Palliative Approach Toolkit*. Queensland: The University of Queensland &, Blue Care Research & Practice Development Centre.

### **Transforming the Palliative Approach in Rural Residential Aged Care Facilities.** [Saturday 12:00, Abstracts 6]

Dr Sarah Wenham, Specialist Palliative Care Physician, Far West Local Health District, Broken Hill, NSW 2880.

Other authors: Rebecca Dalwood; Melissa Cumming; Elizabeth Perrie.

Background: The National Aged Care Alliance (2012) recommends systematically creating good linkages between Specialist Palliative Care (SPC) and Residential Aged Care Facilities (RACF) to improve quality of palliative care provision and outcomes for individuals and families. A Decision Assist grant was used to enhance linkages between a rural SPC Team and three rural RACFs.

Approach: A systematic design and implementation included:

- Stakeholder engagement, planning meetings and mapping workshop with RACF, Primary Care and Hospital clinicians
- SPC Link-Nurse secondment to provide education, mentorship and 'modelling' of the palliative approach in RACFs
- Appointment of Palliative Approach Coordinators within each RACF
- Development of a suite of palliative approach clinical documentation
- Pre and post data collection to measure clinical and educational outcomes

Outcomes / Results: Improved palliative and end-of-life care for RACF residents was demonstrated by:

- Increased coordination of care
- Improved advance care planning
- Reduced unnecessary hospital admissions
- Increased residents dying in RACF
- More timely referrals to SPC for residents with complex needs
- Greater knowledge, skills and confidence of RACF staff and GPs to manage end-of-life care

Take Home Message: Sustainable improvements palliative and end-of-life care in RACFs can be achieved through embedding a systematic clinical approach, education, mentoring and enhancing linkages with SPC.

## **Saturday – Abstracts 7 – Afternoon concurrent sessions**

### **Providing end of life care in rural and regional Australia: optimal expectations versus actual end of life care. [Saturday 13:30, Abstracts 7]**

Peta McVey, Senior Lecturer, Sydney Nursing School, The University of Sydney, email: [peta.mcvey@sydney.edu.au](mailto:peta.mcvey@sydney.edu.au), 0431 101 706

Other authors: Claire Johnson, Hugh Senior, Angela Ives, Geoffrey Mitchell.

**Background:** Providing the best care at end of life (EOL) (the last 6- to 12 months of life) has been identified as a health priority. With an increasingly ageing population, the number of people dying with cancer in Australia is expected to increase substantially. This increase in cancer deaths will produce a range of health challenges including a rise in the demand for medical and support services and for high quality EOL care options. In rural and regional settings in Australia, limited access to specialist palliative care increases general practitioner (GP) responsibility in this area. At present, little is known about how general practice conducts end of life care in Australia.

**Aim:** To explore the characteristics of optimal end of life care from the perspective of people diagnosed with advanced cancer, their carers' and their GPs; and to describe the extent to which rural and regional consumers perceived those expectations were met.

**Method:** A qualitative design with semi-structured interviews was used to explore the characteristics of rural general practice optimal EOL care, from the perspective of people diagnosed with cancer, their carers' and GPs; and to investigate the extent to which actual end of life care addressed these characteristics. Thirteen interviews were conducted with six patients, three informal carers, and four GPs. Themes arising from the data were examined from the perspective of optimal practice and the participants' experiences of whether those standards were met.

**Findings:** Seven themes arose from the data: accessibility and trust, knowledge of the patient, good communication skill, psychosocial support and patient empowerment, symptom management and practical issues, care coordination, and recognising carer needs. The actual care received came close to matching expectations, with the exception that sometimes symptom control was difficult to achieve.

**Implications:** The demand for end of life care is predicted to escalate in the coming years, therefore it is imperative that this issue is addressed so that the primary care workforce is ready to transform end of life care in this setting. Knowing what patients are looking for should shape the education and training of undergraduate students and GP registrars to meet the future demands.

### **Ethical considerations of a longitudinal study of informal care networks across rural and remote NSW. [Saturday 13:50, Abstracts 7]**

Dr Emily Saurman, Research Fellow-Rural Health, Broken Hill University Department of Rural Health, [emily.saurman@sydney.edu.au](mailto:emily.saurman@sydney.edu.au) 08 8080 1206.

Other authors: Dr Emma Webster; A/Prof Megan Passey; Prof David Lyle.

**Background:** The lack of suitable specialist Palliative and End of Life Care (PEoLC) services in many rural and remote communities already places an increased demand on informal carers and primary care services compared with their urban counterparts. Informal care networks are composed of healthcare providers and volunteers as well as a patient's family and friends. They have become integral in providing care in rural and remote communities around Australia, but we do not yet know how these networks evolve, function, and respond to the escalating need for care and support for people with complex health problems nor how they impact the healthcare system. A longitudinal mixed method Project is being developed to examine rural and remote PEoLC informal care networks across rural and remote NSW during the progression of a life-limiting illness, through death, and into bereavement. This paper aims to review the ethical considerations of this study and the broader implications for palliative care research.

Methods: This is a synthesis of a review of published literature on palliative care research ethics and informed by project development discussions.

Key Findings: Conducting research with patients who are dying and their carers is privileged and demands sensitivities to produce the knowledge that will progress the provision of quality palliative and end of life care in the future. Matters of context, language choices, and even the timing of the research activity can be fraught with ethical concerns that inform our approach in order to minimise burden. Longitudinal research specifically is not a common design for palliative and end of life research. It brings an element of progression and continual contact with patients and carers requiring rigorous justification and trust beyond a standard research project. There are also ethical concerns relevant to responsibility and care of the researchers as they will develop relationships with the participants and possibly grieve as well. While there is evidence to support the conduct of palliative and end of life research as well as interest from palliative patients and carers to participate in research activity, there is still a necessary recognition that we are working within the context of dying which demands responsiveness and flexibility not often relevant in other fields of research.

### **Transforming the Landscape: Exploring the experience of Australian Rural Palliative Medicine Specialists. [Saturday 14:10, Abstracts 7]**

**Dr Alison Blight**, Advanced Trainee in Palliative Medicine & Provisional Fellow in Pain Medicine, Newcastle NSW

This study used semi-structured interviews of 11 Fellows of the Australasian Chapter of Palliative Medicine (FACHPM) who identified as currently working in rural areas of Australia (ASGC RA 2-5) to explore their reasons for commencing rural practice in Palliative Medicine (RPPM), experience of challenges and rewards of RPPM, potential reasons for leaving RPPM, and their views on barriers to new AChPM Fellows choosing rural practice in Australia. Participants were from (or had also worked in) all states and territories except South Australia and ACT, and most were based in RA2 or 3 areas, however 8 were responsible for providing services to RA 4 or 5 regions directly by home visits or Outreach Services. 8 were female and 4 were aged >60 years. The majority of participants had been working in RPPM for more than 2 years, and the interviews were conducted between January and April 2016.

- (1) "Reasons" for commencing RRPM included: preference for rural lifestyle (or escape from city living), desire to contribute to areas of need, previous personal experience of rural practice, and partner preference or experience of rural living.
- (2) "Challenges" included: professional isolation, lack of peer support, understaffing, lack of resources, geographical challenges, attitudes and beliefs of other health care professionals (HCP) about Palliative Care, developing a service and providing leadership, difficulties with bureaucracy, administrative systems, management, contracts or remuneration, fulfilling CPD requirements and professional development, and the challenge of boundaries in availability and familiarity in smaller communities.
- (3) "Rewards" included: making a difference to whole communities (not just individuals) and the appreciation and gratitude expressed, the depth & diversity of practice, satisfaction with continuity of care, facilitation of best practice (particularly death at home or in community), connection to landscapes and country, "blank canvas" opportunities to grow new services and creative response to challenges, teamwork and growth of other HCP, academic, educational and career opportunities. Some participants even reported positive experiences with local management – feeling supported, provided with flexibility, and given helpful responses with resource support when under stress.
- (4) "Leaving" included: potential personal or partner health issues (including age/retirement), lack of support or burnout, worsening organisational dysfunction or resource limitation, and extended family issues.

(5) “Barriers” included: lack of job opportunities, family issues, isolation, lack of peer support, security of employment, cover and leave, access to CPD and professional development. Perceptions of rural palliative care practice were highlighted, and that it is not a fit for everyone. Concerns were also expressed about junior Fellows of the AChPM undertaking solo RPPM.

## Saturday – Abstracts 8 – Afternoon concurrent sessions

### **What does it take for people to die where they choose and what effect does this have on formal and informal caring networks? [Saturday 13:13, Abstracts 8]**

**Professor Debbie Horsfall**, School Social Sciences and Psychology, Western Sydney University, [d.horsfall@westernsydney.edu.au](mailto:d.horsfall@westernsydney.edu.au), 02 4736 0093.

Abstract: What happens to caring networks when they care for someone who has chosen to die at home? What can the end of life sector do to better support people’s choices about place of death? These are questions that the *Caring at End of Life* research project sought to answer over a 6 year period. Using community development and social capital as our conceptual frameworks we explored the function and purpose of caring networks for the dying person, primary carers, members of caring networks and the wider community. Through the arts-based methods of photo voice and visual network mapping we spoke with over 300 primary carers, informal care networks and service providers in interviews and focus groups. While caring is often portrayed as a burden and a drain on social capital what emerged in this research were stories of love, joy and privilege and caring work that contributed to social capital. We also found that home, as place of dying, is where communities can learn about dying and death. This engaged learning built death literacy: an outcome of engagement in, and participation with, the care of the dying and each other. This experience was transformational at individual, network, service provider and community levels. It is this transformation which we have defined as ‘death literacy’, or practice wisdom. People and communities with high levels of death literacy have context specific knowledge about death, dying and caring at end of life and the ability to put that knowledge into practice. Once this happens death literacy becomes a resource that people can use for the benefit of themselves, their networks and their communities. This is important if more people are to be supported to die their place of their choice.

### **dying2learn: The first ever Australian MOOC on Death and Dying. [Saturday 13:50, Abstracts 8]**

Sanderson C, Calvary Health Care Kogarah, NSW, Australia; School of Medicine, the University of Notre Dame, Sydney, NSW; CareSearch, Flinders University, Bedford Park, SA.

Other authors: Rawlings D; Parker D; Miller-Lewis L; Tieman, J.

Community attitudes to death and dying may have a significant impact on how people deal with the inevitability of their own death, and that of people close to them. Harnessing the power of the social media to support informed discussions is an important challenge for palliative care practitioners in the 21<sup>st</sup> century, and a Massive Open Online Course (MOOC) provides a unique opportunity for online dialogue on these issues. *Dying 2 Learn* is the first ever Australian MOOC on death and dying, which has been developed by CareSearch, and is being run in July 2016.

The MOOC addresses issues related to:

- Humour, and the language used about death
- Memorialisation of the dead – public and private

- Representations of death in art, film and television
- Modes of death and dying in 21<sup>st</sup> century Australia
- Medicalisation of death
- Digital dying

The free course is delivered over 4 weeks, and the target group is “ordinary Australians” ie those who are neither health care workers, nor currently palliative care patients, although it is open to all comers.

Participants explore a curriculum developed by the CareSearch team. A diverse mix of online materials has been curated, with the aim of educating and stimulating discussion amongst participants, followed by optional activities intended to deepen and personalise their engagement with the information, and to encourage reflection. The MOOC does not privilege a palliative care perspective on death and dying, but rather allows participants to explore materials from various perspectives and to respond in a personal way.

The experience of planning, developing and delivering this MOOC will be described. The evaluation of the MOOC will provide unique information about Australian community attitudes, and the impact of the MOOC on those attitudes is being studied using a pre-test / post-test methodology. Preliminary findings from the evaluation will be presented.

**“The Good, the Bad and the Ugly” – how caring for my dying relatives changed me as a palliative care nurse. [Saturday 14:10, Abstracts 8]**

**Kathleen Wurth, Clinical Nurse Consultant – Palliative Care**

Port Kembla Specialist Palliative Care Community Service, 80-91 Cowper Street Port Kembla, NSW 2505, [kathleen.wurth@sesiahs.health.nsw.gov.au](mailto:kathleen.wurth@sesiahs.health.nsw.gov.au), 0412117180,

This presentation addresses the Conference theme of transforming care holistically as I outline caring for my dying parents in my home over a decade ago. My experience as a seasoned palliative care nurse caring for my own family members taught me more than any text book, university, or professional development course. It taught me about vulnerability, and what it is to face the death of my parents and other relatives. My parents chose to live with me and I had a dual perspective of being a daughter and clinician receiving “support” from formal services. Being on the receiving end of palliative care support services and hearing the “script” and the jarring lectures has given me pause and reflection to my own approach and practices. The intimacy of visiting dying patients in their own home is sacred territory. Entering family systems and relationships is profound and integral to impeccable care of the dying patient. Connection, communication and compassion are cornerstones to the human business of grieving and dying. This presentation will provide a narrative of my experience caring for my mum and dad as they came to the end of their respective illnesses and the interface with the palliative care service. Some of those experiences were patronising and judgemental and others were completely humbling and exquisite. These times influenced my bereavement, my memories and my career.

# Posters

Please note posters are listed here numerically.

## **P1 Physiotherapy in Palliative Care maintains or improves mobility and reduces falls**

Alicia Ludkin.

## **P2 How to promote brilliant palliative care within the community.**

Dr Ann Dadich, Ms Kerrie Womsley, Mr Michael Hodgins, Ms Noemir Gonzalez, Ms Valerie Weller, Dr Aileen Collier, Ms Janeane Harlum, Ms Penny Waldon, Ms Therese Smeal, Prof. Meera Agar

## **P3 What is required to improve the recognition and assessment of delirium by nurses in palliative care inpatient units? A mixed methods study.**

Annmarie Hosie, Meera Agar, Elizabeth Lobb, Patricia Davidson, Jane Phillips

## **P4 Measuring delirium point-prevalence in palliative care.**

Annmarie Hosie, Meera Agar, Liz Lobb, Patricia Davidson, Richard Chye, Lawrence Lam, Jane Phillips

## **P5 Integration of delirium knowledge tools in three palliative care units: an environmental scan.**

Annmarie Hosie, Meera Agar, Liz Lobb, Patricia Davidson, Jane Phillips

## **P6 A Last Days of Life Toolkit: ensuring best possible death and bereavement care for patients and families.**

Bernadette King; A/Prof Amanda Walker.

## **P7 Exploring the provision of “Palliative Care” in the Residential Care Home setting...What does “A Palliative Approach in Residential Care” really look like?**

Bron Heron & Chris Lancaster.

## **P8 The BaptistCare Palliative Approach – a Model of Care within the context of residential aged care.**

Carolyn Moir.

## **P9 A literature review – End of Life Care (EoLC) in Advanced Dementia.**

Carolyn Moir.

## **P10 How to go peacocking in a New Palliative Care Centre.**

Cathy McDonnell.

## **P11 Succession Planning For Palliative Care Clinical Nurse Consultants.**

O'Connor C; Chapman A; Bowen C; West D; Hooper D; De Guzman D; Gordon K; McEvoy L; Astorga C; Peterman D; Glass A; Wright K; Chen T.

**P12 Transforming the future of end-of-life care in hospitals: Utilising patient and family identified areas of importance as the foundation for change.**

Claudia Viridun, Tim Lockett, Jane Phillips.

**P13 Supporting adolescents and young adults whose parents are impacted by cancer.**

Mrs D. Jerushah Connell, CanTeen Australia.

**P14 The impact of community palliative care nurse practitioners in helping home-based dying patients, with the support of their care givers, make choices about their preferred place of death.**

Dawn Hooper; Julie Edwards.

**P15 Emergency department presentations by community palliative care patients at end-of-life: A retrospective review.**

Berry D & Pery A; Schofield K; Glavan M; Womsley K; Smith L; Everett B; Sadozai A.

**P16 Development of patient self-management resources to address patient, provider and systems barriers to cancer pain assessment and management.**

Tim Lockett; Patricia M Davidson; Anna Green; Natalie Marie; Mary-Rose Birch; John Stubbs; Jane Phillips; Meera Agar; Frances Boyle; Annmarie Hosie; Melanie Lovell

**P17 Pilot of pain indicator audit tool as part of a complex intervention to improve cancer pain outcomes.**

Tim Lockett; Melanie Lovell; Mary-Rose Birch; Patricia M Davidson; John Stubbs; Jane Phillips; Meera Agar; Frances Boyle; Odette Spruyt.

**P18 Self-management to reduce avoidable Emergency Department presentations for breathlessness: a strengths-based approach using qualitative methods.**

Tim Lockett; Prof Jane Phillips; Prof Miriam Johnson; Maja Garcia; Priyanka Bhattarai; Anne Hutchinson; Prof David Currow; Dr Rebecca Disler; Prof Virginia Carrieri-Kohlman; Bridget Whelan; Dr Phillip Newton; Prof Meera Agar; A/Prof Richard Chye; Dr Caitlin Sheehan; Serra Ivynian; Prof Patricia Davidson.

**P19 Clinical trials of medicinal cannabis for symptoms from advanced cancer: A survey of preferences, attitudes and beliefs among patients willing to consider participating.**

Tim Lockett; Jane Phillips; Nicholas Lintzeris; David Allsop; Jessica Lee; Nadia Solowij; Jennifer Martin; Lawrence Lam; Rajesh Aggarwal; Nicola McCaffrey; David Currow; Richard Chye; Melanie Lovell; Iain McGregor; Meera Agar.

**P20 Pragmatic cluster randomised controlled trial of facilitated family case conferencing versus usual care for people with advanced dementia living in aged care – effects on end of life care.**

Tim Lockett; Prof Meera Agar; Dr Georgina Luscombe; Prof Jane Phillips; Prof Elizabeth Beattie; Prof Dimity Pond; Prof Geoffrey Mitchell; Prof Patricia M Davidson; Janet Cook; Deborah Brooks; Dr Jennifer Houltram; A/Prof Stephen Goodall; Prof Lynnette Chenoweth.

**P21 A Mapping Study of Palliative and End of Life Care in Far West NSW.**

Dr Emily Saurman; Dr Sarah Wenham; Melissa Cumming; Prof David Lyle.

**P22 Transforming Conversations: enabling stories around death and dying.**

Gabrielle Asprey; Sally Carveth; Kim Pearce.

**P23 Title: Enhancing patient and family quality of life in a palliative care setting through music.**

Helen Dawson; Mary Ashton; Anne Johnson; Mary McEneaney.

**P24 EMU: The End-of-life Minimum Universal clinical quality and outcomes reporting tool.**

Dr Inca Hutchinson, Dr Emily Saurman.

**P25 What is the evidence for conducting family meetings in palliative care? - A systematic review.**

Professor Jane Phillips; Philippa Cahill; Professor Elizabeth Lobb; Associate Professor Christine Sanderson.

**P26 Exploring the sleep of caregivers looking after someone in palliative care for advanced cancer.**

Ms Kirstin F Maltby; A/Prof Christine Sanderson; Prof Elizabeth A Lobb; Prof Jane L Phillips.

**P27 Exploring how education strategies can address barriers to early implementation of palliative care.**

Miss Laura Southam.

**P28 Transforming the last days of life: Evaluation of a home-based palliative care support service.**

Dr Linda Kurti & Dr Caroline Tomiczek; Louise Farrell.

**P29 Randomised double blind placebo controlled phase II trial of melatonin for prevention of delirium in inpatients with advanced cancer**

Dr Tim Lockett.

**P30 GET READY, GET SET, GO! An exploration into patient access to a Specialist Palliative Care Unit.**

Marie Chapman.

**P31 Sleep disturbance of adults with brain tumour and their family caregivers: A Systematic review.**

Ms Megan Soohwa Jeon; Dr Haryana M Dhillon; A/Prof Meera Agar.

**P32 Where's the competency? Allied health involvement in palliative care in rural and remote settings.**

Melanie Blair & Danielle Kennedy

**P33 Changing Landscapes – From arid to bountiful Allied Health education in Palliative Care.**

Michael Bayley; Claire Tamone.

**P34 The Memory Garden Series: Transforming the Landscape of Paediatric Death.**

Natasha Samy & Elizabeth Shepherd.

**P35 Identifying opioid medication error types, incidence and patient impact in adult palliative care and cancer services: a systematic review.**

Ms Nicole Heneka & Prof Jane Phillips; Prof Tim Shaw; Adjunct A/Prof Debra Rowett.

**P36 Identifying opioid error types and patient impact in specialist palliative care services - preliminary results from a multi-site quality audit.**

Ms Nicole Heneka; Prof Tim Shaw; Adjunct A/Prof Debra Rowett; Dr Sam Lapkin; Prof Jane Phillips.

**P37 Transforming the Palliative Approach in Residential Aged Care Facilities in Broken Hill.**

Ms Rebecca Dalwood; Dr Sarah Wenham; Ms Melissa Cumming; Ms Elizabeth (Liz) Perrie.

**P38 The Supportive and Palliative Care Indicators Tool (SPICT): can it be used to trigger transition to a palliative approach and improve care for patients with a non-malignant life-limiting disease in a remote care setting?**

Dr Sarah Wenham; Dr Emily Saurman; Jeffrey Duncan.

**P39 Developing Rural and Remote Palliative and End-of-Life Care Research in Far West NSW: the story so far...**

Dr Sarah Wenham.

**P40 Assessment and Treatment of Lower Limb Radiation Induced Fibrosis and Lymphoedema in Palliative Care.**

Tara Quinn.

## **About Us**

The Palliative Care NSW State Conference is held every 2 years (2014 Sydney, 2012 Dubbo) in venues around NSW. The Conference has gained a strong reputation as being the lead Palliative Care Conference in the state and for producing a successful and valuable program.

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