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HARC Scholarship Report

Improving the end of life experience for patients and their families in NSW public health facilities

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- Bridgepoint Active Healthcare, Toronto, Canada
- University of Washington, Medical Centre, Seattle, USA

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1. Executive Summary

This report outlines the research findings from the international study undertaken through a Hospital Alliance for Research Collaboration (HARC) scholarship. The focus of the study tour was to look at and learn from oversea expert clinicians and organisations on their approach to improving end of life care. With the support of the scholarship I was able to visit centres of excellence and meet with experts in the United Kingdom (UK), Canada and the United States of America (USA) to identify best practices in relation to end of life care.

The scholarship included the following activities:

- attendance at International Conference on End of Life: Law, Ethics, Policy and Practice, Brisbane
- visits to multiple NSH trust hospitals in the UK
- visit to Bridgepoint Health, Toronto, Canada
- visit to University of Washington, Palliative Care Centre of Excellence, Seattle, USA

International Conference on End of Life: Law, Ethics, Policy and Practice, Brisbane

This international interdisciplinary forum brought together practitioners and scholars in health and law to discuss the law, ethics, policy and practice relating to the end of life. A program highlight was a debate on the opening night between Professor Peter Singer, a philosopher and ethicist from Australia, and Associate Professor Charles Camosy, a health care ethicist from the United States. The debate was on *"Ethics of euthanasia and assisted suicide"* which set the tone for the discussions over the three days. Conference speakers were from Australian and international universities, including Dr Peter Saul, Professor Michael Ashby, Professor Jocelyn Downie, Professor Sheila McLean and Dr Dale Gardiner.

NSH trust hospitals in the UK - *'Transforming end of life care in acute hospitals'* program

In England I visited nine NHS Trust Hospitals and met with both medical and nursing staff working on end of life care. The 'Transforming end of life care in acute hospitals' program is made up of six approaches that can be implemented along the patient's end of life trajectory. End of life care is seen as a priority in the patient's management and this is aided by having an EOL and/or AMBER care bundle Facilitator position. The AMBER care bundle is embedded in end of life programs but it was interesting to see some of the issues we found in the NSW pilot are still an issue for NHS hospitals. The removal of the Liverpool Care Pathway (LCP) has seen a major shift in caring for patients in the last days of life and at most sites visited it was seen as a loss. The Priorities of Care for the Dying Person which has replaced the LCP uses the principle of the patient centred approach with individualised plans developed. Assessing for the patient's preferred place of care / death is usual practice and this is supported by the excellent district / community nurse support for people to die at home.

Bridgepoint Health, Toronto, Canada

In Toronto Canada I met with team members of the research facility and inpatient services at Bridgepoint Active Health Care. This hospital focuses on the chronic care model where the patient is assessed and managed both in the inpatient setting and community setting. Here I found that Advance Care Planning (ACP) is commenced on diagnosis and is a usual part of the patient’s management plan throughout disease trajectory and inpatient admissions. The patient’s management is driven by the multidisciplinary team (MDT) with all being involved in the ongoing end of life conversations with the patient and family. The research team are looking at ways of improving the work being done around end of life but also looking at whether the chronic care model developed by the facility has improved end of life care for their patients.

University of Washington, Palliative Care Centre of Excellence, Seattle, USA

In Seattle I met with a group of medical clinicians who work as researchers as part of the Palliative Care Center of Excellence at the University of Washington. This team has been involved in end of life work focusing on clinician engagement and early conversation over the last five years. Interestingly the issues we’re facing in NSW now, they did and sometimes still do. The overarching message from the meetings was that one of the main platforms for change is education programs and working with clinical teams to support them having conversations early in a patient’s diagnosis.

Overall the experience of meeting with experts and being able to hear of their challenges and successes with implementing large scale change was invaluable. The findings from this study tour will be fundamental to the ongoing program development and strategic direction of the CEC’s End of Life program.

Recommendations

Recommendation 1: Incorporate tools and resources gained from the study tour into the CEC End of Life program

The CEC EOL program is focusing on four priority areas: these include the implementation of a standardised death screening tool and database where EOL care is measured for all patients who die in NSW hospitals; the introduction of the AMBER care bundle; a communication framework to educate and mentor clinicians in difficult conversations at the EOL; and the planning for development of a 'last days of life toolkit'.

Tools such as the AMBER care bundle; SPICT™ (Supportive & Palliative Care Indicators Tool) and the *Priorities for Care of the Dying Person* were seen in practice in the acute care environment in managing patients approaching the end of their life. The key principles associated with each tool allow the ability to transfer and localise them to the NSW health environment from a system perspective as well as from the individual clinical setting.

Recommendation 2: Continue to develop and implement the AMBER care bundle to acute care services in NSW Health

The AMBER care bundle is a key component for the CEC's End of Life program. The care bundle is designed to prompt and enable multi-disciplinary team decision-making for patients whose recovery is uncertain including established thresholds for intervention and escalation, and involving patients and their families in end of life discussions and decision-making. It is recommended that the AMBER care bundle continues to be spread across NSW facilities providing a framework which allows patients to receive active treatment alongside an end of life care planning approach.

It is also recommended that a structured evaluation framework should be developed in collaboration with a tertiary education / research organisation with ongoing liaison with the UK team.

Recommendation 3: Develop a last days of life toolkit that incorporates the principles of the *Priorities for Care of the Dying Person* that ensures a patient centred approach to caring for the dying patient in any setting

While a lot of work has been done at the local level around developing tools/resources/pathways for the dying patient in NSW there is no consistent approach or minimum standard. The intended approach will see the various tools that become part of the toolkit describe high-quality care that when delivered collectively, contribute to improving the effectiveness, safety and experience of care for the dying patients as well as the experience of their families and carers while still focusing on the individual needs of the patient. The learnings from the review of the Liverpool Care Pathway and introduction of the *Priorities for Care of the Dying Person* will be utilized in the approach decided.

Recommendation 4: Establish an end of life interest group with the purpose of spreading and sharing knowledge related to implementation of quality systems around end of life care

The NSW public health system has an enormous resource of knowledgeable and expert clinicians and managers who are continually involved in the generation of solutions to the challenges that they face every day in delivering high quality end of life care to patients. 'Craft groups' and communities of practice (CoP) are plentiful around clinical service delivery, but it is less common to find such groups formed around the design and implementation of quality systems or models of care. The aim of the EOL CoP would be to provide a forum for sharing of innovations and solutions in implementing end of life care improvements between clinicians, NSW Ministry of Health and Pillars.

Recommendation 5: Maintain and strengthen relationships with the *'Transforming end of life care in acute hospitals'* team

The CEC should continue its partnership with the AMBER care bundle team at Guy's and St Thomas's as well as develop links with the *Transforming end of life care in acute hospitals'* team. The experience of implementing a whole of system change to improving end of life care can only be of benefit to the work being done in NSW.

2. Introduction

Dying patients are cared for in many settings including intensive care units, general medical and surgical wards, aged care units and mental health units. Early identification of those who may have end of life care needs is the foundation of excellent end of life care. If early identification does not take place then appropriate planning, transfer, interventions and communication with the person and their family cannot take place. While palliative care services play a critically important role in managing end of life care for patients and their families all health specialties and professionals have a role to play.

In 2011-12, there were 50,500 deaths in New South Wales with just over 50% of deaths occurring in the acute care setting[i]. Increasingly the type of care and services utilised by these patients is being examined especially in relation to their end of life care. In NSW the Between the Flags program, as well as an increasing number of IIMS reports and Root Cause Analyses, has shown that a common concern is the failure of treating teams to identify patients at risk of dying, and then develop and document appropriate treatment plans and communicate appropriately with patients and carers. Documentation rarely demonstrates that patients and carers have been consulted about their preferred place of care. From the 2012 QSA Self-Assessment the greatest challenges when providing end of life care identified by staff related to staff discomfort initiating conversations with patients and carers; incomplete documentation; failure to recognise when patients are starting to die; and poor communication between staff and patients and carers[ii].

At the National level the Commission on Safety and Quality in Health Care (ACSQHC) has identified end of life as one the main priority areas for action and improvement plans to incorporate end of life into the National Safety and Quality Health Service Standards. The Commission recently released the *National Consensus Statement: Essential elements for safe and high quality end of life care in acute hospitals* that outlines expected standard of end of life care for patients.

In 2013 in response to the growing evidence and concerns around the provision of safe, quality end of life care in NSW public health organisations (PHOs) the Clinical Excellence Commission's (CEC's) EOL program was established. The program is responsible for leading and managing the implementation, evaluation and refinement of the Clinical Excellence Commission's responsibilities as outlined in the Ministry of Health *Advance Planning for Quality Care at End of Life: Action plan 2013 – 2018.* This includes the introduction of the AMBER care bundle, development of last days of life toolkit and the introduction of a statewide mortality screening and review process. As part of the strategic planning process for the EOL program the HARC scholarship offered the opportunity to visit lead organisations and meet with experts; identify any gaps in the program priorities; and identify tools and resources that could be localised and integrated into the NSW end of life program.

3. Literature review

The literature review focused on some of the main issues affecting how we recognise the dying patient and how we can deliver safe, quality end of life care. The following table outlines the key literature in the areas and findings that are relevant to this study.

PUBLICATION	OBJECTIVE	METHODS	RELEVANT FINDINGS/CONCLUSION
The Australian Commission on Safety and Quality in Health Care's **National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care**	Identify what are the issues and barriers to providing safe, quality end of life care to patients in Australian acute care facilities	Literature review and Australian wide consultation with clinicians and consumers	The consultation document identified 10 essential elements to describe the features of a system providing care to patients approaching EOL. A) Processes of care 1. Patient-centred communication and shared decision-making 2. Teamwork and coordination of care 3. Components of care 4. Using triggers to help recognise patients approaching the end of life 5. Responding to concern B) Organisational prerequisites 6. Leadership and governance 7. Education and training 8. Supervision and support for interdisciplinary team members 9. Evaluation, audit and feedback 10. Systems to support high-quality care[iii]
The Australian Commission on Safety and Quality in Health Care (ACSQHC) **National Consensus Statement– discussion document : Essential elements for safe and high quality end of life care in acute hospitals**	The Australian Commission on Safety and Quality in Health Care undertook scoping and preliminary consultation work to identify the key factors affecting the quality of end of life care in acute hospitals.	Australia wide consultation with consumers and clinical staff.	▪ Acute care focusses on diagnosis, treatment, cure and discharge rather than end-of-life care. ▪ Deaths are evaluated in terms of unexpectedness and potential preventability, rather than on quality of end of life care. ▪ Physicians often delay or lack the capacity to communicate with patients and families about the goals of care, limitations on treatment, terminal care or psychosocial and spiritual needs. ▪ Control of symptoms and pain is suboptimal. ▪ End-of-life care is 'out-sourced' to the medical emergency team, the palliative care team or the intensive care team, even when a death could have been anticipated. Care may then be provided by strangers and in urgent circumstances. ▪ Junior physicians are often responsible for care but lack

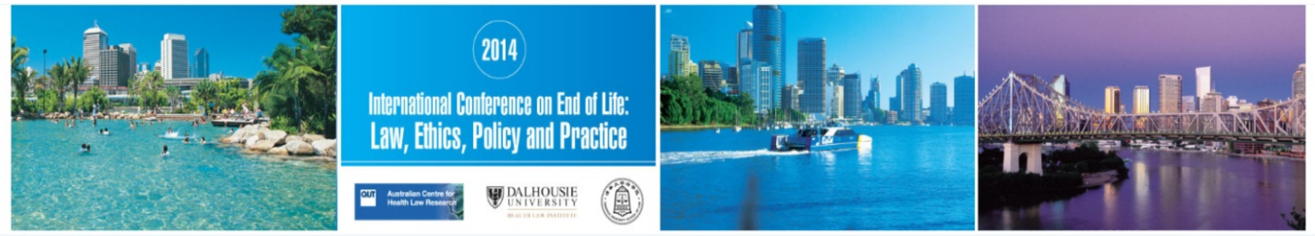
PUBLICATION	OBJECTIVE	METHODS	RELEVANT FINDINGS/CONCLUSION
			experience in end of life care. They delay contacting senior staff even when a patient has complex needs. Care is often focussed on a single organ or disease group, instead of a holistic approach. ▪ There are limited supports and options for end of life care in non-acute settings.
One chance to get it right: improving people's experience of care in the last few days and hours of life. Leadership Alliance for the Care of Dying People, June 2014.	In response to the recommendations following the independent review of the Liverpool Care Pathway *'One Chance to get it Right'* was published. This document sets out the approach to caring for dying people that health and care organisations and staff caring for dying people in England should adopt. The *Priorities for Care* approach should be applied irrespective of the place in which someone is dying: hospital, hospice, own or other home and during transfers between different settings.		The Priorities for Care set out in sequential order the principles of care when it is thought that a person may die within the next few days or hours: 1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly. 2. Sensitive communication takes place between staff and the dying person, and those identified as important to them. 3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants. 4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible. 5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.[iv]
The Agency for Clinical Innovation (ACI) ***Blueprint for Improvement: Palliative and End of Life care***	Aims to provide all clinical staff guides and resources to meet the needs of people approaching and reaching the end of life, their families and carers.	A multi methods approach - Fact of death analysis - Commissioned consultation with primary and residential aged care facilities including GPs across NSW - ACI consultation with clinicians and families/carers through Palliative Care Network and Palliative Care conferences	Ten essential components guide the model: 1. Informing community expectations and perceptions on death and dying 2. Discussions about palliative and end of life care and planning for future goals and needs 3. Access to care providers across all settings who are skilled and competent in caring for people requiring palliative and end of life care 4. There is early recognition that a person may be approaching the end of life (i.e. last year of life)

PUBLICATION	OBJECTIVE	METHODS	RELEVANT FINDINGS/CONCLUSION
			5. Care is based on the assessed needs of the patient, carer and family 6. Seamless transitions across all care settings 7. Access to specialist palliative care when needs are complex 8. Quality care during the last days of life 9. Supporting people through loss and grief 10. Quality care is supported through access to reliable, timely clinical information and data [v]
H. Baird, B. King, R. Kerr, & A. Walker. April 2013. *Care for the Dying in NSW: A review of the data from the 2012 Quality Systems Assessment*, Clinical Excellence Commission	The Clinical Excellence Commission identified end of life care as a major theme for NSW public organisations to examine as part of the 2012 Quality Assessment Process. .	This report was based on the findings of multi-level online self-assessments, onsite verification visits, feedback and reporting which involved 1,513 respondents from 1,130 clinical units in 17 LHDs, Ambulance Service and the Justice Health and Forensic Mental Health Network	Key self-assessment findings included: ▪ 63% of LHDs and Justice Health (JH) clinical units provide care for people who are dying or approaching the end of their life, ▪ 61% of clinical units reported they identify patients who were likely to die in the next 6-12 months; ▪ 42% of clinical units follow a standardised approach to treating patients in their last days of life; ▪ The most challenging issues when managing patients at the end of life were incomplete documentation in the medical records (59%), staff members not feeling comfortable initiating the conversation with the patient, their family or carer (53%) and poor communication between staff and family or carers (31%); ▪ 32% of clinical units did not monitor any performance measures relating to end of life care.
Orosz, M. Bailey, M. Bohensky, M. Gold, S. Zalstein and D. Pilcher. **Deteriorating patients managed with end-of-life care following Medical Emergency Team calls** Internal Medicine Journal. Volume 44, Issue 3, 246–254, March 2014	Describe characteristics of patients whose end of life care was initiated in response to a medical emergency team (MET) call. From this develop a predicative score to aid prospective identification of those patients	Retrospective study of all MET calls in tertiary teaching hospital between April 2010 – March 2011	The study found that patients commencing EOL care after a MET call are more likely to be elderly, be admitted under medical team, have a malignancy or chronic disease and receive multiple MET calls. the authors also found that the issue of lack of senior staff involvement in management panning or earlier recognition of the dying patient was in evidence in a majority of cases
Jones DA1, Bagshaw SM, Barrett J, Bellomo R, Bhatia G, Bucknall TK, Casamento AJ, Duke GJ, Gibney N, Hart GK, Hillman KM, Jäderling G, Parmar A, Parr MJ. **The role of the medical emergency team in end-of-life**	Investigate role of medical emergency teams (MET) in end of life planning	prospective audit of 518 patients who received MET calls over one month in seven hospitals in Australia, Canada and Sweden	The majority of MET calls occurred out of hours and for elderly medical patients. a proportion of these patients had limitation of medical treatment instituted within 24-48 hours prior to death.

PUBLICATION	OBJECTIVE	METHODS	RELEVANT FINDINGS/CONCLUSION
care: a multicentre, prospective, observational study.. doi: 10.1097/CCM.0b013e31822e9d50.			
Scarborough JE1, Pappas TN, Bennett KM, Lagoo-Deenadayalan S. **Failure-to-pursue rescue: explaining excess mortality in elderly emergency general surgical patients with pre-existing "do-not-resuscitate" orders**. Annals of Surgery. 2012 Sep;256(3):453-61.	To describe the outcomes of elderly patients with do-not-resuscitate (DNR) status who undergo emergency general surgery and understand the relationship between preoperative DNR status and postoperative mortality	Patients 65 years or older who had undergone emergency operation for 1 of 10 common general surgical diagnoses were extracted from the 2005-2010 US National Surgical Quality Improvement database.	The authors found that patients with pre-operative DNR orders who underwent emergency surgery have significant rates of post-operative morbidity and mortality. it was acknowledged that the reason could be that patients who have a preoperative DNR fail to pursue rescue when major postoperative complications occur.
Garside J1, Barley T, Wellings V. **Collaborative services show positive outcomes for end of life care.** Nursing Management. 2013 Nov;20(7):16-22.	To outline the benefits of a Trust participating in the Transforming end of life care in acute hospitals program and the introduction of the AMBER care bundle	Description of implementation of a program that incorporates palliative and end of life care in a structured approach across an acute hospital NHS Trust.	The introduction of the program has led to better end of life care in the acute hospital setting. They achieved positive outcomes for their patients and a cohesive pathway of care and new ways of approaching EOL care
Ken M. Hillman, Magnolia Cardona-Morrell. **The ten barriers to appropriate management of patients at the end of their life.** Intensive Care Medicine, March 2015	To identify the barriers faced by intensivists in managing EOL and their role in managing society and medicines expectations of what intensive care units can achieve and what they can’t	Discussion around the use of ICUs and the increased role of intensivists taking on diagnosing the dying.	Ten barriers identified included: ▪ Unrealistic societal expectations ▪ Reluctance of society to discuss ageing, death and dying ▪ Lack of effective medical training in dealing with end-of-life (EoL). Doctors are often programmed to treat, not to reflect on the context of treatment ▪ Medical specialisation resulting in overlooking the patient’s overall clinical condition and prognosis ▪ Uncertainty is an integral part of medical practice and may be used as a reason for continuing active management indefinitely ▪ Some healthcare systems provide financial incentives to physicians for continuing active treatment ▪ Ethical ambivalence ▪ Legal pressures ▪ The conveyor belt to intensive care—healthcare systems tend to have inflexible approaches to dealing with serious illness, resulting in the inevitable admission of the patient from the community to acute hospitals and intensive care units regardless of prognosis ▪ Lack of alternative and perhaps more appropriate EoL care in many societies

4. HARC Scholarship Program

4.1 Conference Attendance



The International Conference on End of Life: Law, Ethics, Policy and Practice was held between 13 - 15 August 2014 in Brisbane, Australia. The aim of the conference was to provide a global forum at which health law scholars, bioethicists, legal and health practitioners, and health law and bioethics institutions could meet to discuss and present on law, ethics, policy and practice relating to end of life. The main themes of the conference included:

- withholding and withdrawal of potentially life-sustaining treatment (e.g. advance care planning, futile treatment)
- palliative care and terminal sedation
- euthanasia and assisted suicide
- determination of death and organ and tissue donation.

Keynote speakers included:

Prof Peter Singer, Princeton University
Prof Sheila McLean, Glasgow University
Prof Jocelyn Downie, Dalhousie University
Assistant Prof Charles Camosy, Fordham University
Dr Dale Gardiner, Nottingham University Hospitals
Dr Peter Saul, John Hunter Hospital
Prof Michael Ashby, Royal Hobart Hospital and Southern Tasmania Health Organisation
Prof Linda Ganzini, Oregon Health & Science University
Prof Luc Deliens, Vrije Universiteit Brussel & Ghent University
Prof Agnes van der Heide, Erasmus University Medical Center
Prof Glynn Owens, University of Auckland
Associate Prof Thaddeus Pope, Hamline University
Associate Prof Colin Gavaghan, University of Otago
Prof Ben White, Queensland University of Technology

Summary or Activities

While all the sessions I went to were interesting the following are a summary of the ones that I felt were most relevant to the project.

Session title: How we die: an intensive care perspective

Presenter: Dr Peter Saul, John Hunter Hospital

Summary:

This paper was an intensivist's view of dying in 2014 and the medicalization of dying especially in the intensive care setting (ICU). The session focused on the fact that in 2014, most Australians live to be old, but die in acute care hospitals with an array of subspecialists mustering complex technologies beyond the ken of patients and their families. Most patients are chronically ill, with diseases that can only be managed, not cured. Multiple trips to an emergency department punctuate the last year of life, though few are aware that their time is so limited. The final illness brings with it a lack of decision making capacity, so decisions to withhold or withdraw life-prolonging technologies are shared between doctors with little idea of that patient's uniqueness and families with no real understanding of the choices to be made or their role in making them. Data about how people die following a stay in ICU was presented. They have found that:

- the majority of patients discharged for ICU are discharged to residential aged care and life extension of these patients is usually less than 12 months and
- the ICU tam are often the ones having to make decision around patient management and end of life plan

Session title: Drivers of futile treatment: An empirical study

Presenter: Lindy Willmott, Ben White, Cindy Gallois, Malcolm Parke, Sarah Winch, Nicholas Gravesa, Nicole Shepherd, Eliana Close

Summary:

While there is divergence about what the term "futility" means there is general consensus that futile treatment is provided at the end of life. To date, there has been very little empirical research as to why doctors sometimes provide treatment knowing that treatment to be medically futile. This presentation reported on the results of 96 semi-structured interviews with doctors from a range of specialties in three Queensland public tertiary hospitals. It explored why doctors provide treatment they consider to be futile, strategies that they use to avoid providing it as well as suggestions for systemic change that is needed to reduce the provision of futile treatment. Findings revealed that the drivers of futile treatment fall into one of three categories:

1. Patient related factors (including family or patient request for treatment and lack of information about patient wishes);
2. Clinician related factors (including the fact that doctors are trained to treat and tend to look at a particular organ or system of a patient rather than the patient as a whole): and
3. Institutional factors (including increased specialisation and the difficulty at a tertiary hospital in stopping treatment once it has started)

Good communication with the patient and family was the most common strategy nominated by doctors to prevent futile treatment being provided. Improved medical education and training, community education about the realities of dying in hospitals and preparing advance directives, as well as structural reform including drafting of policies on limiting treatment and improved decision-making models were some of the suggestions made by doctors for systemic change. These findings have implications for how medical practice at the end of life can be improved.

Session title: Terminal Sedation: Good medicine? Good ethics? Good law?

Presenter: Prof Sheila McLean, Glasgow University

Summary:

The use of sedation at the end of life is, according to the literature, becoming increasingly frequent. The practice has many names from terminal to palliative to continuous deep sedation, among others. Clearly each of these terms has a normative impact and their use may serve to reflect what professionals and others perceive to be the goal of the use of sedation. In addition, sedation may be accompanied - or not - by the instigation or continuance of assisted nutrition and hydration (ANH); again with specific goals in mind. The presentation explored primarily the ethical and legal status of the practice of terminal sedation without the provision of ANH.

A study quoted noted that medical clinicians develop idiosyncratic reasons which influence use of terminal sedation. Attitudes such as pro euthanasia or religion can influence decisions and this sees decisions not solely based on the needs of patients. The speaker made the point that there is a role for law in end of life decisions as the law must step in to assist in doctors uncertainty / struggle with decision.

Session title: Barriers and facilitators to advance care planning: Perspectives of healthcare providers, patients and families

Presenter: Kim Taylor, Anita Ho, Martha Spencerj

Summary:

Advance care planning (ACP) has been advocated as a means to support patients in making healthcare decisions should they lose such capacity. Nonetheless, studies indicate that end-of-life communication and documentation patients' of wishes are inadequate. This presentation focuses on findings from a larger Canadian study on the intersecting factors affecting the ability of patients' families of diverse backgrounds to make complex healthcare decisions. It compares health care providers' (hcps), patients' and family members' views towards ACP barriers, as well as their recommendations to enhance supportive advance care decision-making.

Semi-structured interviews with 54 patients, 25 family members, and 37 hcps were conducted. Participating patients had both acute and chronic health conditions. HCP participants ranged across various disciplines within acute, community, and long term care settings. Transcribed interviews were coded by two researchers. Grounded theory informed an inductive thematic analysis and constant comparative techniques were employed to explore patterns of ACP experiences across and between datasets.

Although participants believed that ACP was beneficial, multi-level barriers were reported across all groups. Micro barriers centered on relational dynamics between patients, family and/or hcps (e.g. Distrust, difficult family dynamics) as well as individual communication barriers (e.g. HCps' own reluctance to initiate conversations). Meso-level issues such as lack of coordination of care and poor communication across and

within multi-disciplinary teams and institutions were reported. Macro-level systemic barriers included lack of training opportunities for hcps to engage in ACP conversations. Participants' recommendations highlighted the critical role of hcps' communication skills, the importance of trust relationships, and the need to engage patients and families in ongoing ACP processes.

Findings from this study demonstrate that ACP is underutilized despite its perceived importance. To correct this discrepancy, micro, meso, and macro-level strategies are needed to help support patients and their families in making informed healthcare decisions and respecting these decisions.

Session title: Implementing the Goals of Patient Care summary: decisions, discussions and documentation

Presenter: Catherine Brimblecombe, Barbara Hayes, David Crosbie, Kwang Lim.

Royal Melbourne Hospital, Victoria

Summary:

Background: Doctors, patients and families have difficulty assessing and discussing current and future treatment plans in relation to the constraints of contemporary medicine, potential treatment outcomes, and patients' overall healthcare goals. The Goals of Patient Care summary has been introduced to encourage routine, proactive consideration of these issues for hospitalised patients.

Aims: Review implementation of the Goals of Patient care (GoPC) summary amongst adult medical inpatients for uptake, outcomes, and documentation of decision-making and discussion process. Assess prevalence of existing advance care planning. Assess prevalence of and modification to GOPC at Medical Emergency Team (MET) calls for all adult inpatients.

Method: Single centre cross-sectional study.

Results: 82/101 patients reviewed had a GOPC summary completed. Few had evidence of previous advance care planning, with one patient having an advance directive and six a substitute decision-make appointed. 42 GoPC summaries contained clear records of discussion with the patient or family member, with eight were supplemented by details of the decision-making process. A decision to limit the extent of treatment had been made in 48 cases. Three of 23 MET calls triggered de-escalation of care, although the GoPC summary had been completed prior to only nine METs.

Conclusion: few medical inpatients have previously undertaken advance care planning. The prevalence of decisions to limit the extent of treatment suggests that many hospitalised patients have chronic medical conditions impacting overall treatment goals, or express treatment wishes not previously documented. Some are likely to benefit from further formal advance care planning, although the GoPC serves as a useful adjunct during acute hospitalisation. There is room for improvement in documentation of the discussion and decision-making process. Patients requiring a MET call are less likely to have a GoPC summary than the overall cohort, and the role of the GoPC summary in this setting requires further evaluation.

Session title: Improving end of life decisions by addressing myths and misunderstandings about the law in NSW

Presenter: Julie Letts, Kit Leung

Summary:

In 2013 the NSW Minister for Health released the state Advance Planning for Quality Care at End of Life: Action plan 2013-2018. This aims to improve end of life care by embedding advance care planning as a routine aspect of managing those with chronic life-limiting illness. Consultations undertaken by the Ministry of Health since 2010 had underscored that an important barrier to end of life decision-making amongst NSW health professionals was fear of legal vulnerability related lo these decisions. This is fuelled, in part, by misunderstandings about what the law in NSW provides in relation to end of life decisions. Common law coupled with legislation regarding substitute decision-making (NSW Guardianship Act 987) govern end of life decisions. An early implementation priority was thus to develop a resource addressing these concerns. An expert advisory group comprising representatives from key statutory bodies, respected health law academics, clinicians and health consumers was convened to develop an authoritative, case based resource targeted at health professionals and accessible via the internet. Focus issues included the status of advance care directives, the primacy of but limits on autonomous decisions, interpreting the Guardianship Act in relation to the authority of the Person Responsible, and pathways for legal support and resolution of disputes about end of life decisions with the patient or family in the hospital setting. This process highlighted some interesting issues in relation to law and the clinical practice, including the difference between how lawyers and clinicians sometimes 'see' the dynamics of decision-making and the practical constraints and requirements of clinical practice. Not surprisingly, this complex area of case law posed challenges in providing simple, definitive statements on some issues. However, focus testing demonstrated the resource nonetheless provides clarity and reassurance to health professionals not well versed in this important aspect of end of life decision-making.

Implication for NSW and EOL program

Overall this was one of the best conferences I have been to in some time. The international speakers and the perspective they brought to issues facing policymakers and clinicians around the ethical, legal and clinical aspects for caring for patients at the end of their life was thought proving but optimistic. The overriding feature of all speakers was the importance to focus on patients having the information and conversations around what is important to them in their death.

4.2 Overseas Visits

4.2.1 United Kingdom

NHS Improving Quality

Transforming end of life care in acute hospitals

Acknowledgment:

- **Ms Anita Hayes**, NHS Improving Quality Programme Delivery Lead End Of Life Care, Mental Health and Dementia
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- **Ms Sheryl Cox**, PA to Anita Hayes
- **Ms Chris Sutcliffe**, Delivery Support Manager, Transforming EoLC in Acute Hospitals. NHS Improving Quality – Delivery Team
- The members of the NHS Improving Quality End of Life Care, Mental Health and Dementia team

About 'Transforming end of life care in acute hospitals'

The Transform program aims to improve the quality of end of life care within acute hospitals across England. The program focuses on both the quality of care provided by acute hospitals, as well as the important role acute hospitals have, as one of many organisations that may provide care for people who are approaching end of life. End of life care includes care for people in their last years, months and days of life as well as care after death.

The approach of the program, depending on the patient's individual needs, includes:

- Supporting or initiating advance care planning conversations with patients
- Co-ordination of care with GPs and community services, using Electronic Palliative care co-ordinations systems (EPaCCs) where these exist in the hospital's catchment area
- Recognition of patients whose potential for recovery is uncertain, supporting shared decision making with them to enable choice, making sure their clinical uncertainty is well managed by their team including planning ahead if their condition deteriorates further (eg the AMBER care bundle for patients whose recovery is uncertain)
- Effective, fast and where necessary, rapid systems for discharge processes to meet individual's preferences, including to their preferred place of care and death (e.g. Rapid Discharge Pathway)
- Meeting the Priorities for Care for the dying person
- Effective care after death, including bereavement and mortuary services.

The Program is a collaboration of over 70 acute hospitals Trusts in England.

http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care.aspx

I was able to spend a day with the senior members of the NHS IQ End of Life Care, Mental Health and Dementia team at their monthly team meeting. This was a great opportunity to see how the team work as individuals in their own areas of responsibility but also how that work is used to ensure a whole of system approach is achieved for the program.

Summary of meeting

I was impressed with all team members and the work they are doing. The meeting provided the forum for all leads to meet and discuss their programs, share ideas and report outcomes. The meeting also sets the direction of the NHS EOL program and its implementation at the local level.

I was able to give an overview of the NSW health system and how the CEC works with clinicians within the system for improvement. I outlined how the CEC's EOL program came about and the planned direction of the program. I was also able to give the team an overview of how we are localising the AMBER care bundle for use in NSW acute hospitals and the results of the recent pilot.

The area of some difference on how the NHS is approaching EOL from a system perspective relates to the emphasis on providing health as well as social care around EOL.

Implication for NSW and EOL program

While not all of the areas of focus of the transforming end of life care in acute hospitals program are reflected in the CEC's program objectives there is certainly a great deal of synergy and opportunity to expand what we are doing in NSW. Following the discussion with the team the areas that will be given a more focused approach will be the development of links to the aged care networks, the inclusion of a transition to die at home program and development of bereavement support for families/carers.

The Royal Marsden NHS
NHS Foundation Trust

Coordinate My Care (CMC)

Acknowledgment:
→ **Ms Anne Dowling**, CMC – Head of Strategy and Marketing
→ **Ms Diana Howard**, Director of Nursing, CMC
→ **Mr Gerard Bowden**, CMC Clinical Facilitator

About Coordinate My Care (CMC)

CMC has been developed to give people with chronic health care conditions and/or life-limiting illnesses an opportunity to create a personalised care plan in order that they might express their wishes and preferences for how and where they are treated and cared for at the end of their life. The care plan contains information about the patient and their diagnosis, key contact details of their regular carers and clinicians, and their wishes and preferences in a range of possible circumstances. This information is then uploaded to the CMC system to which only trained professionals involved in the patients care can access. This can include ambulance control staff, NHS 111[1] operators, GPs, out of hours GP services, hospitals, nursing and care homes, hospices and community nursing teams[vi].

Summary of visit

The visit with the team at the Royal Marsden focused on how the CMC program was developed and the improvement to communication around patient's end of life wishes that has been achieved. The CMC is web-based record system where information can be assessable to members of staff who care for the patient across the care continuum. All the organisations involved have signed formal agreements that govern how care plan information is used and protected, and they undertake to provide CMC with updated lists of staff that are trained and authorised to access the system. One of the main advantages of the program is that in an emergency situation the Ambulance Service personnel can access the program so that when they are called to the patient's home they can treat the patient as required but do not have to transport the patient to the hospital. At present there are over 15,000 personalised care plans in the program.

Some of the features of the program that were discussed include:

- consent for inclusion / information sharing is verbal agreement between the patient and the clinician developing the plan
- conversations around end of life are multidisciplinary however they can be initiated by nursing staff who can then start the CMC documentation and care planning
- those clinicians that participate in the CMC program receive training on how to create and edit records, initiate end-of-life care conversations, and prepare treatment plans for complex conditions
- SPICT™ (Supportive & Palliative Care Indicators Tool) is recommended for use in assessing patient's suitability for planning development. This has been widely accepted by clinicians as they feel it validates what they see in practice
- at present the program is mainly cancer focused but with the planned redevelopment of the online system there is an opportunity to expand its use

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[1] **NHS 111** is a free-to-call single non-emergency number medical helpline operating in England and Scotland. The service is part of each country's National Health Service and has replaced the telephone triage and advice services provided by NHS Direct, NHS24 and local GP out-of-hours services

- evaluation of the program is ongoing – a business case is presently being developed looking at the money saved with patients not unnecessarily being admitted to hospital and having appropriate treatment that reflects patient's wishes
- an area that is also being evaluated is the number of patients who die in their preferred place of death – presently 82% of patients with a CMC record are achieving their preferred place of death.

A risk for the program is that it is dependent on the 'human' element to complete the form when there is a change in condition, change relating to wishes in relation to care, or when the patient dies. The program has 'quality control' member who follows up with clinicians if they've commenced the data entry but not completed the plan as well as check with death registries regarding who has died.

Discussion

The 2012 Quality Systems Assessment found that when paramedics were asked about information sharing of patients end of life wishes or plans less than 50% agreed there was a process in place where hospitals or other agencies can alert the call centre and subsequently the paramedic regarding existence of any end of life plans. Als only 17% responded that paramedics were able to access timely clinical advice and decision support 24/7 in relation to end of life issues "always" or "often". A recommendation from the self-assessment report called for a state-wide system to identify those patients with advance care planning documents to ensure accessibility to all health professionals including paramedics[vii].

In NSW the IT systems used by the Ambulance Service, GPs and PHOs do not 'speak' to each other so problems around communication can occur especially around transitions of care. While the CMC program has an associated cost for the software and training, having a means to share clinical information about a patient's condition and their wishes regarding their care, such as a registry, could enhance improved information sharing across all settings of care thereby benefiting both patients and the system as a whole.

Implication for NSW and EOL program

- The CEC needs to continue to work with ehealth and other organisations to ensure that a 'whole of system' approach to end of life care planning and communication is designed into the next version of the electronic medical record. This would see patient's wishes being known by all who come into contact with the patient including the Ambulance Service, GP, Community Nurses and the acute hospital system
- As part of the AMBER care bundle education test the use of the SPICT in assisting staff to identify patients for early intervention of end of life care planning.

Guy's and St Thomas'
NHS Foundation Trust NHS

Acknowledgment:

- → **Dr Adrian Hopper** - Deputy Medical Director for Patient Safety, Guy's and St Thomas Foundation Trust, UK
- → **Dr Irene Carey** - Clinical Lead Specialist Palliative Care, Guy's and St Thomas' Foundation Trust, UK
- → **Ms Susanna Shouls,** Program Manager AMBER care bundle team. Senior Data analyst
- → **Ms Charlene Davis** - AMBER care bundle design team
- → **Ms Michelle Morris**, Matron, Palliative Care, Guys Hospital
- → **Juliette Culora** – Matron, Palliative Care, Guys Hospital
- → The staff of **Samaritan Ward**, Guys Hospital
- → The staff of the **Victoria** and **Sarah Swift** wards St Thomas's

About Guy's and St Thomas' NHS Foundation Trust
Guy's and St Thomas' NHS Foundation Trust includes two of London's most famous teaching hospitals, providing patients with treatment and care from two central London sites near Waterloo and London Bridge. Both hospitals provide a full range of hospital services and have integrated community services in Lambeth and Southwark into the Trust. Guy's and St Thomas' was where the AMBER care bundle was developed by Dr Adrian Hopper and Dr Irene Carey.

Summary of meetings (visits undertaken over three separate days)

Matron team meeting – Palliative Care department Guys Hospital

This meeting covers all aspects of end of life care, including patients being supported by the AMBER care bundle in Guy's and St Thomas's hospital and the community services. The meeting also provides a forum for ensuring team coordination between the inpatient and community district nurses as the district nurses have only recently come under the governance of the Trust.

The introduction of the Priorities for Care of the Dying Person is still in early stages. Nursing staff are able to initiate the conversation with the patient and family but it was noted that the standard of documentation around the outcomes of the discussion with the medical staff can still be an issue.

In discussion with the team it was evident that the nursing staff are the leaders in a lot of the work done around end of life. This is possible due to the relationship and trust of the medical staff in senior nurses, such as Palliative Care CNCs, to lead this body of work.

Multidisciplinary Team (MDT) meeting - Palliative Care department Guys Hospital

The MDT was represented by medical staff (consultant and registrar), nursing staff, EOL facilitator, Social Worker and Chaplain. The team discuss inpatient management plans, discharges and all deaths that occur under the Palliative Care team. It covers all issues such as readmissions, adverse events and patient outcomes as well as social and spiritual issues. The discussion is led by the Consultant with an active role played by the EOL facilitators – all members are encouraged to participate and contribute. Most patients had been assessed for or commenced on the AMBER care bundle and it was very much seen as an integral assessment of patients for end of life care and management.

Presentation to General Medical Staff – Elderly Care Seminar St Thomas' Hospital

I was asked to present to the weekly Elderly Care Seminar on the work the CEC is doing around EOL and specifically the experience of piloting the AMBER care bundle. There were 12 senior specialists and some interns (F1s) in attendance who were interested in the transferability of the AMBER care bundle to our setting. There was some discussion around the type of issues identified in NSW with agreement that the same issues still occur in the UK setting especially related to clinician engagement.
The AMBER care bundle is mainly used by the clinicians in the medical wards.

Walk the Ward – St Thomas' Hospital

Following the presentation I was taken around Victoria and Sarah Swift wards to see the AMBER care bundle in 'action'. I had the opportunity to speak to the nursing staff who were caring for patients supported by the AMBER care bundle and those that were responsible for implementing it. All nursing staff were positive about the AMBER care bundle and were confident in encouraging medical staff to commence appropriate patients. It is also seen as assisting in discharge planning.
"It (AMBER care bundle) provides the framework for what we should be doing anyway"

Meeting with staff on Samaritan ward – Guys Hospital

I met with the Nurse Manager and two nursing staff to talk about how they see EOL management on their ward. Samaritan ward specialises in caring for patients with different types of cancer and undergoing chemotherapy. It was great to get the staff's perspective on how the AMBER care bundle and Priorities for Care of the Dying Person work in caring for their patients. They felt the tools gave them the opportunity to highlight EOL issues with the medical staff and confidence to advocate for their patients.
"It's best practice… just the right thing to do"

AMBER care bundle team meeting – Guys Hospital

The meeting with the AMBER care bundle team was on the last day of my visit to the UK. I was able to discuss my reflections and learning of the 2 week visit and the findings that I wanted to bring back to our program especially in regard to having some formalised evaluation done.
The AMBER care bundle tool is currently being reviewed, issues for consideration include:

- clarity around 'trigger' questions / identifying the patients
- clearer direction around having family involvement in the 4 and 12 hour actions
- daily ACT as part of usual daily documentation not 'add on'
- ceasing the AMBER care bundle support should be done later rather than sooner

These issues are something that have come up in NSW and our education packages will be updated to reflect this thinking.

Implication for NSW and EOL program

The visits to Guy's and St Thomas' clarified some of the issues I had around implementing the AMBER care bundle but also cemented in my mind our priority areas of focus for the NSW EOL program:

- Further develop education and support resources for the AMBER care bundle and actively promote the program
- develop the last days of life toolkit using the patient centred principles of the Priorities for Car of the Dying Person
- focus on measuring outcomes such as achieving preferred place of death
- use validated tools such as SPICT for identifying patients to assist / support clinician decision making
- identify champions / early adopters who will act as change agents
- develop clinical indicators that have some meaning to them not just a 'number' to be collected
- develop formal bereavement and family follow up processes
- develop formal questionnaire / interview program to measure family / carer satisfaction of the care they and their loved one received in the last days of life

Acknowledgment:

- → **Mr Michael Thomas**, End of Life/Liverpool Care Pathway Education Facilitator
- → **Dr Rachel Newman**, Palliative Care Specialist
- → **Sister Sarah Wonnacott** - Ward Manager Wellington
- → **Mr Ian Moyle** - Clinical Matron
- → **Ms Amanda Thompson** - Learning and Development

About Royal Cornwall Hospital NHS Trust

Royal Cornwall Hospital NHS Trust (RCHT) is the principal provider of acute, specialist and community healthcare to the people of Cornwall and the Isles of Scilly on three hospital sites – Royal Cornwall Hospital in Truro, West Cornwall Hospital in Penzance and St Michael's Hospital in Hayle.

Summary of meeting

I sat in on the 9am 'rapid handover' on Wellington Ward. The meeting has representatives of all members of the multidisciplinary team including medical staff and the EOL Facilitator and is led by the Nurse Manager. The aim of the meeting is to have a quick 'catch up' on what's happening with each patient, which includes resuscitation status and identifying whether the patient is being supported by, or appropriate for, the AMBER care bundle. The meeting took 10 minutes with 28 patients discussed.

Following this I was given a presentation of the results of a program the Wellington Ward had just completed around improving the care and management of the deteriorating patient. The project was called POW (Power of Wellington) and with five specific changes they had seen a reduction of cardiac arrest by 50% in the one year. The five changes included:

1. all observations are done manually – all dynamaps were removed and they invested in sphygmomanometers and giving each staff member their own stethoscope
2. patients at risk of acute deterioration were identified and given 'code blue' so increased surveillance and monitoring of the patient occurred
3. a structured ward round was introduced where decisions around escalation / end of life were discussed and documented – a MEWS score is used to identify those patients at risk[2]
4. there is a nurse led response to deteriorating patient with standard treatment orders
5. documentation standards established around escalation of care and identifying ceilings of care

While they have seen success and improvement in the ward around patient outcomes and the way the team works within the ward, they have also seen an increase in the amount of time a nurse spends with a patient during their shift from 30% to 70%. The staff was extremely proud of the work they had done and outcomes achieved. Unfortunately funding for the project and the EOL Facilitator position is not being renewed.

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[2] A Modified Early Warning Score (MEWS) is a bedside score and track & trigger system that is calculated by nursing staff from the observations taken. To obtain the total MEWS each individual observations is scored according to criteria. Then each individual score is added to give you a total MEWS.

Brighton and Sussex University Hospitals NHS Trust

Acknowledgment:
Ms Jane Stokes, End of Life Care Facilitator

About Brighton and Sussex University Hospitals
Brighton and Sussex University Hospitals (BSUH) is an acute teaching hospital working across two sites: the Royal Sussex County Hospital in Brighton and the Princess Royal Hospital in Haywards Heath. The Brighton campus includes the Royal Alexandra Children's Hospital and the Sussex Eye Hospital. The hospitals provide general, specialist and tertiary services, including Cancer Services (Sussex Cancer Centre), Cardiac (heart) Surgery, Maternity Services, Renal (kidney) Services, Intensive Care for Adults and Intensive Care for new born babies.

Summary of meeting

Jane is a real leader around end of life for the Trust in her role of EOL Facilitator. I was able to spend the morning discussion her role and the various programs that she is involved with.

The main issues discussed with Jane were around the role of the multidisciplinary (MDT) team and gaining clinician engagement in end of life care. The AMBER care bundle is used for appropriate patients and is a means for ensuring there is MDT input and agreement around the patient's management plan. The hospitals and their staff are still coming to terms with the removal of the Liverpool Care Pathway and introduction of the Priorities for Care of the Dying Person.

Derby Hospitals NHS Foundation Trust

Acknowledgment:
Mr Rob Smith – AMBER care bundle / End of Life Facilitator

About Derby Hospital
The Derby Hospitals NHS Foundation Trust provides both acute hospital and community based health services, serving a population of over 600,000 people in and around Southern Derbyshire. There are two hospitals: the Royal Derby Hospital, which incorporates the Derbyshire Children's Hospital, and London Road which is the Trust's Community Hospital. Services provided include a wide range of inpatient and outpatient surgical and medical specialities, intensive care, maternity services, community and children's services and accident and emergency care.

Summary of meeting

The main issues discussed were around how the AMBER care bundle is used in the hospital and the role of the AMBER care bundle facilitator. While AMBER is established within most units of the hospital Rob agreed that it does need to have a person to continually provide education, support, monitoring and feedback to clinicians. It was noted the role has expanded over time as needs and priorities around end of life arise – an example of this is the change of direction of care planning following the removal of the Liverpool Care Pathway and introduction of Priorities for Care of the Dying Person.

The team is led by a Palliative Care physician and meet regularly to monitor progress of program.

University Hospitals of Leicester NHS
NHS Trust

Acknowledgment:
- → **Ms Jane Lee** –Palliative Care/EoLC Lead Nurse
- → **Ms Chris Britwistle** – RN, Hospice Care
- → **Ms Becky Motley** – AMBER care bundle facilitator

About University Hospitals of Leicester

University Hospitals of Leicester is one of the biggest and busiest NHS trusts in England, incorporating the Leicester General, Glenfield and Royal Infirmary hospitals. The trust has a Children's Hospital and runs one of the country's leading heart centres.

Summary of meeting

I had a general discussion with the team around end of life issues within an acute hospital system. The end of life program is still mainly palliative care led but within their service they have seen an increase in the number of non-palliative care patients who are referred. While this is led by one clinician it is increasingly seen by the Trust as a priority of care for all patients. The AMBER care bundle is embedded in the hospital but it was admitted that the success of the program can be dependent on having a facilitator who drives it.

Warrington and Halton Hospitals NHS
NHS Foundation Trust

Acknowledgment:
- → **Ms Joanne Meredith** – AMBER care bundle facilitator
- → **Ms Margaret Kendall** – Palliative Care Clinical Nurse Consultant (CNC)

About Warrington and Halton Hospitals NHS Foundation Trust

Warrington and Halton Hospitals NHS Foundation Trust manages Warrington Hospital and Halton General Hospital in the North West of England. The majority of the trust's emergency and complex surgical care is based at Warrington whilst Halton is a centre of excellence for routine surgery.

Summary of meeting

I had the opportunity to spend the day with Joanne and see how her role as AMBER care bundle Facilitator works within the hospital. The role itself is diverse and includes going onto the wards and rounding with staff to identify patients, providing support to those staff that care for patients approaching end of life and providing staff education around end of life issues.

Having an AMBER care bundle facilitator has seen the program gain traction in most wards. A process has been implemented where a notification is sent to Joanne by staff when a patient is commenced on the AMBER care bundle and assistance required. During my visit a notification came where a nurse on a ward had concerns around a patient being supported by the AMBER care bundle - there was documentation in the management plan but nothing around the medical team having a conversation regarding goals of care. Joanne went to the ward and spoke with the nursing and medical team and was able to facilitate the conversation being had.

The AMBER care bundle and the introduction of the Priorities for Care of the Dying Person has seen end of life be seen as an important and usual part of the patients management plan and receives strong Board and Executive support. The end of life program is nursing led with the Palliative Care outpatient clinic managed by the Palliative Care CNC.

Implication for NSW and EOL program

The opportunity of being able to visit the various sites that were actually 'doing' the work around end of life care was invaluable. Being able to see the AMBER care bundle in practice and seeing the process around implementing the Priorities for Care of the Dying Person program gave me a real insight into what can be achieved in the work we are starting in NSW. One area that really impressed me were the Bereavement Units in each hospital. The usual process is for the family to come to the hospital the day after their family member died to get the death certificate – they collect it from the Bereavement Unit where the staff are able to talk to the family, provide them with information around burial and finances if required and importantly give them the "VOICES" survey[3].

The priorities identified through the visits include:

- Identify clinical leads / champions for the AMBER care bundle program in each facility it is implemented
- Further develop education and support resources for the AMBER care bundle
- Use the patient centred principles of the Priorities for Car of the Dying Person in the development of the last days of life toolkit
- use validated tools such as SPICT for identifying patients to assist / support clinician decision making
- develop formal bereavement and family follow up processes
- develop formal questionnaire / interview program to measure family / carer satisfaction of the care they and their loved one received in the last days of life

The generosity of time given and the sharing of experiences and resources provided by all I met over the two weeks in the UK was incredible and I was very grateful for the opportunity to meet with them all.

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[3] The National Survey of Bereaved People (VOICES, Views of Informal Carers – Evaluation of Services) collects information on bereaved peoples' views on the quality of care provided to a friend or relative in the last three months of life for England.

Acknowledgment:
Dr Jonathan Koffman, Senior Lecturer in Palliative Care & Sub Dean for Postgraduate Teaching in the School of Medicine

About Cicely Saunders Institute

The Cicely Saunders Institute is the first purpose built institute for research into palliative care. The goal is to find what will provide the best possible quality of life for patients and their families, which includes control of pain and other symptoms, and attention to psychological, social and spiritual problems.

About Jonathan Koffman

Jonathan is the Senior Lecturer in Palliative Care and Course Co-ordinator for the inter-professional Postgraduate Certificate, Diploma and MSc in Palliative Care. His research covers such areas as: social disadvantage and social exclusion at the end of life; black, Asian and minority ethnic (BAME) groups, illness and symptoms attributions; religion and spirituality; quality improvement; mixed methods and qualitative research; phenomenological approaches to illness; the philosophy of palliative care[viii].

Summary of meeting

This was an opportunity to meet with Jonathan in relation to the overall work he is doing at the Cecily Saunders Institute and the work that has been specifically undertaken by his team around the evaluation of the AMBER care bundle in the UK. We had a great discussion around evaluating programs and the importance of doing so in a structured, scientific approach. Main points of the discussion included:

- evaluating the AMBER care bundle and its impact on patient outcomes is essential
- there is a need to have a research focus to the evaluation *"treat it like implementing a new drug"*
- a step wedge model would be appropriate to use for the evaluation method
- collecting qualitative data through patient and family experience is required

Implication for NSW and EOL program

There is an opportunity for the UK evaluation team and NSW team to collaborate as part of the AMBER care bundle evaluation.

The CEC team will continue discussions with David Currow (Chief Cancer Officer of NSW and Chief Executive Officer of the Cancer Institute NSW) and his team around developing a scientific approach to the evaluation of the AMBER care bundle in NSW.

4.2.2 Canada

BRIDGEPOINT
active healthcare

Acknowledgment:
→ **Ms Usha Thomas** - Patient Care Manager – Dialysis & Renal Care
→ **Ms Daníelle Donadio** - Chief, Communications & Public Affairs
→ **Mr Peter Allatt** – Ethicist
→ **Ms Jan Fraus** – Cleric / Spiritual Care
→ **Ms Wendy Cameron** – Social Work, Palliative/Renal Services
→ **Ms Brenda Stein** - Social Work, Palliative Care
→ **Ms Emma Elliot** – Social Work Student

About Bridgepoint Active Healthcare

Bridgepoint Active Healthcare is a complex care and rehabilitation hospital and research centre in Toronto Canada. Its focus is to transform care for patients living with complex health conditions so they can live better. Bridgepoint Active Healthcare operates under four pillars that support the diagnosis, treatment, management, research and teaching of leading healthcare practices for patients with multiple health conditions:

- **Bridgepoint Hospital** is a purpose-built facility designed to enable patients to be active in their care.
- **Bridgepoint Collaboratory for Research and Innovation** conducts pioneering research to find new ways to treat people that will immediately improve health outcomes, performance and system sustainability. It is one of the only research enterprises in the world to focus exclusively on complex chronic disease.
- **Bridgepoint Family Health Team** is a community-based practice focused on transitioning patients back home and keeping them connected with primary care, home care and other community services.
- **Bridgepoint Foundation** raises money on behalf of Bridgepoint Active Healthcare to fund Bridgepoint's vision of helping people with complex health conditions live better.

Summary of visit

Meeting with team form Bridgepoint Collaboratory for Research and Innovation

As part of the visit I was invited to meet with the MDT from the Bridgepoint Collaboratory for Research and Innovation. The discussion focused on what were the priority areas of research the team are targeting around chronic care management and end of life management. The team takes a 'holistic' approach with a focus on changing policy and creating best practice models of care. Areas of research are focused on chronic care conditions but an important area within that research includes how patients with many conditions move through the system and the care they receive along that continuum - from family doctor to specialists, through acute care, rehab and to home care. An important aspect of that care continuum is identifying when to commence discussions around end of life and ensuring that they continue throughout the patient journey.

I was able to present to the team the work of the CEC and the EOL program and discuss with them the barriers that affect good EOL care for all patients.

Meeting with team members form Bridgepoint Hospital

I then visited the team who work in the inpatient setting; this included the Nurse Manager of the Renal Unit, the hospital Ethicist, Social Workers and Chaplain. We were able to have a general conversation around the issues that can support or put barriers up around end of life care and management.

The team were extremely generous in their time and sharing of lessons learned and approaches taken at their local level. In discussing what issues affect good EOL care the experience of the team was that there needs to be recognition of the time to have the discussion with the patient and their family and willingness of medical staff to do so.

For all patients admitted to the Renal Unit an escalation plan is developed by the nursing staff and then signed off by the physician.

Other issues covered in the conversation included:

- early recognition and discussion around EOL with chronic care patients needs to be done i.e. a chronic condition is a life limiting condition so setting realistic goals of care with the patient is essential
- there needs to be clear systems and processes within hospital for EOL conversations such as who can initiate them, documentation standards and communication across multiple transitions of care
- need to have alliance and communication strategies in place with GPs for care continuum
- the multidisciplinary team are an important part of chronic care planning and need to be part of and aware of the end of life care plan
- the conversation is an ongoing process with the patient, family and clinical management team

Implication for NSW and EOL program

The issues highlighted in the discussion are similar to the NSW setting. The areas of focus we are taking around early identification and conversations are heading in the right direction.

We need to continue to make connections with community teams and GPs.

4.2.3 United States of America

PALLIATIVE CARE CENTER OF EXCELLENCE
UNIVERSITY of WASHINGTON

Acknowledgment:

→ **Dr Randy Curtis** - Professor of Medicine Director, UW Palliative Care Center of Excellence, Section Head, Pulmonary and Critical Care Medicine, Harborview Medical Center
→ **Dr Helene Starks** - Associate Professor, Dept. of Bioethics and Humanities Director, Metrics, Quality & Evaluation Core, Palliative Care Center of Excellence
→ **Dr Ann O'Hare** – Nephrologist, Seattle VA Hospital
→ **A/Prof Erin Kross** – Division of Pulmonary and Critical Medicine
→ **Mr Jimmy Hoard** - Program Operations Specialist, Palliative Care Center of Excellence

About University of Washington Palliative Care Center of Excellence

The Palliative Care Center of Excellence mission is to improve the palliative care received by patients with life-threatening or life-limiting illness and their families, support clinicians providing this care, and to generate new knowledge and educational and clinical resources to improve palliative care regionally, nationally and globally. The Center does this through enhancing inter-professional and interdisciplinary research, education, and clinical practice in palliative care. In addition the Center integrates, coordinates, and augments the clinical palliative care provided throughout UW Medicine and in the region through key activities such as development and implementation of standards, program evaluation, and program development support.

Meeting with Dr Helene Starks – University of Washington Medical Clinic

Helene Starks, PhD MPH, is an Associate Professor in the Department of Bioethics and Humanities and Adjunct Associate Professor in the Department of Health Services at the University of Washington School of Medicine. Dr Starks' research interests include issues related to palliative and end-of-life care for patients, their family members, clinicians, and health systems; medical decision-making and clinician-patient communication.

The main issue discussed with Helene was around clinician engagement in end of life – this included recognising it, acknowledging it and commencing the conversations and care planning early on in the patient's disease trajectory. The main issues Helene highlighted in the discussion included:

- End of life planning is not a failure of the medical clinician as the acute / medical model of care doesn't work for those patients approaching end of life.
- The use of triggers to identify patients is essential to guide clinical staff, it's difficult to assign a 'time' trigger but if patients have 4 admissions in 6-12 months that really is a lot of time to spend on the patient without making a plan for end of life.
- Use case studies or M&M as a forum to review and discuss patients deaths
- Coordination of patients care across all services is vital – an example of what they do is give the patient a copy of the *not for resuscitation* order so it can be displayed on the fridge for Ambulance personnel / GP to see/access.
- measure what you are doing but pick something meaningful – the patient / family experience is a 'true' reflection of how care and death is managed

Meeting with A/Prof Ann O'Hare – Nephrologist, Seattle Veterans Affairs Hospital

Dr O'Hare is Associate Professor of Medicine, Division of Nephrology. Dr. O'Hare is affiliated with Harborview Medical Center, University of Washington Medical Center and VA Puget Sound Healthcare Seattle Division. Her clinical and research interests include palliative and end-of-life care in older adults with kidney disease

The main issues highlighted in discussion with Ann related to Advance Care Planning (ACP).

- EOL in chronic patients is difficult and usually based on developing relationships with the patient and family over time
- Delays in developing a goals of care / ACP can relate to the practitioners confidence in having the conversation with the patient early enough
- Agree the benefits to the patient having earlier palliative care involvement are positive
- Hospice plays a big part in management of dying patients in the US

Meeting with Dr Erin Kross – A/Prof of Medicine, Division of Pulmonary and Critical Medicine

Dr. Kross is an assistant professor of medicine in the Division of Pulmonary and Critical Care Medicine. She practices critical care medicine, inpatient pulmonary consultation medicine and has a general outpatient pulmonary clinic at Harborview Medical Center. She also attends on the inpatient palliative care consultation service at Harborview. Her clinical and research interests are focused on patient and family-centered palliative care during critical illness.

The main issue highlighted in discussion with Erin was around end of life planning especially in the critical care setting.

- end of life planning should be done in partnership with patients – ask them what they want for themselves, how they see their death
- clinician engagement is essential
- the use of the M&M meeting to concentrate on how the patient dies rather than why is a way of encouraging earlier recognition and of patients who may need end of life planning

Meeting with Dr Randy Curtis – Professor, Division of Pulmonary and Critical Care Medicine; A. Bruce Montgomery - American Lung Association Endowed Chair in Pulmonary & Critical Care Medicine Section Head, Harborview Medical Center Director, UW Palliative Care Center of Excellence

Dr. Curtis is the A. Bruce Montgomery-American Lung Association endowed chair in pulmonary and critical care medicine, UW professor of medicine and section head for pulmonary and critical care medicine at Harborview Medical Center. He is also the director of the new UW Palliative Care Center of Excellence. Dr. Curtis's research focuses on improving palliative and end-of-life care for patients with critical illness and patients with chronic and life-limiting illnesses as well as patients' families.

The main issue highlighted in discussion with Randy was that education and support systems for clinicians to identify patients and commence the conversation around end of life is essential for any success or culture change. The program has been in place for over 10 years and they are starting to see the change in culture around end of life management but still the issues identified in NSW are just as prevalent in the US.

Implication for NSW and EOL program

Working with clinicians in developing ACP and discussing goals of care with patients earlier in the disease trajectory is important. Achieving engaged clinicians in EOL needs to be strategic with long-term commitment and support.

5. References

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