Conflict resolution in end of life treatment decisions: a rapid review

Ken Hillman, Jack Chen

THE UNIVERSITY OF
NEW SOUTH WALES
SYDNEY · 2052 · AUSTRALIA

The Simpson Centre
for Health Services Research
INNOVATION · INTERVENTION · IMPLEMENTATION

the saxinstitute
RESEARCH PARTNERSHIPS FOR BETTER HEALTH

NSW☒HEALTH

This report was prepared and written by:

Ken Hillman and Jack Chen from The Simpson Centre for Health Services Research, University of New South Wales.

Enquiries regarding this report may be directed to the:

Manager
Knowledge Transfer Program
The Sax Institute
www.saxinstitute.org.au
Phone (02) 9514 5950
Fax (02) 9514 5951
Email: directorate@saxinstitute.org.au

Suggested Citation:

Hillman, K., Chen, J. Conflict resolution in end of life treatment decisions: An *Evidence Check* rapid review brokered by the Sax Institute (http://www.saxinstitute.org.au) for the Centre for Epidemiology and Research, NSW Department of Health; 2008.

Disclaimer:

CONTENTS

EXECUTIVE SUMMARY

While there are many documents and published articles around end-of-life (EOL) care, including withdrawing and withholding treatment, there are very few that directly refer to how to manage conflict and even fewer that have scientifically tested or compare different approaches. This is not surprising, as the management of conflict does not readily lend itself to scientific and rigorous testing using conventional research methodologies. There is an inherent assumption that if the many guidelines around how to manage EOL care are followed, there will be minimum conflict. While this assumption has not been tested, it is intuitively appealing.

Conflict around EOL issues can occur between clinicians, between patients and their relatives; or between the relatives of patients, especially when the patient is incompetent; or between relatives and clinicians who disagree about the most appropriate management plan. There is also an inherent conflict between society and its expectations around what modern medicine can potentially offer.

Potentially irresolvable conflict is usually related to either to a decision to cease active management or around how the process of withdrawing or withholding treatment should occur.

NSW Health explores existing options for directly resolving conflict in EOL care in its document, 'Guidelines for End-of-Life Care and Decision Making' (http://www.health.nsw.gov.au).

Obviously, there are no straightforward solutions to EOL conflict. Rational arguments can often be made for either party's approach. Because of the very nature of the conflict, it is important, whenever possible, that a conclusion is reached rather than a judgement. Judgements neither reflect the complex nature of the issues nor do they allow satisfactory resolution of the highly charged emotional nature of the conflict.

This review explores some of the ways to prevent EOL conflict, starting with community awareness and advance planning for EOL, especially in the event of the person being incapacitated and unable to make rational decisions.

There are currently attempts around Australia to better inform our society of the need for advanced care planning in case the person is not capable of making decisions at the EOL. However, these are often imprecisely constructed and do not involve all the potential parties involved in EOL care. The State of Oregon in the United States of America (USA) has developed a State-wide initiative which uses standardised forms, filled in by clients in conjunction with family doctors. It is agreed that the directive is always placed on the front page of the patient's notes in hospital. Admission to hospital is often prevented by shared electronic information between nursing homes, ambulance services and emergency departments (EDs). This multifaceted approach

has been successful in decreasing hospital admissions and making patient's wishes explicit, therefore probably reducing the risk of EOL conflict.

Many episodes of conflict at the EOL, especially in the intensive care unit (ICU) come about when other hospital specialists on general wards avoid discussions around dying and use phrases such as ...."do you want everything done?" with patients and their families. This leads to unrealistic expectations by relatives and potential conflict at the EOL. Specialists working in intensive care may have to increasingly be involved with the diagnosis of dying as they best understand the limitations and potential benefits of further active treatment and therefore are key players in making a diagnosis of dying, when further active treatment would be futile. Increased consultations with intensivists may decrease unrealistic expectations and potential conflict. NSW Health could encourage hospitals to take up these issues when formulating local policies.

Hospitals around the world are increasingly employing rapid response systems (RRS) such as medical emergency teams (MET) in order to recognise and respond to serious illness early. However, many patients who are naturally dying in a predictable way are increasingly being subject to these emergency calls. Early studies in Australia suggest that this can also be an opportunity for diagnosing and managing dying patients at an earlier stage and, together with palliative care teams, provide more appropriate and earlier care. As NSW has pioneered the concept of RRS, the Department may consider supporting pilot trials in this area.

These, and other initiatives around managing dying patients in general hospital wards, can also be reinforced by the use of integrated care plans such as the one used in Liverpool, in the United Kingdom (UK) and adopted by the National Health System (NHS). This could be an opportunity for NSW Health to bundle standardised initiatives for managing EOL patients.

Communication is probably the most important element in preventing EOL conflict both in the prevention of conflict and resolving it once it has occurred. This is intuitive and well known but the challenge is how to improve communication. Some of the communication strategies that have been used include a standardised brochure on dying, including withdrawing and withholding treatment, which could be made available in all NSW hospitals, especially in ICUs. There are many published practical points using strategies which could also be summarised and provided to all staff in ICUs and other parts of the hospital. Improved undergraduate and postgraduate education in these areas is probably easier said than done. It is probably more realistic for NSW hospitals to include clear guidelines around communication in a standardised State care plan around EOL care. Another option that could be considered is to sponsor a course similar to the American Medical Association, conducted over two days, which is specifically designed to address care at the EOL. Many of the above strategies have some evidence to support their effectiveness in improving EOL care but little in the way of specifically reducing conflict.

As with the principles of communication, there is no shortage of excellent documents from many countries, governments and professional bodies around guidelines on how to manage EOL matters effectively. However, as with the principles of communication, the challenge is how to implement the guidelines. There is the danger that, as with many guidelines and published glossy pamphlets, they sit on shelves or do not make their way down to the patient/clinician interface in a meaningful way. Perhaps incorporating guidelines and the principles of communication into State-wide and standardised care plans with appropriate dissemination and sustainability programmes may assist in implementing the excellent theory into everyday practice.

In some areas of NSW, over half the population were born outside the country. The next generation of these immigrants may also have different attitudes and beliefs around EOL issues. A summary provided by NSW Health with practical suggestions of how to deal with the many different cultural, racial and religious groups in our society may be useful for staff working in areas where EOL issues are common.

All of these preventative strategies could potentially result in better management of the dying and reduced conflict at the EOL.

However, there will always be a situation where, despite even the most effective preventative strategies, a seemingly irresolvable conflict arises. There are several possible strategies that can be used in these situations. Existing strategies include time and repeated discussions, time limited treatment trials and transfer of the patient to another institution. The use of a second medical opinion can also be used but there is no documentation on its frequency or success rate, either in the short- or long-term.

The NSW Health document specifically does not mention ethics committees as a way to resolve conflict. This form of resolution is more common in the USA and there are few reports in Australasia. The 'ethical' framework for practising medicine – beneficence, non-maleficence, autonomy and justice – could, in fact, cover almost any decision on EOL matters. Having said this, there are several studies which have reported successful prevention and resolution of EOL conflict using ethicists and ethical committees. The word 'ethics' in this context may be misleading as the strategies involved others who were not 'ethicists' and employed intense and lengthy communication strategies which have also been shown to be successful by non 'ethicists'.

The area of facilitation could be explored in more detail. Apart from a medical second opinion, the NSW document recommends that a third senior person within the hospital may be useful as a facilitator. A problem with this suggestion may be that any employee of the institution could be seen to reinforce and support the opinion of other hospital employees, no matter how objective the facilitator was. Although there is little scientific evidence, there are now many examples of

specifically trained facilitators who mediate in areas where previously there was only legal intervention. It appears that the generic skills of mediation are just as important as having content knowledge in the specific area under dispute. For the purposes of this document two forms of facilitation are explored: mediation or conciliation, where an outcome is facilitated by an expert but ultimately decided by the two parties in conflict; and adjudication (also called expert determination or arbitration) where a third party, specifically trained in conflict resolution, offers a judgement after hearing the case. In theory, this form of conflict resolution could be used in EOL disputes with the level of knowledge and experience of the facilitator being defined by NSW Health. The facilitators could be employed directly by NSW Health or contracted out. There are many examples where the NSW government uses this form of conflict resolution, including in the family court and in disagreements around failure to comply with contracts.

A Tribunal can be used as another form of conflict resolution. End-of-life matters can be referred under the NSW Guardianship Act when patients lack decision-making capacity. This rarely happens in its current form. The Tribunal is usually referred to patients who are incompetent and where there are no known contacts to act in their interest. The Tribunal can also act in accord with disputes around the accepted hierarchy of those close to the patient in regard to who can make a decision on behalf of the incompetent patient. The Tribunal could act more in an arbitration fashion with matters referred to it after a predefined mediation process has failed. Under current legal practices around the world, there is usually an appeal process even after arbitration.

Most of the reviewed literature counsels avoidance of legal intervention if at all possible in EOL conflicts. This is not surprising. The law is specific on points such as euthanasia but withdrawing and withholding treatment at the EOL is, in theory, both possible and not possible. The opinion of the law would, therefore, be no more or less informed than from other options such as mediation or Tribunals. There are also many practical problems with legal solutions, such as time pressures and prolonged suffering by all parties involved in the dispute. Legal intervention would also offer little in the way of resolving long term psychological and general well being of the parties involved in the conflict. To work through a process with the active involvement of all parties, no matter how difficult, intuitively offers a more robust solution than a legal one. Because of the failure to accommodate modern medical practice, including the ability to inappropriately prolong life, with appropriate legislation, we have the perverse situation where the law can determine medical practice at the EOL. In other words, the fear of arbitrary legal prosecution can result in prolonging potentially futile care at great financial and personal cost to all involved.

We are facing an ageing population with often unrealistic expectations around what modern medicine can offer. As a result many deaths now occur in ICUs and are often unnecessarily prolonged and undignified, resulting in suffering both for the patient and their families and friends as well as resulting in increasing costs to our society.

NSW Health probably has a unique opportunity to construct and promote its own system for delivering EOL care, which would, hopefully, reduce potential conflict. As with all new systems it would be important to include a rigorous evaluation strategy.

Finally, it is probably timely for governments to facilitate a wide-ranging discourse with society around issues such as the often unreal expectations around what modern medicine can offer and the provision of EOL care. Perhaps a summit could be supported by NSW Health and involve participants such as governments, professional bodies and consumers.

SUMMARY OF POTENTIAL STRATEGIES TO REDUCE CONFLICT AT THE EOL

- ***Advanced Care Directives*** using a model such as used in the State of Oregon, involving the family doctor as well as being accessed at many points in the system, eg nursing homes. The plan is displayed on the front page of the patient's clinical notes in a standardised format and can be accessed by many points of potential care, eg pre-hospital ambulance services and EDs

- ***Communication*** according to the literature is the key to both preventing and resolving conflict at the EOL. There is abundant evidence to suggest that consumers want better communication and that clinicians are often not skilled in that area. Suggestions include better under and postgraduate education; specific courses for hospital staff; the provision of specific cultural material; and embedding communication goals in State-wide and standardised EOL care plans similar to those used in the UK.

- ***Early Palliative Care Involvement*** has been shown to be effective in improving EOL care. Palliative care is no longer confined to patients who have cancer. There are models that involve them in a wide range of all hospitalised patients at an early stage where there is a high likelihood of death and even in parallel with active management.

- ***Early Identification*** of patients with a high likelihood of dying in the general wards; EDs and, as a result of early emergency calls to at-risk patients can, be used to develop systems to proactively manage EOL care in a more effective fashion. Situations where conflict is likely can also be identified. Pre-emptive strategies could then be embedded in standardised EOL care plans.

- ***Ethics Consultations*** are probably more commonly used in the USA and trials that have shown their success have also involved other strategies such as intense communication plans and the provision of specific written information.

- ***Mediation, Adjudication and Tribunals*** are all useful ways of resolving otherwise unresolvable conflict. It seems important that specific training and experience in managing conflict is at least as important as having specific content knowledge. There are many models that have been successfully employed to resolve conflict that would have otherwise been referred for legal resolution.

- ***Legal Solution****s* have been seen as a last, and often unsatisfactory, resort as it is difficult to frame legislation around matters where there are few concrete rights and wrongs. Several countries have attempted to frame specific legislation around EOL matters but have had to face the same wide discretionary interpretations as those countries without specific legislation.

- ***Involving Society*** in the increasing problem of unrealistic expectations around modern medicine is becoming more important as our population ages. Specialties such as intensive care, with the support of governments, could take a lead role in such a discourse at State and National levels.

STRATEGIES TO AVOID EOL CONFLICT	COMMENTS	POSSIBLE ACTION
Advanced Care Directives	General consensus by community and health industry that these would make EOL care easier and would improve care.	Need to provide interdisciplinary and multi-level strategies to improve uptake and include GPs/acute hospitals/nursing homes legal services and community in a concerted and co-ordinated way.
Early Identification and Involvement of Palliative Care Services for Dying Patients in Hospital	There already exists widespread use of early response systems in NSW hospitals as a vehicle for early recognition of the dying patients. Palliative care services could interact more formally with early response systems and other parts of the hospital to provide early palliative care interventions for a wide range of dying patients.	Need to develop systems for more effective integration of acute and palliative care services in acute hospitals.
Improved Communication	Well developed and organised specialties of intensive care and emergency medicine. Large multicultural population. High level of clinical services in acute hospitals.	Standardised State-wide care plans for the dying which cover patient's hospital journey, including guidelines for with-holding and withdrawing care once patient identified. Specific communication courses for clinicians working in acute hospitals. Specifically designed material for both patients from a multicultural background as well as for staff treating them.
Ethics Committees	Seems to be more commonly employed in the USA and are institutionally based.	Could integrate a version of this strategy in combination with communication and mediation strategies.
Mediation Adjudication Tribunals	Potential to develop specifically designed system in NSW using a combination of these strategies.	High level working group to study systems already in use in NSW and other States which address similarly highly charged conflict areas.
Legal Solutions	Universal desire to avoid the legal intervention if possible in the literature; by individual institutions, by governments and usually by the community as well. Where specific EOL laws are in place eg Texas and Israel there remains value laden questions which do not lend themselves to simple solutions.	Involvement of legal experts in constructing a specifically designed system in NSW would minimise need for legal solutions.

INTRODUCTION

There is an assumption by both physicians and society that admission to hospital implies treatment will be available that will positively address their medical problems. However, we have little information on the number of patients who are admitted to hospital where active treatment will make little difference to outcome. And yet, the expectation of society is usually that hospitals will provide improvement in the clinical condition, not that patients are admitted to hospital knowing that death is the most likely outcome.

The specialty of intensive care medicine, including the care of neonates, children and adults is increasingly being involved in EOL care. Twenty per cent of Americans die in ICUs. More than a quarter of intensive care patients will die before leaving hospital[1]. The majority of patients who die in intensive care do so after a decision to limit therapy as opposed to dying despite continuing full and active treatment[2,3]. Moreover, evidence suggests that end-of-life care for the critically ill is inadequate with a high prevalence of pain and other distressing symptoms[4-7];as well as poor communication from clinicians[8-10]; and discordance among families and clinicians about care plans and goals[11-13]. Intensive care clinicians report awareness that their treatment of dying patients is often sub-optimal and recognise their own deficiencies in knowledge and skills for EOL care[14,15]. The Institute of Medicine in the USA has identified improved quality of end-of-life care as a major goal[16] and several documents, position statements and practice guidelines have been published around this area[17-20].

There are increasing pressures to admit patients into ICUs. The majority of Australians now die in institutions, rather than at home. Even terminally ill patients in nursing homes sometimes find their way into acute hospitals. Once in the ED they are often assessed and admitted to hospital as the history and prognosis may not be clear initially; and because it is usually easier, in purely practical terms, to admit a terminally ill elderly patient rather than arranging appropriate support in the community. Once in an acute hospital there are expectations, realistic or not, that there is some hope. The conveyor belt to intensive care is further facilitated by increasingly specialised physicians who often do not understand the way different co-morbidities and multi-organ involvement influences the patient's prognosis. Similarly, surgeons may seek a short-term answer by operating on a patient even when the situation is otherwise hopeless. Despite a poor outlook, it is difficult to say exactly when active treatment would be futile and, as such, many patients are admitted and given a trial of intensive care. If that trial fails, intensivists are often faced with the sometimes difficult challenge of withdrawing and withholding treatment.

Factors which drive patients to be admitted to an ICU, especially unrealistic expectations, are also the factors which can give rise to conflict, usually around whether further active treatment is appropriate.

The conflict can occur as a result of a difference of opinion between an admitting clinician and an intensive care physician or even between intensive care clinicians. These are usually resolved in-house. Conflict can occur between relatives/friends of a patient who is incompetent, where there is a difference of opinion about the appropriateness of further treatment. These are also usually resolved without referral to a third party outside the hospital system.

The most challenging conflict occurs when relatives/friends of an incompetent patient, usually in an ICU, do not agree with the caring clinician/s.

This document covers all these forms of conflict but concentrates on the latter form of conflict and explores ways in which it can be resolved. The document does not separately address conflict around EOL in neonates and children. However, reference is made to this type of conflict throughout the document.

One of the major challenges in the preparation of the document was to specifically support the different options for resolving EOL conflict with conventional scientific evidence. There are many documents and studies around strategies that potentially may decrease conflict, such as policy statements from governments and professional bodies; and large bodies of work on concepts such as communication and mediation. However, there is little in the way of evidence to suggest which may work in practice. In areas such as the use of Tribunals or the legal system, the conventional evidence for their efficacy is almost non-existent.

The document is therefore divided into two distinct sections. The first section reports strategies that have been used to reduce conflict at the EOL. The summaries are specifically constructed to inform NSW Health on options which are currently utilised and others which the Department may wish to consider. These options are separately referenced. The second section specifically addresses the 10 questions asked by NSW Health and attempts to summarise the existing evidence for many of the strategies outlined in the first descriptive section.

It was thought that by simply concentrating on the specific questions with their emphasis on evidence, we would lose important qualitative information which NSW Health may wish to consider when constructing policies. We believe both sections complement each other and we have tried to avoid overlap and repetition.

The document is considerably longer than that requested by the department. The subjects covered are multidisciplinary and complex. There are many possible options for resolving conflicts from areas other than the traditional medical ones. Users are encouraged to examine the specific answers to the Department's questions but also to drill down on other options, where there is little in the way of traditional scientific evidence to support them.

REFERENCES

1. Nelson JE, Angus DC, Weissfeld LA, Puntillo KA, Danis M, Deal D, Levy MM, Cook DJ. Critical Care Per Workgroup of the Promoting Excellence in End-of-Life Care Project. End-of-Life care for the critically ill: A national intensive care unit survey. *Critical Care Medicine* 2006;34(10):2547-2553.

2. Sprung CL, Cohen SL, Sjokvist P, et al. Ethicus Study Group. End-of-Life practice in European intensive care units: The Ethicus Study. *Journal of the American Medical Association* 2003;290:790-797.

3. Turner JS, Michell WL, Morgan CJ, et al. Limitation of life support: Frequency and practice in a London and a Cape Town intensive care unit. *Intensive Care Medicine* 1996;22:1020-1025.

4. Nelson JE, Meier DE, Oei EJ, et al. Self-reported symptom experience of critically ill cancer patients receiving intensive care. *Critical Care Medicine* 2001;29:277-282.

5. Stein-Parbury J, McKinley S. Patients' experience of being in an intensive care unit: A select literature review. *American Journal of Critical Care* 2000;9:20-27.

6. Puntillo KA. Pain experience of intensive care unit patients. *Heart and Lung* 1990;19:525-533.

7. Desbiens NHA, Wu AW, Broste SK, et al. Pain and satisfaction with pain control in seriously ill hospitalised adults: Findings from the SUPPORT research investigations. *Critical Care Medicine* 1996;24:1953-1961.

8. Curtis JR, Wenrich MD, Carline JD, et al. Patients' perspectives on physician skill in end-of-life are: Differences between patients with COPD, cancer, and AIDS. *Chest* 2002;122:356-362.

9. Azoulay E, Chevret S, Leleu G, et al. Half the families of ICU patients experience inadequate communication with physicians. *Critical Care Medicine* 2000;8:3044-3049.

10. Teno JM, Fisher E, Hamel MB, et al. Decision-making and outcomes of prolonged ICU stays in seriously ill patients. *Journal of the American Geriatric Society* 2000;48:S70-S74.

11. Breen CM, Abernethy AP, Abbott KH, et al. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *Journal of General Internal Medicine* 2001;16:283-289.

12. Cook DJ, Guyatt GH, Jaeschke R, et al. Determinants in Canadian health care workers of the decision to withdraw life support from the critically ill. *Journal of the American Medical Association* 1995;273:703-708.

13. Asch DA, Hansen-Flaschen J, Lankeen P. Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: Conflicts between physicians' practices and patients' wishes. *American Journal of Respiratory and Critical Care Medicine* 1995;151:288-292.

14. Solomon MZ, O'Donnell L, Jennings B, et al. Decisions near the end of life: Professional views on life-sustaining treatments. *American Journal of Public Health* 1993;83:14-23.

15. Vincent JL. European attitudes toward ethical problems in intensive care medicine: Results of an ethical questionnaire. *Intensive Care Medicine* 1990;16:256-264.

16. Field MJ, Cassel CK (eds). Approaching death: Improving care at the end of life. Washington, DC: *National Academy Press* (Institute of Medicine), 1997.

17. Carlet J, Thijs LG, Antonelli M, et al. Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care, Brussels, Belgium, April 2003. *Intensive Care Medicine* 2004;30:770-784.

18. Clarke EB, Curtis JR, Luce JM, et al. Quality indicators for end-of-life care in the intensive care unit. *Critical Care Medicine* 2003;31:2255-2262.

19. Truog RD, Cist AF, Brackett SE, et al. Recommendations for end-of-life care in the intensive care unit. The Ethics Committee of the Society of Critical Care Medicine. *Critical Care Medicine* 2001;29:2332-2348.

20. Danis M, Federman D, Fins JJ, et al. Incorporating palliative care into critical care education: Principles, challenges, and opportunities. *Critical Care Medicine* 1999;27:2005-2013.

METHODOLOGY FOR SEARCHES

Although this work has been commissioned as a rapid review, we have made an extensive and systematic search of the literature. This is related to the broad scope of the definition used in EOL care[1] and the general lack of robust research in the scientific literature. In order to have a good grasp of the literature we searched many disciplines including palliative care, intensive care, emergency medicine, social sciences, ethics, law as well as age and aging.

We consulted a medical librarian for advice on ways of approaching the grey literature in the most time-effective fashion. We divided our search strategy into five steps:

1. Searched electronic databases according to the developed strategies.
2. Reviewed the titles and abstracts according to a set of pre-assigned criteria.
3. Retrieved the full text articles after selection.
4. Reviewed the articles/reports and the listed references.
5. Retrieved articles of interest after the review process.

We used the following search strategies to search Medline, EMBASE, PsychInfo, Cochrane Collaboration Evidence Based Medicine Database Collection (Cochrane DSR, ACP Journal Club, DARE, CCTR, CMR, HTA, NHSEED):

1. "Dissent and Disputes"/
2. "Conflict (Psychology)"/
3. Euthanasia, Passive/ or Terminal Care/ or end of life.mp. or Palliative Care/ or Withholding Treatment/ or hospice care/
4. 1 and 3
5. 2 and 3
6. 4 or 5

For CANHIL and SCOPUS databases, we used the following search strategy:

1. 'Palliative care' and 'conflict* OR dispute'
2. 'End of life' and 'Conflict* OR dispute'

We made a specific effort to retrieve important (with a focus on reviews) articles specifically about ethics consultation, advanced care planning (including but not limited to advanced directives) and communication during EOL care. For SCOPUS, we used the following search strategy to search for title, abstract and key words:

1. 'Palliative care' and 'ethics consultation*'
2. 'End of life' and 'ethic consultation*'
3. 1 or 2

For advanced care planning and advanced directives;

1. "Palliative care" or "End of life"
2. advance* care planning
3. advance* directive
4. 1 or 2
5. 1 or 3
6. 4 or 5

For communication;

1. "Palliative care" and "communication*"
2. "End of life" and "communication*"
3. 1 or 2

SEARCHING FOR GREY LITERATURE

Because of the nature of the topic there are a large number of sources in the so-called grey literature, including the ethical dilemmas around the futile treatment in EOL. Given the time constraints and limitation of the resources, we made a focused but limited attempt to review grey literature. We also reviewed the bioethics website as compiled by the University of New South Wales (UNSW) library. We conducted a search using "(end-of-life) and conflict*" or "(palliative care) and conflict*" in the SCOPUS database in article titles, key words and abstracts and reviewed the top 100 websites listed. We also used the same strategy using the Google search engine and reviewed the top 100 websites. We contacted over a dozen experts in the areas of intensive care, aged care, ethics, medical law and guardianship in order to identify missed reports or literature in the area. We also reviewed the reference lists from the retrieved full text articles for useful links and reports.

Search Results
We have reviewed more than 2600 titles in abstract form and selected more than 300 articles to retrieve the full text. We eventually reviewed 260 full articles, including more than 20 reports from the grey literature.

REFERENCES

1. National Institutes of Health. National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care, 2004; (available electronically
http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm)

DEFINITIONS USED IN THIS DOCUMENT FOR ISSUES RELATED TO END-OF-LIFE (EOL) CARE

Advanced Directive – is a document drafted by a competent adult stating wishes in the event of incompetency.

Enduring Power of Attorney – the appointment of someone empowered within NSW legislation to carry out the wishes of a patient in the event of incompetency.

Terminal Illness – is defined as a condition which is irreversible, untreatable and likely to result in death within a year.

Loss of Cognitive Function – is defined as an irreversible and untreatable loss of all capacities to communicate or respond to external stimuli.

Competent Patients – is defined as understanding the nature and consequences of one's actions. These patients are allowed by NSW law to refuse treatment even if it is deemed medically necessary.

Incompetent Patients – are those who do not understand the nature and consequences of one's actions and, therefore, decisions have to be made by a third party, eg spouse, who has been appointed as an advocate with enduring power of attorney.

Vegetative State (www.nhmrc.gov) or post-coma unresponsiveness – encompasses clinical states that follow coma, in which there is an apparently complete lack of purposeful responsiveness, with preservation of sleep-wake cycles and cardiorespiratory function and partial or complete preservation of hypothalamus and brain-stem function.

A Dying Patient – one who will die within six months despite medical therapy

Final Stage – last two weeks of expected life.

A DESCRIPTION OF STRATEGIES USED TO AVOID CONFLICT

PRE-EMPTIVE MEASURES TO AVOID CONFLICT

Community Awareness and Advance Directives
The use of advance directives assists greatly in avoiding conflict around EOL decisions.

A model for the widespread uptake of advance directives has been developed in Oregon in the USA. They use a one page Physician Order for Life-Sustaining Treatment (POLST) document (www.ohsu.edu/ethics/polst). It is printed on a pink page and users are encouraged to put it on their refrigerator with a provided magnet. Knowledge of patient's wishes is made electronically available to many potential points of care such as ambulance services and EDs ensuring the wishes of the patient are known and respected before the patient is admitted to hospital.

Enduring Guardian
Under NSW legislation, if one loses the capacity to make your own decisions, an enduring guardian can make personal decisions on your behalf, including the medical treatment you may or may not receive. This is different from the Enduring Power of Attorney which covers financial matters. The NSW legislation governing enduring guardianship is the *Guardianship Act 1989*
 (http://www.austlii.edu.au/au/legis/nsw/consol_act/ga1987136/)

Other states and territories in Australia have their own legislation. The Guardianship Tribunal can suspend, revoke, confirm or vary the appointment of an enduring guardian. It can also declare the appointment has effect. The fact sheet is available in many different languages (http://www.lawlink.nsw.gov.au).

Many of the studies around the effectiveness of advance care planning are related to cancer. One review suggests the success of advance directives depend on how the message is conveyed[1]. One interesting study suggests that a multifaceted approach to advance care plans reduces length of stay (LOS) in intensive care[2]. There appears to be more people die at home if advance directives are made[3]. There is also some evidence to suggest that involving skilled facilitators can increase the rates and effectiveness around advance directives[4] Patients and their carers are encouraged to bring their advance directive to hospital, where it is displayed on the front page. The POLST document is part of a state-wide initiative summarised in "The Oregon Report Card: Improved Care of the Dying" (www.ohsu.eu/ethics/docs/barriers/. NSW Health provides an excellent document on Advance Care Directives[5]. However, it lacks the same widespread community implementation plan. Another document was prepared for the Office of the Public Advocate in Victoria[6] and reviews the role of Advance Directives in many countries.

An intensive care specialist, William Silvester, from the Austin Hospital in Melbourne is part of a programme which works with neighbouring aged care facilities in order to explain EOL issues and assist them documenting their own wishes (www.respectingpatientchoices.org.au). The programme is being taken up in other states, including the John Hunter Hospital in NSW. The programme had a significant impact on consumer involvement[7]. Barriers to implementation include staff time of individuals who were not funded as part of this initiative; the lack of dedicated staff; and the variation of statutory documents between States.

The programme is being extended to identify, by diagnostic groups and demographics, individuals who may require proactive EOL planning on admission to hospital.

These strategies could reduce conflict at the EOL but there is, as yet, little specific evidence to substantiate this.

REFERENCES

1. Guo B, Harstall C. Advance directives for end-of-life care in the elderly – Effectiveness of delivery modes, Edmonton, Alberta, Canada: *Alberta Heritage Foundation for Medical Research*, 2004.

2. Baggs JG. End-of-Life care for older adults in ICUs. *Annual Review of Nursing Research* 2002;20:181-229. [PMID:12092510]

3. Higginson IJ, Finlay IG, Goodwin DM, Cook AM, et al. The role of palliative care teams: systematic review of their effectiveness and cost-effectiveness. Report to Wales Office of Research and Development of the National Assembly of Wales. London: King's College, 2000.

4. Lorenz KA, Lynn J, Dy SM, et al. Evidence for improving palliative care at the end of life: A systematic review. *Annals of Internal Medicine* 2008;148:147-159.

5. NSW Health Department. Using Advance Care Directives. *Better Healthcare Centre – Publications Warehouse,* 2004 ISBN07347 3675 4. (available electronically http://www.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_056.pdf)

6. Advance Directives: The Legal Issues was prepared for the Office of the Public Advocate in Victoria. (available electronically www.publicadvocate.vic.gov.au).

7. Lee MJ, Heland M, Romios P, Naksook C, Silvester W. Respecting patient choices: Advance care planning to improve patient care at Austin Health. *Health Issues* 2003;77:23.26.

Futility

One of the challenges in resolving conflict around EOL issues is the concept of certainty of death inevitably occurring in the near future, despite active measures. Prognosis almost always has certain degrees of certainty attached to it[1,2]. Prognostic information substantially influences treatment decisions[3,4] and physicians' prognostic estimates are reasonably accurate[5,6].

There usually comes a time when the disease process is so advanced that the patient's condition is worsening despite massive amounts of support. The challenge is to predict futility at a time which minimises the patient's and their carers' suffering.

Clinicians are usually conservative in withdrawing and withholding treatment. Part of the reason is a failure to agree on how to define futility.

There is no absolute agreement around the definition of futility and the lack of agreement can be the basis for differences of opinions between clinicians and patients or, as occurs more commonly in ICUs, their proxy. Definitions of futile care are value laden and as such, universal agreement around its meaning is unlikely.

The American Medical Association Council on Ethics and Judicial Affairs recommends a process involving at least four steps aimed at deliberation and resolution including all involved partners[7].

1. Try to establish boundaries for futility, usually in the early stage of illness.
2. Try to establish goals for treatment.
3. Use of a second opinion, consultant or patient representative to facilitate discussions.
4. Institutional committee to make recommendations if disagreements are irresolvable.

As part of this process, and if the physician does not agree to the outcome, arrangements could be made for the patient's transfer to another institution.

The article, summarised above, from the American Medical Association discusses the concept of futility very well[7]. However, the proposed solutions, with its emphasis on individual institutions, may be less relevant to NSW. The use of scoring systems performed on admission to the ICU in order to predict mortality also have their limitations.

Despite broad agreement around the meaning of the word futility – 'because it offers no reasonable hope of recovery or improvement, or because the patient is permanently unable to experience any benefit' – in one of the more comprehensive surveys, 87% of doctors in intensive care and 95% of nurses reported that futile care was provided in the ICU[8].

REFERENCES

1. Miller DW Jnr, Miller CG. On evidence, medical and legal. *Journal of the American Physicians and Surgeons* 2005;10(3):70-75.

2. Lantos J. When parents request seemingly futile treatment for their children. *The Mount Sinai Journal of Medicine* 2006:73:587-589.

3. Murphy DJ, Burrows D, Santilli S, et al. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *New England Journal of Medicine* 1994;330:545-549.

4. Lloyd CB, Nietert PJ, Silvestri GA. Intensive care decision making in the seriously ill and elderly. *Critical Care Medicine* 2004;32:649-654.

5. Kruse JA, Thill-Baharozian MC, Carlson RW. Comparison of clinical assessment with APACHE II for predicting mortality risk in patients admitted to a medical intensive care unit. *Journal of the American Medical Association* 1988;260:1739-1742.

6. Rocker G, Cook D, Sjokvist P, et al. Clinician predictions of intensive care unit mortality. *Critical Care Medicine* 2004;32:1149-1154.

7. Council on Ethical and Judicial Affairs, American Medical Association. Medical futility in end-of-life care. Report of the Council on Ethical and Judicial affairs. *Journal of American Medical Association* 1999;281(10):937-941.

8. Palda VA, Bowman KW, McLean RF, Chapman MG. "Futile" care: Do we provide it? Why? A semistructured, Canada-wide survey of intensive care unit doctors and nurses. *Journal of Critical Care* 2005;20:207-213.

Strategies to Avoid Conflict in Acute Hospitals Before Admission to the ICU

There is a paucity of scientific references on managing conflict at the EOL outside the ICU. Presumably this is related to the fact that patients outside the ICU are usually competent and able to make decisions around how their own EOL care should be managed. If a patient, being managed on the general wards is incompetent, it is usually as a result of a temporary and reversible disorder or as part of a natural and predictable dying process. Others who are incompetent as part of their illness and where there is doubt about their prognosis, are often transferred to the ICU.

Although there is little scientific literature on avoiding conflict in patients outside the ICU, many of the reasons for conflict within the ICU have their origins there.

The reasons are many and include: failure of doctors to diagnose dying; reluctance to discuss death and dying with patients and relatives; and fear of criticism or litigation. Admitting doctors often do not know what intensive care can offer and may give relatives false hope by the way they communicate with them. For example, they may offer care that is inappropriate by asking them …"do you want everything done". Following this, the message passed on to the intensivist is "the relatives want everything done". The seeds of conflict are sewn when the intensivist has to either refuse admission or withdraw/withhold treatment[1]. Some of these issues will be covered when the literature around communication is reviewed.

Rapid Response Systems such as the MET concept[2,3] are becoming increasingly employed to identify and respond to seriously ill patients. The response teams were not only being called to seriously ill patients where there was a large reversible element but also to patients who were dying in an expected fashion[4]. The reasons are many, but include a general reluctance to discuss dying amongst many clinicians; and sometimes just an inability to diagnose dying. Thus, the response teams, usually as an outreach of intensive care have, in many cases, become the surrogate 'dying team', often having to talk to relatives and explain to the home medical team that there is little more to offer in the way of active management.

There are some, as yet, unpublished experiences around a closer co-operation of RRS with a 24/7 palliative care response in order to provide early and appropriate care for the dying (personal communication with Rinaldo Bellomo, an Intensivist from the Austin Hospital in Melbourne). It may be assumed that this approach may decrease the incidence of conflict around EOL as there would be early and appropriate communication with patients and their carers.

In order to institute a more effective plan for management of the dying in acute hospitals, consideration could be given to a standardised and integrated care plan. Care plans have the potential to set standards and be used for quality assurance activities[5]. Perhaps the best known of these is the Liverpool Care Pathway for the Dying Patient (LCP) (www.mcpcil.org.uk). The programme recognises the transition from active to palliative care, encouraging early recognition of patients who may eventually move wholly into EOL care. The care plan has been recommended in the NHS guidelines for EOL care[6].

While palliative care services are traditionally available to patients with cancer, there is little awareness around similar services being offered to seriously ill hospitalised patients. And yet the rate of death from chronic conditions is far higher than deaths from cancer[7]. One of the reasons for this is that accurate prognostication is more difficult for patients with conditions such as chronic heart failure, chronic obstructive airways disease (COAD) and dementia[8-12]. This is sometimes referred to as "prognostic paralysis"[9]. It is suggested that this very uncertainty should be the basis for initiating EOL discussions[12]. Some units are documenting a care plan with parallel palliative and active care for patients with COAD[13].

Currently, only the problem of managing EOL in the general wards and some early pilot models are being reported. There is no level 1, 2 or 3 evidence that such strategies could prevent conflict at the EOL. Nevertheless, the concept is intuitively appealing. NSW Health could encourage the development of such models, while, at the same time, begin to collect evidence with regard to their effectiveness.

Professional societies and government could take the lead in acknowledging that death and dying occur and that the miracles of modern medicine have limitations. Death and loss probably needs to be put back on the public health and community agenda[14].

REFERENCES

1. Reignier J, Dumont R, Katsahian S, et al. Patient-related factors and circumstances surrounding decisions to forego life-sustaining treatment, including intensive care unit admission refusal. *Critical Care Medicine* 2008;**36**(7):2076-2083.

2. Lee A, Bishop G, Hillman KM. Daffurn K. The medical emergency team. *Anaesthesia and Intensive Care* 1995;**23**:183-86.

3. Hourihan F, Bishop G, Hillman KM, Daffurn K, Lee A. The medical emergency team: a new strategy to identify and intervene in high risk patients. *Clinical Intensive Care* 1995;**6**:269-72.

4. Jones DA, McIntyre T, Baldwin I, Mercer I, Kattula A, Bellomo R. The medical emergency team and end-of-life care: A pilot study. *Critical Care and Resuscitation* 2007;**9**(2):151-156.

5. Ellershaw J. Clinical pathways for care of the dying: An innovation to disseminate clinical excellence. *Journal of Palliative Medicine* 2002;**5**(4):617-621.

6. NHS Guidelines for EOL care.

7. World Health Organization. Preventing chronic diseases: A vital investment. Geneva: *WHO Global Report*, 2005.

8. World Health Organization. Palliative care for older people. Geneva: *WHO*, 2004.

9. Murray SA, Boyd K, Sheikh A. Palliative care in chronic illness. *British Medical Journal* 2005;**330**:611-612.

10. Coventry PA, Grande GE, Richards DA, Todd CJ. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: A systematic review. *Age and Ageing* 2005;**34**:218-227.

11. Glare PA, Sinclair CT. Palliative medicine review: Prognostication. *Journal of Palliative Medicine* 2008;**11**:84-103.

12. Reisfeld GM, Wilson GR. Palliative care issues in heart failure. *Journal of Palliative Medicine* 2007;**10**:247-248.

13. Murray, SA, Sheikh A. Making a difference. Palliative care beyond cancer. Care for all at the end of life. *British Medical Journal* 2008;**336**:96:958-959.

14. Ashby MA, Kellehear A, Stoffell BF (ed). Resolving conflict in end-of-life care. *Medical Journal of Australia* 2005;**183**(5):230-231.

Communication

Communication is one of the more important strategies to avoid conflict at the EOL, not only in the ICU, but also throughout the patient's hospital journey. Epidemiological studies have identified specific needs of the family at this time and where those needs have not been met[1-5]. The literature focuses on content, timing and settings in which bad news can be delivered[6-10]. There is also some evidence that EOL family conferences assist them when difficult decisions need to be made[11-15]. The use of a brochure on bereavement and using a proactive communication strategy in the ICU showed a lower burden of bereavement using three validated scales 90 days after the patient's death[16]. This is the only multicentre and randomised study demonstrating that a proactive communication strategy conducted according to specific guidelines improved relative satisfaction. The study was conducted in France which may make generalisations to a NSW setting difficult.

The EOL family conference in this article was structured around the neumonic, VALUE:

- Value and appreciate what family members say.
- Acknowledge the family's emotions.
- Listen.
- Ask questions which would help the caregiver understand who the patient is.
- Elicit questions from the family members.

Other communication, such as ethics consultations, have been shown to decrease non-beneficial life-sustaining treatments in the ICU in a randomised controlled trial conducted in the UK[17]. Early palliative care consultation for dying patients in the ICU improved patient outcome[18]. These articles are discussed in more detail in the section answering specific questions.

Most of the more qualitative descriptions of how to effectively communicate around EOL emphasise a consensual model of shared decision making and avoid 'who has the legal right to decide' wherever possible. The goal is to establish robust trust and mutual understanding between the family and the ICU team. 'Seeking consensus'

should be aimed for, not 'asking permission'. Some of the specific points that are emphasised in the literature include[2,11,12,14,15,17-31].

- Inform families of high-risk patients (eg post-cardiac arrest, hypoxic encephalopathy, severe traumatic brain injury) within 24 hours of admission to the ICU of the high possibility of death.
- Avoid euphemisms or medical terminology.
- Emphasise 'intensive caring' as part of the EOL process.
- Ensure families have access to patients with as little restriction as possible.
- Advise relatives to look after their own health in this process… "This could be a long distance race, not a 100 metre dash."
- Identify with the patient early… "We never got to know Mrs X, can you tell me a bit about her".
- Emphasise the point that "while we may not be able to always offer a cure, we can promise you that they won't suffer".
- Add that… "I (as the intensivist) cannot afford not to be honest with you (the patient/relative). It may sound blunt but we will always try to reflect exactly what we think the patient's chances are."
- Be active listeners and try to detect early hints of discord which may lead to conflict.

While there was no direct association between these recommendations and decreased conflict it could be assumed that conflict may be reduced.

Communication skills are generic in managing EOL conflict. However, there are some special circumstances which are challenging. Conflict between functional and legal family units is relatively common[32]. Often there has been simmering resentment and disagreement between the two units, sometimes over many years. This then comes to a head when EOL issues arise. Clinicians in these cases need to be flexible about the relative importance of a close friend or significant other compared to other 'family' members as to who would be the more appropriate decision maker[33]. While these guidelines are offered there is, again, little evidence as to which of these is the most effective in resolving conflict. The guidelines for communication and gaining of consensus are otherwise generic in EOL issues.

The same failure of communication exists in paediatric[34-39] and neonatal ICUs[40-42].

What can we learn from the literature on communication around EOL issues as it may apply to NSW? The concept of improved communication is probably easier to include in documents than to actually ensure there is a comprehensive plan of implementation. Even with senior clinicians who supposedly understand the importance of communication, the actual application of the principles fall short of what happens in practice[13,43,35]. However, with relatively inexpensive training, communication skills can be markedly improved[35]. As discussed, there is one randomised controlled and multicentre trial suggesting that a standardised approach to family conferences together with brochures providing specific information to

relatives of dying patients improves outcome[8]. A standardised brochure could be developed and distributed to NSW ICUs and paediatric services. The standardised approach to family conferences could be part of a comprehensive care plan aimed at patients who may be likely to need EOL care, similar to the one used in the National Health Service (www.mcpcil.org.uk).

Then there is the daunting task of improving communication skills around EOL issues across all nursing and medical undergraduate and postgraduate educational facilities. The American Medical Association has an education programme aimed at improving the communication skills of undergraduates and postgraduates – Education for Physicians in End-of-Life Care (EPEC) (www.ama-assn.org/EPEC).

The project aims to reach every practising physician in the USA. The course runs over 2½ days and its curriculum covers key competencies around issues such as ethical decision making, communication and psychological aspects of care at the EOL. The conference is divided into four 30 minute workshops. Conference participants not only participate as trainees but are taught how to learn from others using the EPEC curriculum in a way similar to the ALST/EMST course in how to manage trauma.

The establishment and maintenance of such a programme would require considerable resources but thought could be given to an initiative involving universities and professional colleges as well as NSW Health.

REFERENCES

1. Covinsky KE, Goldman L, Cook EF, et al. The impact of serious illness on patients' families. *Journal of the American Medical Association* 1994;**272**:1839-1844.

2. Cuthbertson SJ, Margetts MA, Streat SJ. Bereavement follow-up after critical illness. *Critical Care Medicine* 2000;**28**:1196-1201.

3. Azoulay E, Pochard F, Kentish-Barnes N, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *American Journal of Respiratory and Critical Care Medicine* 2005;**171**:987-994.

4. Malacrida R, Bettelini CM, Degrate A, et al. Reasons for dissatisfaction: a survey of relatives of intensive care patients who died. *Critical Care Medicine* 1998;**26**:1187-1193.

5. Abbott KH, Sago JG, Breen CM, Abernethy AP, Tulsky JA. Families looking back: One year after discussion of withdrawal or withholding of life-sustaining support. *Critical Care Medicine* 2001;**29**:197-201.

6. Ptacek JT, Ederhardt TL. Breaking bad news: A review of the literature. *Journal of the American Medical Association* 1996;**276**:496-502.

7. Larson DG, Tobin DR. End-of-life conversations: Evolving practice and theory. *Journal of the American Medical Association* 2000;**284**:1573-1578.

8. Buckman R. How to break bad news: A guide for health care professionals. Baltimore: *John Hopkins University Press*, 1992.

9. Education for Physicians on End-of-Life Care Trainer's Guide, Module 2, EPEC Project. Chicago: *American Medical Association*, 1999.

10. Solomon MZ. Communicating effectively with patients and families when death is near. *Forum* 1995;**16**(2):8-10.

11. Curtis JR, Patrick DL, Shannon SE, Treece PD, Engelberg RA, Rubenfeld GD. The family conference as a focus to improve communication about end-of-life care in the intensive care unit: Opportunities for improvement. *Critical Care Medicine* 2001;**29**(Suppl 2):N26-N33.

12. Azoulay E. The end-of-life family conference: Communication empowers. *American Journal of Respiratory and Critical Care Medicine* 2005;**171**:803-804.

13. Curtis JR, Engelberg RA, Wenrich MD, Shannon SE, Treece PD, Rubenfeld GD. Missed opportunities during family conferences about end-of-life care in the intensive care unit. *American Journal of Respiratory and Critical Care Medicine* 2005;**171**:844-849.

14. Lilly CM, Deo Meo DL, Sonna LA, et al. An intensive communication intervention for the critically ill. *American Journal of Medicine* 2000;**109**:469-475.

15. Azoulay E, Pochard F, Chevret S, et al. Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients: A multicenter, prospective, randomized, controlled trial. *American Journal of Respiratory and Critical Care Medicine* 2002;**165**:438-442.

16. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. *New England Journal of Medicine* 2007;**356**(5):469-478.

17. Schneiderman LJ, Gilmer T, Teetzel HD, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: A randomised controlled trial. *Journal of the American Medical Association* 2003;**290**:1166-1172.

18. Campbell ML, Guzman JA. Impact of a proactive approach to improve end-of-life care in a medical ICU. *Chest* 2003;**123**:266-271.

19. Levy MM. End-of-life care in the intensive care unit: Can we do better? *Critical Care Medicine* 2001;**29**(Suppl 2):N56-61.

20. Davidson JE, Powes K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centred intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. *Critical Care Medicine* 2007;**35**(2):605-622.

21. Fassier T, Lautrette A, Ciroldi M, Azoulay E. Care at the end of life in critically ill patients: The European perspective. *Current Opinions in Critical Care* 2005;**11**:616-623.

22. Heyland DK, Rocker GM, O'Callaghan CJ, Dodek PM, Cook DJ. Dying in the ICU: Perspectives of family members. *Chest* 2003;**124**:392-397.

23. Keenan SP, Mawdsley C, Plotkin D, Webster GK, Priestap F. Withdrawal of life support: How the family feels, and why. *Journal of Palliative Care* 2000;**16**(Suppl):S40-44.

24. Way J, Back AL, Curtis JR. Withdrawing life support and resolution of conflict with families. *British Medical Journal* 2002;**325**:1342-1345.

25. McDonagh JR, Elliott TB, Engelberg RA, et al. Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Critical Care Medicine* 2004;**32**:1484-1488.

26. White DB, Curtis JR. Care near the end-of-life in critically ill patients. A North American perspective. *Current Opinions in Critical Care* 2005;**11**:610-615.

27. Cook D, Rocker G, Marshall J, et al. Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit. *New England Journal of Medicine* 2003;**349**:1123-1132.

28. Sprung CL, Cohen SL, Sjokvist P, et al. End-of-life practices in European intensive care units: The Ethicus Study. *Journal of the American Medical Association* 2003;**290**:790-797.

29. Azoulay E, Pochard F, Chevret S et al. Family participation in care to the critically ill: Opinions of families and staff. *Intensive Care Medicine* 2003;**29**:1498-154.

30. Cabana MD, Rand CS, Powe NR, et al. Why don't physicians follow clinical practice guidelines? A framework for improvement. *Journal of the American Medical Association* 1999;**282**:1458-1465.

31. Gonzales R, Dever R, Singleton KA. Conflicting demands between functional and legal family units. *Dimensions of Critical Care Nursing* 1997;**16**(2):96-100.

32. Jonsen AR, Siegler M, Winsdale WJ. Clinical Ethics, 2nd edn. New York: *Macmillan Co*, 1986.

33. Cohen S, Sprung C, Sjokvist P, et al. Communication of end-of-life decisions in European intensive care units. *Intensive Care Medicine* 2005;**31**:1215-1221.

34. Vernon DD, Dean JM, Timmons OD, et al. Modes of death in the pediatric intensive care unit: Withdrawal and limitation of supportive care. *Critical Care Medicine* 1993;**21**:1798-1802.

35. Burns CA, Byrne P, Kuhn S, et al. End-of-life care in the pediatric intensive care unit: Attitudes and practice4s of pediatric critical care physicians and nurses. *Critical Care Medicine* 2001;**29**:658-664.

36. Devictor DJ, Nguyen DT. Foregoing life-sustaining treatments: How the decision is made in French pediatric intensive care units. *Critical Care Medicine* 2001;**29**:1356-1359.

37. Willems DL, Daniels ER, Wal G van der, et al. Attitudes and practices concerning the end of life: A comparison between physicians from the United States and the Netherlands. *Archives of Internal Medicine* 2000;**160**:63-68.

38. Committee on Bioethics, American Academy of Pediatrics. Guidelines of foregoing life-sustaining treatment. *Pediatrics* 1994;**3:**532-536.

39. Committee on Bioethics, American Academy of Pediatrics. Ethics and the care of critically ill infants and children. *Pediatrics* 1996;**98:**149-152.

40. van der Heide A, van der Mass PJ, van der Wal F, et al. The role of parents in end-of-life decisions in neonatology: Physicians' views and practices. *Pediatrics* 1998:**101**:413-418.

41. Leeuw R de, Beaufort AJ de, Kleine MJK de, et al. Forgoing intensive care treatment in newborn infants with extremely poor prognoses. *Journal of Pediatrics* 1996;**129:**661-666.

42. Moskop JC. End-of-life decisions in Dutch neonatal intensive care units. *Journal of Pediatrics* 1996;**129**627-630.

43. Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a Cancer Research UK communication skills training model for oncologists: A randomised controlled trial. *Lancet* 2002;**359**:650-656.

Clinical Practice Guidelines For End-Of-Life Care And Decision Making

There are many excellent guidelines for EOL care and decision making; NSW Health has published their own version[1], which comprehensively covers all aspects of EOL care, especially in the context of intensive care, children and young people. Apart from the NSW Health Guidelines, there are many other important documents and references from other countries.[1-14]

The assumption appears to be that if all of these guidelines are applied in a clinically relevant way then it would be unusual to have to resort to conflict resolution. There is probably a lot of truth in this assumption as the recommendations are exhaustive and clinically relevant.

The recommendations covered in these documents cover most aspects of how to provide a 'good death' in the ICU. The document produced by the Society of Critical Care Medicine (SCCM) is accompanied by an exhaustive reference list; clinically relevant tables and summaries; and detailed descriptions of the different clinical scenarios which may occur in the ICU and how to deal with them[2]. Interestingly, there is little discussion around the practical issue of conflict resolution between patients/surrogates and treating health care teams when these strategies have failed

Some of the issues covered in the SCCM guidelines include:

General Principles
- Be aware of changing context of treatment limitation decision.
- Collaborative process involving all caregivers.
- Using a consensus model when the patient is incapable of making decisions.
- Early involvement of palliative care.
- Careful documentation of all decisions.

Preparation of the Family

Frequent and honest communication with the family about the patient's condition and the likelihood of not surviving.
- Most important needs of the family:
  - To be with the person
  - To be helpful to the dying person
  - To be informed of the patient's changing condition
  - To understand what is being done and why
  - To be assured of the patient's comfort
  - To be comfortable
  - To vent emotions
  - To be assured that their own feelings are appropriate
  - To be fed, hydrated and rested

Ensuring the Comfort of the Patient

Intensive care medicine has, for many years, been grounded in the curative model of care as opposed to the palliative model, where interventions are aimed at improving symptom relief, improving functional status or ameliorating emotional, psychological or spiritual concerns[15,16]. The transition from the curative to the palliative model often occurs in a preconceived fashion. A practical point is to consider viewing the whole of the patient's orders and care plan if ceasing active or curative treatment is being considered. Each monitor, investigation and intervention could be seen in a different light[17,18].

Important issues that need to be addressed include:
- Assessment and relief of pain – most patients die with untreated pain, even in ICUs[19].
- Assessment and treatment of suffering – 'pain' and suffering are not synonymous but neither are they inherently distinct. Suffering is more a global term unrelated to physical symptoms[20].
- Alleviation of specific symptoms – such as dyspnoea and agitation[21-24]. Others like thirst, dry oral mucosa and hunger are not usually encountered in ICU. Anxiety and delirium often occur at the EOL. Pharmacological management rather than physical restraint should be employed.
- Other factors – there is some evidence that better hospital design improves patient outcomes and relative satisfaction[25-30]
- Withdrawing and withholding protocols – these are well covered in many publications[2,7,13,31-35].

All of these factors need to be taken into account when considering avoidance of conflict at the EOL. However, there is almost no level 1-3 evidence linking these factors with a decrease in conflict. A recent extensive review article from the American College of Critical Care Task Force 2004-2005[7] examines over 300 studies and in all cases the level of evidence was at Cochrane Level 4 or 5 – the lowest level of evidence. The article provides an excellent summary of mainly pre-emptive strategies which could prevent conflict but falls short of discussing conflict resolution when these measures fail.

Despite these guidelines being freely available many families are dissatisfied with the care they receive at the EOL[2,36].

Another challenge is considering how much of this literature, including well thought out national guidelines, are actually translated into the every day practice in ICUs and other places where EOL patients are managed.

NSW Health could consider shaping its recommendations around EOL care into a standardised State-wide Care Plan for care of patients at the EOL which may result in a more consistent approach. Precedents include more general care plans for the dying in hospitals[37-39]. This could be incorporated into more general care plans for

patients dying in acute hospitals or be specifically designed for ICUs. As there is no research around how effective these plans are in NSW, consideration could be given to supporting research which may help to evaluate the effectiveness of the care plans.

REFERENCES

1. NSW Health Department. Guidelines for end-of-life care and decision-making. Gladesville: *Better Health Centre – Publications Warehouse*, 2005. (ISBN: 0 7347 3785 8). (available electronically http://www.health.nsw.gov.au)

2. Truog RD, Cist AF, Brackett SE, et al. Recommendations for end-of-life care in the intensive care unit. The Ethics Committee of the Society of Critical Care Medicine. *Critical Care Medicine* 2001;**29**(12):2332-2348.

3. Nelson JE, Angus DC, Weissfeld LA, et al. End-of-life care for the critically ill: A national intensive care unit survey. *Critical Care Medicine* 2006:**34**(10):2547-2553.

4. Breslin JM, MacRae SK, Bell J, Singer PA and the University of Toronto Joint Centre for Bioethics Clinical Ethics Group. Top 10 health care ethics challenges facing the public: Views of Toronto bioethicists. *BMC Medical Ethics* 2005;**6**:5 (available electronically http://www.biomedcentral.com/1472-6939/6/5).

5. Mularski RA. The search for a good death – Are there quality insights accessible from medical records? *Critical Care Medicine* 2008;**36**(4):1372-1373.

6. Glavan BJ, Engelberg RA, Downey L, Curtis JR. Using the medical record to evaluate the quality of end-of-life care in the intensive care unit. *Critical Care Medicine* 2008;**36**(4):1138-1146.

7. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. *Critical Care Medicine* 2007;**35**(2):605-622.

8. Rocker G, Dunbar S. Withholding or withdrawal of life support: The Canadian Critical Care Society Position Paper. *Journal of Palliative Care* 2000;**16**(Suppl):S53-S63.

9. British Medical Association Ethics Committee. Withholding and withdrawing life-prolonging medical treatment. Guidance for decision making. *BMJ Publishing Group*, 1999.

10. Palliative Care is the area of health care in which doctors can make the greatest difference to their patients. *Medical News Today* 25th April 2008. (http://www.medicalnewstoday.com/articles/105340.php).

11. Charatan F. AMA issues guidelines on end of life care. *British Medical Journal* 1999;**318**:69.

12. General Medical Council. Withhold and withdrawing life-prolonging treatments: Good practice in decision-making. London: *GMC*, 2002.

13. Statement of withholding and withdrawing treatment. *Australian and New Zealand Intensive Care Society*, 2003.
    (available electronically
    http://www.anzics.com.au/files/withhold@withdraw_v1.pdf

14. Sprung CL, Cohen SL, Sjokvist P, et al. End-of-life practices in European intensive care units: the Ethics Study. *Journal of the American Medical Association* 2003;13:**290**(6):790-797.

15. Danis M, Federman D, Finss JJ et al. Incorporating palliative care into critical care education: principles, challenges and opportunities. *Critical Care Medicine* 1999;**27**:2005-2013.

16. Brody H, Campbell ML, Faber-Lengendoen K et al. Withdrawing intensive life-sustaining treatment – Recommendations for compassionate clinical management. *New England Journal of Medicine* 1997;**336**:652-657.

17. Faber-Langendoen K, Bartels DM. Process of forgoing life-sustaining treatment in a university hospital. *Critical Care Medicine* 1992;**20**:570-577.

18. Campbell ML, Frank RR. Experience with an end-of-life practice at a university hospital. *Critical Care Medicine* 1997;**25**:197-202.

19. SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Journal of the American Medical Association* 1995;**274**:1591-1598.

20. Cassell EJ. The nature of suffering and the goals of medicine. *New England Journal of Medicine* 1982;**306**:639-645.

21. Campbell ML. Forgoing life-sustaining therapy. Aliso Viejo CA: *American Association of Critical Care Nurses*, 1998.

22. Bizek KS. Optimizing sedation in critically ill, mechanically ventilated patients. *Critical Care Nursing Clinics of North America* 1995;**7**:315-325.

23. Mancini I, Body JJ. Assessment of dyspnea in advanced cancer patients. *Support Care Cancer* 1999;**7**:229-232.

24. Wilson RC, Jones PW. A comparison of the visual analogue scale and modified Borg scale for the measurement of dyspnoea during exercise. *Clinical Science* 1989;**76**:277-282.

25. Long R. Healing by design. *Health Facility Management* 2001;**14**:20-22.

26. Murphy E. The patient room of the future. *Nursing Management* 2001;**31**:38-39.

27. Pangrazio JM. Room with a view. *Health Facility Management* 2003;**16**:30-32.

28. Rollins JA. Evidence-based hospital design improves health care outcomes for patients, families, and staff. *Pediatric Nursing* 2004;**30**:338-339.

29. Sadler B. Designing with health in mind. *Modern Healthcare* 2004;**34**:28.

30. Sandrick KA. Higher goal: Evidence-based design raises the bar for new construction. *Health Facility Management* 2002;**16**:16-21.

31. Rabow MW, Hardy GE, Fair GM, et al. An evaluation of the end-of-life care content in 50 textbooks from multiple specialties. *Journal of the American Medical Association* 2000;**283**:771-778.

32. Ho KM, Liang J. Withholding and withdrawal of therapy in New Zealand Intensive Care Units (ICUs): A survey of clinical directors. *Anaesthesia and Intensive Care* 2004;**32**(6):7891-786.

33. Carlet JJ, Thijs LOG, Antonelli M, et al. Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. *Intensive Care Medicine* 2004;**30**:770-784.

34. Bryce CL, Loewenstein G, Arnold RM, et al. Quality of death: Assessing the importance placed on end-of-life treatment in the ICU. *Medical Care* 2003;**42**:406.

35. Faber-Langendoen K, Lanken PN. Dying patients in the intensive care unit: Forgoing treatment, maintaining care. *American Internal Medicine* 2001;**133**:555-558.

36. Ward NS, Levy MM, Teno JM. Role of the ICU in care for dying patients. Transfers and quality of end of life care. *American Journal of Respiratory Critical Care Medicine* 2004;**169**:A624.

37. Ellershaw JE, Murphy D, Shea T, Foster A, Overill S. Developing an integrated care pathway for the dying patient. *European Journal of Palliative Care* 1997;**4**:203-207.

38. Ellershaw J, Smith C, Overill S, Walker S, Aldridge J. Care of the dying: Setting standards for symptom control in the last 48 hours of life. *Journal of Pain Symptom Management* 2001;**21**:12-17.

39. Ellershaw J. Clinical Pathways for care of the dying: An innovation to disseminate clinical excellence. *Journal of Palliative Care* 2002;**5**(4):617-621.

Cultural, Religious And Racial Aspects Around EOL Conflicts

In some areas of NSW more than half of the population were born outside Australia. Moreover, the next Australian born generations of these immigrants are also influenced in many different ways in terms of their values, attitudes and beliefs around dying and death.

In order to minimise any potential conflict, health care workers should have some understanding of different cultural attitudes around EOL issues. A recently published summary of the views around EOL have been published in the Lancet[1-6]. In this review, Islamic, Jewish, Buddhist and Christian views are summarised. The articles discuss how families can negotiate their rituals within the space of secular health care initiatives.

There have also been some insightful reviews discussing the general issue of how to design culturally specific EOL care[7-9]. However, there are dangers in designing EOL care specifically around different cultural, religious and racial groups. For example, African Americans prefer more aggressive end-of-life interventions[9]. There would be an inherent injustice in shaping EOL decisions around the different wishes of individual groups to demand more aggressive treatment. This may be relevant in the Australian setting where some religious and cultural subgroups may also demand more aggressive EOL care than others. No direct evidence to support this could be found. The right of the individual as a determinant in conflict resolution would probably not be as paramount in Australia as it is in the USA, where these references were from. The other feature of non-Australian articles is the emphasis on separate institutions developing separate conflict resolution mechanisms[7,9,10], as opposed to State or National initiatives.

None of these articles specifically addressed the issue of conflict at EOL. There is no evidence base around whether educational strategies improve communication and decrease conflict at the EOL. It is probably assumed that if the content of the articles is applied effectively that most conflict would be avoided.

In view of the great cultural differences within NSW, the Health Department may consider constructing a concise summary of how to conduct EOL plans for different

racial and national groups using the available evidence. This material could be used as an educational resource for educating health care deliverers but also made freely available for staff working in acute hospital areas such as EDs; intensive care and palliative care units. As communication is crucial around conflict at EOL, the use of interpreters would need to be freely available.

REFERENCES

1. Sachedina A. End-of-Life: The Islamic view*. Lancet* 2005;**366**:774-1132.

2. Firth S. End of Life: A Hindu view. *Lancet* 2005:**366:**682-686.

3. Dorff EN. End of Life: A Jewish perspective. *Lancet* 2005:**366:**862-865.

4. Keown D. End of Life: The Buddhist view. *Lancet* 2005:**366:**952-955.

5. Englehardt HT Jnr, Iltis AS. End of Life: The traditional Christian view. *Lancet* 2005:**366:**1045-1049.

6. Markwell H. End of Life: A Catholic view. *Lancet* 2005:**366:**1132-1135.

7. Crawley LM, Marshall PA, Lo B, Koenig BA for the End-of-Life Care Consensus Panel. Strategies for culturally effective end-of-life care. *Ann Intern Med* 2002;**136**(9):673-679.

8. Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. *Social Science and Medicine* 1999;**48**:1779-1789.

9. Hopp FP, Duffy SA. Racial variations in end-of-life care. *Journal of the American Geriatrics Society* 2000;**48**(6):658-663.

10. Wojtasiewicz ME. Damage compounded: Disparities, distrust, and disparate impact in end-of-life conflict resolution policies. *American Journal of Bioethics* 2006;**6**(5):8-12.

OTHER REFERENCES RELEVANT TO THIS SUBJECT

▪ Vincent JL. Cultural differences in end-of-life care. *Critical Care Medicine* 2001;**29**:N52-N55.

- Waters CM. Professional nursing support for culturally diverse family members of critically ill adults. *Research in Nursing and Health* 1999;**19**:401-415.

- Betancourt JR. Cultural competence – Marginal or mainstream movement? *New England Journal of Med* 2004;**351**:953-955.

- Groman R, Ginsburg J. Racial and ethnic disparities in health care: A position paper of the American College of Physicians. *Annals of Internal Medicine* 2004;**141**:226-232.

- Morrison RS, Zayas LH, Mulvihill M et al. Barriers to completion of health care proxies: An examination of ethnic differences. *Archives of Internal Medicine* 1998;**158**:2493-2497.

- Bowman KW, Richard SA. Cultural considerations for Canadians in the diagnosis of brain death. *Canadian Journal of Anaesthesia* 2004;**51**:273-275.

- Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "You got to go where he lives". *Journal of the American Medical Association* 2001;**286**:2993-3001.

- Danis M. the role of ethnicity, race, religion and socio-economic status in end-of-life care in the ICU. In: Curtis JR, Rubenfeld GD (eds) Managing death in the intensive care unit. New York: *Oxford University Press.*,

DIRECT INTERVENTIONS DEALING WITH CONFLICT AT THE EOL

1. Striving for Consensus
2. The Role of Ethical Guidelines in conflict resolution
3. Mediation
4. Tribunals
5. The Legal System

The guidelines covering strategies dealing with EOL issues listed in the previous section cover pre-emptive strategies to prevent conflict. They are comprehensive and cover much of the same areas, despite coming from many different countries, organisations and professional bodies The issue around prevention of conflict is probably not so much related to the comprehensiveness of the guidelines but more to the effectiveness of the implementation of the guidelines.

Once there is conflict around decisions being contemplated at EOL, there are various strategies to defuse and limit the conflict. These are covered in the NSW document[1] and include: time and repeated discussions; seeking another medical opinion or another opinion from within the health service; transfer to another institution; or

referral to ethics committees. If these measures fail and conflict is either unresolved or escalates, there is the possibility of mediation or referral to a Tribunal. Finally, if these measures fail the matter can be referred to the legal system.

Recent UK guidelines from the General Medical Council offer a framework for dealing with conflict at the EOL. Some of the more relevant ones include: (www.gmc-uk.org/guidance; *Consent: patient and doctors making decisions together*)

- A competent patient has the right to refuse treatment and their refusal must be respected, even if it will result in their death.
- Doctors are under no legal or ethical obligation to agree to a patient's request for treatment if they consider the treatment is not in the patient's best interests.
- A decision for, or on the behalf of, a person who lacks capacity must be done, or made, in his best interests.

The guidelines are consistent with laws across the UK. The booklet containing the guidelines is easy to understand and covers many important areas including how the law interacts with health around conflict. This is a broader document than the NSW Health[1] one which specifically covers withdrawing and withholding treatment. NSW Health may wish to also consider producing a similar document .

Striving For Consensus

It is important that the transition from pre-emptive conflict resolution to more direct forms of intervention is not abrupt. There is always hope that the conflict will be resolved by continuing pre-emptive strategies. Moreover, it is important that both parties feel that the process has been fair, whatever the ultimate outcome, and that health care deliverers have acted in a professional and sensitive way.

The NSW Health document[1] includes many of the pre-emptive strategies for resolving conflict in its suggestions for continuing to resolve conflict. These strategies include 'time and repeat discussion', emphasising that time to come to terms with impending death is important and further discussions are important to resolve outstanding issues. The document also suggests using a 'time limited treatment trial' in order to clarify prognostic uncertainty. Continued use of sound communication principles and EOL guidelines outlined in the first section of this document are probably also important.

All of these strategies are intuitively sensible but as with many suggestions around resolving conflict in EOL issues, there is little specific evidence apart from that already described under communication.

REFERENCES

1. NSW Health Department. Guidelines for end-of-life care and decision-making. Gladesville: *Better Health Centre – Publications Warehouse*, 2005 (ISBN: 0 7347 3785 8) (available electronically http://www.health.nsw.gov.au)

The Role of Ethical Guidelines in Conflict Resolution

The word ethics used in situations of conflict resolution around EOL care in itself implies that a rational and just framework for resolving issues exists. It is probably more common in the USA to refer EOL conflict situations to an ethics committee.

The Texas Advance Directives Act
(http://tlo2.tic.state.tx.us/statutes/docs.HS/content/htm) is constructed around the concept of a hospital-based ethics committee. In the case of intractable conflict, the institutional ethics committee negotiates between the clinicians and family, usually around withdrawing treatment when it is thought to be futile by the treating clinicians. If this fails, attempts to transfer the patient to another institution are made. If that fails, the hospital can unilaterally withdraw treatment. The patient or surrogate can request a delay, which will only be allowed if there is a reasonable chance of transfer. Otherwise, the judge, under provisions in the law, can allow unilateral withdrawal by the treating team with immunity from civil and criminal prosecution.

Under this *Act* the ethical committee is acting as a surrogate judge and jury. In most cases the committee is made up of mainly 'insiders', employed by the hospital and hospital appointed community representatives[1]. In a recent case reported in the same article where the patient died despite the mother wanting treatment to be continued, she was a low-income woman of colour; making transfer to another institution difficult, simply on the basis of her inability to afford the costs of prolonged care. In cases where hospital ethics committees have been used, they agreed with the treating clinicians in 43 of 47 cases[2].

One of the main challenges with using the word 'ethics' to resolve conflict is that the four main ethical principles governing medical care lack precision and can be contradictory.
The four ethical principles are:

- Beneficence – to do good.
- Non-maleficence – avoid harm.
- Justice – provision of health for all.
- Autonomy – patient orientated decision making.

While these principles are universally accepted, they are difficult to apply in practice and, in many cases, are ambiguous and even in conflict with one another. For example, patients in intensive care are often not competent and therefore autonomy can be a problem; doing harm (prolonging suffering) or good (prolonging life) may

depend on the clinical outcome and this is often uncertain; and acting in the patient's interest can be open to different interpretations. Moreover, for a clinician to simultaneously consider whether providing extra resources to sustain the life of one patient is consistent with the fair provision of therapy for all makes the application of these principles even less relevant[3-6].

Applying ethical theory is also made difficult by factors such as the lack of robustness around the concept of 'futility'[7-10].

Managing the critically ill population has unique problems, including:

- Futility is difficult to accurately define.
- Autonomy is rarely possible in seriously ill patients unless they have clearly stated their wishes beforehand.
- A patient's quality of life (QOL) is best predicted by the patients themselves and has been shown to be inaccurately determined by others.
- Involving family members can be problematical.
- Critical care is an expensive and limited resource.

The medico-legal position is that withdrawal of treatment is not causing death; the disease is causing the death, which would not have been prevented by the provision of therapy. Allowing for problems around defining futility, there is no moral obligation to continue treatment that is futile[11].

While intuitively appealing, referring patients to 'ethical' adjudicators has problems. Ethics in intensive care medicine has many inherent ambiguities and conflicts[12]. It may be useful to employ ethical perspectives in decision making but the 'right' thing to do will vary depending on the ethical perspective adopted and there will never be an ethical system satisfactory to all people, or even to a single person in different circumstances[13-15].

If NSW Health were considering the option of hospital ethics committees, thought would have to be given to how they were constituted and the principles under which they operated. There is little evidence on which to base these considerations.

Perhaps if an 'ethics' committee reflects a wide range of professional and community views more than the various schools of ethical teachings, it may represent a legitimate forum for resolving conflict. It has been suggested that rather than use 'ethical experts' to make judgements, that ethics committees instead adopt a 'mediation model,' facilitating wide ranging dialogue among disputing parties[16]. Along the same lines, it has been suggested that the role of an ethics committee is to facilitate open discussion where relevant facts are clarified, competing values are identified and where the parties can explore the various options for resolution[176]. There is no data on the effectiveness of variously constituted ethics committees in resolving conflict around EOL.

REFERENCES

1. Truog R. Tackling medical futility in Texas. *New England Journal of Medicine* 2007;357:1-3.

2. Fine RL, Mayo TW. Resolution of futility by due process: early experience with the Texas advance directives. *Annals of Internal Med* 2003;**138**:743-746.

3. Zawacki BE. ICU physician's ethical role in distributing scarce resources. *Critical Care Medicine* 1985;**13**:57-60.

4. American Lung Association, American Thoracic Society. Official statement on the fair allocation of intensive care unit resources. *American Journal of Respiratory and Critical Care Medicine* 1997;**156**:1282-1301.

5. The American College of Chest Physicians and Society of Critical Care Medicine. Consensus Panel: Ethical and moral guidelines for the initiation, continuation and withdrawal of intensive care. *Chest* 1990;**97**:949-958.

6. Scheinkestel CD. The evolution of the intensivist: From health care provider to economic rationalist and ethicist. *Medical Journal of Australia* 1996;**164**:758-759.

7. Nyman DJ, Sprung CL. End of life decision making in the intensive care unit. *Intensive Care Medicine* 2000;**26**(10)1414-1420.

8. McTurk L. Rational resource allocation: Ethical perspectives,. In Pace NA, McClean SAM (eds). Ethics and the Law in Intensive Care, Oxford: *Oxford University Press*, 1996.

9. McNarry AF, Goldhill DR. Intensive care admission decisions for a patient with limited survival prospects: A questionnaire and database analysis. *Intensive Care Medicine* 2004;**30**(2):325-330.

10. Atkinson S, Bihari D, Smithies M, et al. Identification of futility in intensive care. *Lancet* 1994;**344**(8931):1203-1206.

11. Keown J. Euthanasia, ethics and public policy. The value of human life. Cambridge: *Cambridge University Press*, 2002.

12. McCullough LB. A transcultural, preventive ethics approach to critical-care medicine: Restoring critical care physicians power and authority. *Journal of Medicine and Philosophy* 1998;**23**(6):628-642.

13. Cook D. Patient autonomy versus parentalism. *Critical Care Medicine* 2001;**29**(2)(Suppl):N24-25.

14. Smart JJC.   Utilitarianism and justice.   In: Utilitarianism: For and Against. Cambridge: *Cambridge University Press*; 1973. pp 67-73.

15. Tillyard A, Kuper M, Brett S. The difficulties that exist putting ethical theory into practice in critical care. *Clinical Intensive Care* 2006;**17**(1/2):1-7.

16. West M, McIver Gibson J. Facilitating medical ethics case review: What ethics committees can learn from mediation and facilitation techniques. *Cambridge Quarterly of Healthcare Ethics* 1992;**1**:63-74.

17. Waldman E. Hospital ethics committees balance life and death. *Alternatives* 1999;**17**:14.

Mediation

Mediation could be considered as an extension of the NSW guidelines[1] such as using time and repeated discussions to defuse and limit conflict. There is no evidence to suggest that it should be used parallel to, or after, efforts by treating clinicians and relatives to resolve conflict. Nor is there any information on the timing of mediation in relation to seeking second opinions, transferring to another institution, referral to Tribunals or recourse to the legal system.

For the purposes of this document the following definitions have been used:

Mediation or Conciliation refers to someone trained in mediation who brokers an agreement between two parties. The expert acts purely as a facilitator and the final decision comes from the two parties. The decision can be legally binding. For example, in the case of *'The Family Law Act'* in NSW, mediation is compulsory before the matter is referred to the legal system.

The term mediation is sometimes also used as a general term in this review to cover both areas of mediation and adjudication and refers to mediation conducted by people specifically trained in managing conflict and who, for the purposes of this review, would not be working in the same institution, where the conflict is occurring.

Adjudication (also called Expert Determination, Arbitration or Third Party Decision Making) can be used as a process in its own right or after mediation has failed. It is used when two parties, who are having a disagreement over a matter, are referred to an expert who makes a decision based on factors such as written submissions or interviews and in line with the processes of natural justice. The adjudicator can call on other experts in assisting him/her within his/her determination.

In the case of, for example, *The Commercial Arbitration Act* in NSW (http://www.austlii.edu.au/au/legis/cth/consol_act/fla1975114/)*;* the expert determination is legally binding under specific legislation. Similarly, in the case of

disputes between neighbours over buildings, a Commissioner can be appointed under 'the Land and Environment Court' (www.lawlink.nsw.gov.au, Section 34) to arbitrate matters. The Commissioner takes written submissions, conducts interviews and can consult expert opinion before making a decision.

Currently, examples of mediation and adjudication remain subject to appeals to the traditional legal system.

The most frequent reason for conflict is related to breakdown in communication[2]. An increasing number of disputes and matters of conflict are now handled by mediation and/or adjudication rather than directly through the courts.

The process of mediation and adjudication results in most cases being resolved before recourse to traditional legal systems[2-8].

Both mediation and adjudication use people specifically trained in the generic aspects of dispute resolution as much, if not more, than in the content area of the particular dispute. If NSW Department of Health were to consider a mediation or adjudication option it could either employ them within the health system or investigate further the many consultants and businesses currently providing these services. Obviously, their underlying understanding and experience would also have to be considered in much the same way as Tribunal members or Commissioners in other areas of dispute resolution.

The Department could also consider broadening the brief of these proposed mediators and adjudicators to deal with other areas of conflict between consumers and the health industry. Specific legislation to cover these areas would also need to be considered.

No research on the effectiveness of mediation in EOL conflict was found in Australia. However, some of the potential advantages of external mediation include:

- Using people specifically trained in conflict resolution.
- Working to a solution that would not leave either party feeling resentment and having long term resolution issues.
- Using a third party outside the health system.
- Offering both parties a neutral, no-fault solution.
- Providing both parties with timely resolution, hopefully before positions are polarised.
- Avoidance of litigation and legal solutions.
- To use expert opinion (eg medical and legal) where necessary.

One of the few studies using external mediation in EOL conflict reported success in 11 out of 12 cases[8]. All cases were referred to an ethics committee following failure to resolve conflict. Interestingly, many conflicts were resolved, especially intra-family

ones, before mediation occurred, simply during the process of obtaining consent to undergo mediation. The authors identified blocks to mediation including:

- Low institutional visibility. This issue may be resolved by using a State-wide initiative in NSW.
- 'Turf issues' with hospital ethics committees, physician resistance, a strong institutional momentum to save lives and a reluctance to 'wash dirty linen' in public[3].

The study found that so-called 'bioethical dilemmas' were usually related to a breakdown in communication around perceptions and interpretations of medical factors, different understanding of prognoses and different personal values and beliefs[8].

The time frame of the study was short (6 months); it was observational; and there were only 12 cases. Thus, the results were more subjective impressions rather than quantifiable. Nevertheless, it was a promising pilot study and one of the few that studied extra-hospital mediation as a means of dealing with EOL conflict.

Other strategies using models steeped in psychology have also been employed but only in a descriptive sense, suggesting that they may be useful in stressful situations. These include using the framework of 'crisis therapy' with relatives of the critically ill[9,10]. Another study used interpretative phenomenology to highlight the need for more training of nurses in dealing with hostile colleagues and relatives[11].

REFERENCES

1. NSW Department of Health. Guidelines for EOL care and decision-making. Gladesville: *Better Health Centre – Publications Warehouse*, 2005. (ISBN: 0 7347 3785 8). (available electronically http://www.health.nsw.gov.au)

2. Dubler N. Heroic care cases: When difficult decisions about care are near, mediation can help bridge communication gaps. *Dispute Resolution Magazine* 1990;(Spring):7-8.

3. Marcus L. Renegotiating health care. San Francisco: *Jossey-Bass*, 1995.

4. Marcus L. Mediation in medical malpractice. *Law and Contemporary Problems* 1997;60:185.

5. Colorado Dispute Resolution Act. Colorado Revised Statutes, sec. 13-22-301, et seq., provides extensive confidentiality and nondiscoverability for "mediation communication" C.R.S. 13-22-302 (2.5) defines "mediation communication" as "any oral or written communication prepared or expressed for the purpose of, in the course of, or pursuant to, any mediation services, proceeding or dispute resolution program proceeding". The Act (C.R.S. 13-22-307) further provides,

"Mediation communication shall not be disclosed voluntarily or through discovery or compulsory process with limited exceptions for mediator misconduct or danger to a child."

6. West M, McIver Gibson J. Facilitating medical ethics case review: What ethics committees can learn from mediation and facilitation techniques. *Cambridge Quarterly of Healthcare Ethics* 1992;1:63-74.

7. Andrews L. Conflict management, prevention and resolution in medical settings. *Physician Executive* 1999;25:35-40.

8. Buchanan SF, Desrochers JM, Henry DB, Thomassen G, Barrett Jr PH. A mediation/medical advisory panel model for resolving disputes about end-of-life care. *Journal of Clinical Ethics* 2002;13(3):188-202.

9. Aguilera DC, Messick JM. Crisis intervention: Theory and methodology. 5th edn. St Louis: CV Mosby, 1986.

10. Woolley N. Crisis theory: A paradigm of effective intervention with families of critically ill people. *Journal of Advanced Nursing* 1990;15:1402-1408.

11. Chesla CA, Stannard D. Breakdown in the nursing care of families in the ICU. *American Journal of Critical Care* 1997;6(1):64-71.

Tribunals

Tribunals provide a model in NSW for resolving disputes before the legal system has to be resorted to. There are many examples; some of which include: the NSW Guardianship Tribunal; the Victorian Civil and Administration Tribunal (VCAT) the Commonwealth Government Social Security Appeals Tribunal; the Administrative Appeals Tribunal (AAT); the Migration Review Tribunal and the Refugee Review Tribunal. The latter four come under the Federal Government. The Federal Government may proceed with attempts to amalgamate them in the future.

Guardianship Tribunal (http://www.gt.nsw.gov.au)
This body usually works as a last resort when a person is unable to make decisions about important issues such as their health or financial affairs. The Tribunal can consent to medical and dental treatments for people 16 years and over, who are incapable of consenting to their own treatment. While this does not usually apply if there are relatives who can consent for them, the generic model of a Tribunal may be useful when considering dispute resolution around EOL issues. The Tribunal can act at short notice, conduct hearings, often by telephone, and decide on whether consent should be granted or refused. Usually matters are resolved informally, without the need for a hearing.

The Guardianship Tribunal consists of one legal practitioner of at least seven years standing; one professional member (eg doctor, psychologist); and one community worker. The Tribunal conducts hearings. If a specific Tribunal were to be established to consider EOL conflicts, a specific Act, similar to the *Guardianship Act*, may need to be established with stated principles. Alternatively, the brief of the Guardianship Tribunal itself could be extended to be more actively involved in a broad range of EOL conflicts. The Guardianship Tribunal's host department is the NSW Department of Ageing, Disability and Home Care, however, the Guardianship Tribunal is an independent body and operates under the *Guardianship Act*.

The Victorian Civil and Administration Tribunal (VCAT) (www.vcat.vic.gov.au)

The Australian States all have different legislation and arrangements in regard to guardianship. The VCAT was created in 1998 by amalgamating 15 Boards and Tribunals that included guardianship but which also covered many other areas where there can be potential disputes such as building works, discrimination and tenancies. It has a list of sections which specialise in particular types of cases. The VCAT uses processes such as mediation, directions hearings or compulsory conferencing in order to resolve disputes. The VCAT member attempts to give an immediate decision at the end of the hearing. People involved in the disputes may agree to resolve differences at any time. Decisions of VCAT can be appealed to the Supreme Court of Victoria but only on questions of law and, in Australia, if an incompetent patient has a terminal illness with no prospect of recovery, there is little case law and limited legislation that can be used in the situation of conflict. The Act aims to resolve disputes informally and cost-effectively. Mediation or alternative dispute resolution (ADR) is used extensively. The VCAT works closely with the Office of the Public Advocate on these matters (www.publicadvocate.vic.gov.au).

The Guardianship Section is to protect persons aged 18 years or over, who, as a result of a disability, are unable to make reasonable decisions. As with the NSW Guardianship Tribunal, EOL conflict involving an incompetent patient could, in theory, come under this section.

A good summary of the different Australian State laws in regard to guardianship and EOL care is available[1].

The Commonwealth Government Tribunals

While other Tribunals are not involved in EOL disputes, it may be worthwhile for NSW Health to explore the more general aspects of Tribunals and to consider formulating its own version. The Social Security Appeals Tribunal (SSAT) (www.ssat.gov.au) is a statutory body conducting administrative decision reviews within a mechanism that is 'fair, just, economical, informal and quick'. The resolution processes depend on processes such as:

- Mediation.
- Conferencing.
- Neutral evaluation.

- Case appraisal.
- Conciliation.

It is only after these have been exhausted that the matter is referred for arbitration and court procedures or services.

A similar series of processes is conducted by the Migration Review and Refugee Review Tribunals (www.mrt-rrt.gov.au); and the AAT (www.aat.gov.au). An important feature is that courts can only review on legal grounds, ie when the appeal is based on definite legal grounds. As a result, the majority of applications for judicial review are dismissed. Most cases are resolved through non-legal processes. This principle could apply to EOL conflict, as there are few definite legal guidelines.

The *AAT Act* (www.aat.gov.au) requires that proceedings of the Tribunal be conducted with as little formality and technicality and with as much expedition as the requirements of the Act requires before the Tribunal permit. The Tribunal is not bound by the rules of evidence and can inform itself in any manner it considers appropriate. The Tribunal has 87 members, both full and part-time, with a President and Registrar.

The Migration and Refugee Review Tribunal (www.mrt-rrt.gov.au) provides an independent and final review of decisions made in relation to enter or stay in Australia. Both Tribunals are established under specific Acts. While there are many aspects of the Tribunals that would not be relevant to conflict resolution at the EOL, there are some features which may be relevant to resolution of EOL conflict such as:

- Provision of a final review based on available facts.
- Specific time limits.
- The review is conducted in a manner that is fair, just, economical, informal and quick.
- Each case is allocated to a Tribunal member/s.

REFERENCES

1. Young RJ, King A. Legal aspects of withdrawal of therapy. *Anaesthesia and Intensive Care* 2003;**31**:501-507.

The Legal System

An important general comment on the role of the law in resolving EOL conflicts has been published in the New England Journal of Medicine[1]. Its conclusions included:

- These cases are extremely rare and, as such, the problem should not be overstated.

- Patients' families and friends should be encouraged to be involved in early conversations around EOL questions.
- Issues should be solved largely by encouraging communication and reconciliation; avoiding regrets and resentment wherever possible.
- Increased use of mediator based methodology such as that used with divorcing couples and estranged business partners.
- Caregivers should be encouraged to 'assert themselves gently'.

The editorial emphasises avoiding the clear winners and losers involved in legal solutions. It suggests that governments should make legal recourse difficult; encouraging conversation, reconciliation and accommodation.

The editorial outlines the limits of the law in such matters being restricted to areas such as active killing; clear advance directives being followed; and the assistance of physicians in suicide. But within these boundaries, it is suggested that EOL questions need to be almost totally resolved within the private sphere by patients, their physicians, family members, social workers, nurses and others where relevant.

It would appear that there is little satisfactory and consistent legal resolution of the ethical and practical dilemmas surrounding EOL care[2]. Legal resolution can be used as a mechanism for reaching but it relies on an approach that can be more illusory than real and can even risk becoming a rubber-stamp mechanism[3,4].

This is consistent with other international opinion where the legal framework is poorly adapted to the special situations and demands of modern medicine[5-10]. The specific legal situation in other countries is discussed towards the end of this section. The failure of the legal system to reflect the changing relationships between illnesses that would have been otherwise fatal and the ability of modern medicine to sustain life, has resulted in 'legal liabilities anxieties' amongst ICU doctors[11]. In subtle ways, the failure of the legal system to offer clarity around EOL issues, together with the fear, by doctors, of not acting within an ill-defined legal framework has lead to a perverse situation, where the law is often determining the nature of EOL medical care.

There are several excellent summaries around the role of the legal system in resolving EOL conflict in Australia[2,12,13]. It is difficult to summarise these findings in a coherent way and perhaps that is related to the lack of consistent legal resolution in these matters. There is little case law; and almost no specific legislation to direct the decision of whether to withdraw life-sustaining therapy on the grounds of futility or in the patient's best interest. This can be reduced to the law respecting both the medical decision to withdraw treatment and the wishes of the family. How the weight of each is determined is not clear. Given the tenuous legal basis of withdrawing and withholding treatment, the legal system is inadvertently framing EOL medical care. Doctors acting out of fear of prosecution is probably not a positive incentive for medical treatment but perhaps the fear of prosecution may protect the interests of patients by prolonging 'life' until there is almost total certainty around the futility of

such an approach. On the other hand this has implications in terms of financial cost to our society as well as prolonging suffering of both patients and carers.

It is beyond the scope of this review to suggest better legislation in order to prevent EOL conflict, nor to recommend at exactly when is the right moment for the courts to be involved.   There seems to be overwhelming evidence to employ pre-emptive strategies suggested throughout this review and, if conflict remains, then to use other strategies such as mediation, adjudication and Tribunals. The right to appeal through the legal system is an important feature of many countries. Perhaps NSW, or even more appropriately, the nation, could address the issue of framing more appropriate legislation around EOL issues, which would reflect the advances in modern medicine as well as changing attitudes in society.

While there are many descriptions of different legal systems and reports of cases there is no scientific evidence to suggest what may best decrease conflict around EOL issues.

Legal Frameworks in Other Countries for Conflict Resolution

Below we have tried to summarise attempts to resolve EOL conflict by legal means in other countries. They all emphasise the same difficulties that we have in Australia when trying to formulate precise laws when precision is lacking. The selection is not extensive but the countries are chosen on the basis of their different approaches to a common problem.

<u>United Kingdom</u>

There is no formal legislation in the UK governing EOL care[14]. The perspective is therefore an amalgamation of common law, judgements from individual legal cases and elements of statute such as the Human Rights Act 1998 and the Mental Capacity Act (http://www.opsi.gov.uk/acts/acts2005/20050009.htm).   The competent patient has a right to choose treatment options after the provision of full information. This is usually applied to the right to refuse treatment. The right to demand treatment is in a state of flux with court rulings sometimes supporting patient's access to expensive treatment[15]. This position walks an almost impossibly fine line, needing to consider financial restraints but, at the same time, suggesting that the best interests of patients should not be dictated by resources[16,17].

Authority in decision making for the incompetent patient remains contentious. Current UK law allows ultimate authority for medical care of the incompetent adult to rest with the treating physician rather than the next-of-kin or, indeed, courts. The latter's power lies in declaration of the lawfulness or otherwise, of what action is proposed[14].

While the court may be the final arbiter – Europe, like Australia, has had very few EOL disputes referred to them. In England and Wales, relatives of an incapacitated adult do not have decision-making power. And, because the majority of patients involved in relative/clinician disputes are incapacitated, cases referred to courts have

been extremely rare. The two cases so far[18] were resolved around the concept of autonomy as, although severely incapacitated with neurological disorders, both were able to make their own wishes known.

Medical authority is limited to acting in the patient's 'best interest' which is not necessarily just medical 'best interest' but includes the patient's general well being, as well as spiritual and religious welfare[19,20]. The next-of-kin must be included in the process if only to seek their perspective as to the patient's wishes and beliefs. The new *Mental Capacity Act 2005* allows, in the absence of an advanced directive or nominee with lasting power of attorney, for the selection of a court appointed deputy for proxy decision making. This will not, of course, stop the same ethical, legal and logistical difficulties arising.

The criteria for withdrawing and/or withholding treatment is based on futility, whereby there is no chance of a return to an acceptable quality of life or when the harm of ongoing support outweighs any potential benefit. Obviously these words can be interpreted in many different ways and do little to resolve conflict by legal means.

Under UK law, withdrawal and withholding treatment are seen as part of the same spectrum and withdrawing treatment is seen as an omission, not an act.

Israel

In 2005, the Knesset (Israeli Parliament) became one of the few national bodies to execute a specific and detailed law regulating the treatment of the dying patient[21]. Perhaps relevant to NSW, the law was preceded by six years of intensive professional and public debate. There was an overarching committee and many subcommittees (eg ethical, legal, medical) involved in formulating the '*Dying Patient Act*'. There was fundamental agreement around the following issues:

- A dying patient is one who will die within six months despite medical treatment.
- The last two weeks of expected life is defined as the final stage.
- Every person is assumed to want to continue living unless proven otherwise.
- The balance between prolonging life and avoiding unjustifiable suffering is a grey zone.
- Decisions concerning dying patients should be based on:
  - The medical condition.
  - His/her wishes.
  - Degree of suffering.

Interestingly, Israeli law allows withholding but not withdrawing treatment. The distinction is notional and many creative solutions have been developed to blur the difference. Israel is one of the few countries to have developed specific laws for EOL care. While specific, they still use the broad statements and general guidelines issued by professional and government bodies as in other countries.

Italy

Like many countries, there are no specific laws around EOL care in Italy. Decisions are based on civil and penal codes of law, made before the introduction of life-sustaining drugs and equipment. Many clinicians in Italy feel uneasy about leaving decisions around EOL to the courts, as in their eyes it could be interpreted that there is a direct association between, for example, ceasing ventilation and the patient dying. The Penal Code[22] rules that "not to stop an event, which one has a legal obligation to stop, is equivalent to causing it to happen". Another ambiguity occurs around informed consent. Health is a disposable good and one that a person has certain rights over. However, life is not disposable. Refusing life-saving interventions could be interpreted either way. Italy is a civil law country, not a common law one and so past cases have little or no bearing on future ones. One doctor was convicted for refusing to give blood to a Jehovah's Witness. Another was acquitted. Many of these legal anomalies may be resolved by the recently convened Bioethics Commission of the Italian Society of Anaesthesia, Analgesia, Resuscitation and Intensive Care[23].

France

France was faced with an interesting dilemma around EOL conflicts. The French judicial system always rules about facts that have happened and as such a plaintiff can only initiate a lawsuit after an event has occurred.

In November 2004, the French Parliament voted for a law on 'Rights of patients and end-of-life' (http://www.assemblee-nat.fr/12/dossiers/accompagementfinvie.asp). It clearly allows the withdrawal of life support when further treatment is deemed futile. As with much European legislation family members can advise but have no decision-making capacity. This is at odds with the USA, which gives pre-eminence to family members with the physician only advising.

South Africa

The South African situation is interesting as it is a country with a developed-world legal and constitutional framework but one which must work within the resource constraints of a developing nation. This may eventually become important in so-called developed countries. A recent case heard by the courts related to a patient with chronic renal failure who was refused dialysis because he did not meet the criteria for transplantation. The patient argued that his right to life, guaranteed by the constitution, was being infringed. The Constitutional Court found in favour of the hospital, dialysis was denied and the patient died[24]. Cases involving medical decisions in South Africa are heard by a judge with two appropriately qualified doctors acting as assessors.

Resource allocation also plays a role in private health facilities[25]. The ICUs are usually run by non-specialist intensivists who have limited experience in conducting EOL discussions. Usually an overly optimistic attitude to outcome is prevalent in private ICUs. Continued therapy, regardless of prognosis is generally well accepted by both hospital administrators and families. However, the acceptance may be reversed at the point when health benefits are exhausted[25]. Both hospital administrators and families then become concerned around financial losses and crippling debt. The role of the legal system in guaranteeing further treatment or transferring to a public institution has not been tested.

The situation may become important as the legal system may have to increasingly accommodate the reality of resource limitation in society and the ethical principle of social justice. The resolution of conflict then becomes even more complex.

India

The larger interests of society become even more important when considering the role of the legal system in resolving EOL disputes in India (www.ijccm.org). As in many countries, the protection of life and liberty, enshrined in many constitutions has to be reviewed in the light of advances in medicine enabling prolongation of life and where cessation of this therapy results in the loss of life. The Indian Constitution (Article 21) states that: "no person shall be deprived of his life or personal liberty except according to procedure established by law". Indian law does not include any specific provisions around loss of life as a result of withdrawing or withholding treatment at the EOL.

As with many countries, the opinion of professional bodies often precedes the evolution of legal provisions in matters concerning life support. Up until now courts have adopted the stand that doctors should act in conformity with the standards prevailing in his/her profession and the Indian Society of Critical Care Medicine has established guidelines in this area[26]. However, several recent cases[27] have revealed the urgent need in India to revise legislation to cover:

- A *Right to Refuse Treatment Act*
- A *Right to Palliative Care Act*

REFERENCES

1. Bloche MG (ed). Managing conflict at the end of life. *New England Journal of Medicine* 2005;**352**(23):2371-2373.

2. Truog R. Tackling medical futility in Texas. *New England Journal of Medicine* 2007;357:1-3.

3. Fine RL, Mayo TW. Resolution of futility by due process: early experience with the Texas advance directives. *Annals of Internal Med* 2003;**138**:743-746.

4. Fisher MM, Raper RF. Courts, doctors and end-of-life care. *Intensive Care Medicine* 2005;**31**:762-764.

5. Wiedermann CJ, Druml C. End-of-life decisions in Austria's intensive care units. *Intensive Care Medicine* 2008;**34**:1142-1144.

6. Carlet J, Thijs LG, Antonelli M, Cassell J, Cos P, Hill N, et al. Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. *Intensive Care Medicine* 2004;**30**:770-784.

7. Vincent JL. End-of-life practice in Belgium and the new euthanasia law. *Intensive Care Medicine* 2006;**32**:1908-1911.

8. Zamperetti N, Proietti R. End of life in the ICU: laws, rules and practices: the situation in Italy. *Intensive Care Medicine* 2006;**352**:1620-1622.

9. Bell D. The legal framework for end of life care: A United Kingdom perspective. *Intensive Care Medicine* 2007;**33**:158-162.

10. Boles J-M. End of life in the intensive care unit: from practice to law. What do the lawmakers tell the caregivers? A new series in Intensive Care Medicine. *Intensive Care Medicine* 2006;**32**:955-957.

11. Kapp MB. Legal liabilities anxieties in the ICU. In: Curtis JR, Rubenfeld GD (eds). Managing Death in the Intensive Care Unit. New York: *Oxford University Press*, pp 2341-244.

12. Young RJ, King A. Legal aspects of withdrawal of therapy. *Anaesthesia and Intensive Care* 2003;**31**:501-508.

13. Faunce T. Emerging roles for law and human rights in ethical conflicts surrounding neuro critical care. *Critical and Care Resuscitation* 2005;**7**:221-227.

14. Bell, D. The legal framework for end of life care: a United Kingdom perspective. *Intensive Care Medicine* 2007;**33**:158-162.

15. Dyer C. Trusts can take cost into account when deciding drug treatment. *British Medical Journal* 2006;**332**:928.

16. Fisher MM, Raper RF. Courts, doctors and end-of-life care. *Intensive Care Medicine* 2005;**31**:762-764.

17. Woodcock T, Wheeler R,. Glass v United Kingdom and Burke v General Medical Council. Judicial interpretations of European Convention rights for patients in the

United Kingdom facing decisions about life-sustaining treatment limitations. *Intensive Care Medicine* 2005;**31**:885.

18. Tillyard A, Kuper M, Brett S. The difficulties that exist putting ethical theory into practice in critical care. *Clinical Intensive Care* 2006;**17**:1-7.

19. Department of Health. Good practice in consent. HSC 2001/023. *Department of Health*, 2001.

20. General Medical Council. Seeking patients' consent: The ethical considerations. *General Medical Council*, 1998.

21. Steinberg A, Sprung CL. The dying patient: new Israeli legislation. *Intensive Care Medicine* 2006;**32**:1234-1237.

22. Zamperetti N, Proietti R. End of life in the ICU: laws, rules and practices: The situation in Italy. *Intensive Care Medicine* 2006;**32**:1620-1622.

23. Gruppo di studio ad hoc della Commissione di Bioetica della SIAARTI guidelines for admission to and discharge from intensive care u nits and for the limitation of treatment in intensive care. *Minerva Anestesiol* **69**:101-118. (available electronically http://147.163.1.67/mainlineeguida.html

24. Thiagraj Soobramoney vs Minister of Health, Province of Kwazulu-Natal, South Africa. Durban Supreme Court Case Number 5846197, August 1997.

25. Hodgson RE. The management of death in the ICU. The South African Perspective. *Critical Care Resuscitation* 2006;**8**:73-75.

26. Indian Society of Critical Care Medicine. Guidelines for limiting life-prolonging interventions and providing palliative care towards the end of life in Indian intensive care units. http://isccm.org/ISCCM/PDFfiles/Section3.pdf.

27. Balakrishnan, Mani RK. The constitutional and legal provisions in Indian law for limiting life support. *Indian Journal of Critical Care Medicine* 2005;**9**(2):108-114.

ENGAGING SOCIETY

One of the more effective ways of avoiding conflict around EOL is to engage society about options around EOL issues and encourage formalisation of those wishes. Most persons prefer to die at home[1]. A successful model for increased involvement of society in their own EOL care has been developed by the Oregon Health Department in the USA. They provide a form known as the Physician Orders for Life-Sustaining Treatment (POLST)[1]. The existence of the form is widely advertised and made freely available in places such as family physician centres and nursing homes.

The details on the form are made available to ambulance services, EDs and acute hospitals[2]. Oregon now has the lowest rate of people dying in acute hospitals in the USA and the highest rate of those dying at home[3].

One of the more important challenges for society is to be involved in discussions around EOL issues. There are many drivers in a system which encourages active treatment, even if it may be futile to move the terminally ill along a conveyor belt from their homes to EDs, into acute hospitals and finally into ICUs. Interestingly, this is less the case with patients suffering from cancer than it is for patients with other end-stage diseases. Intensivists, and their professional bodies, could play a major role in facilitating a discourse with society around the whole issue of EOL and what modern medicine can offer and, just as importantly, what it can't. Governments and health administrators would find it difficult to lead this debate as they would be seen to have a conflict of interest; to put it bluntly, it may be seen simply as a cost-cutting exercise. Others, of course, would need to be included: other members of the health industry; other professions such as legal and ethical participants; as well as a broad range of representatives from our community. However, the intensive care profession has a unique understanding of what their own specialty can offer and where their limitations are. Every day they are directly facing the increasing pressure to offer futile treatment.

The intensive care profession could inform public debate as to the importance of the issue and provide them with examples, as well as state of the art consensus statements from their own professional organisations on what has largely been a hidden matter. It would be equally important that the law acknowledges the dilemmas that have emerged as a result of advances of modern medicine and reflect more accurately society's attitudes around EOL challenges.

Society, by and large, asks ICU doctors to withdraw futile care when it is seen to prolong the suffering of patients where further active treatment is futile. However, medical practitioners need to be unambiguously protected by law. It does not help to know that in such cases judges are usually lenient. Clear legislation arising from an extensive public discourse is probably overdue.

Ways of engaging society include conducting workshops and public meetings such as the two-day workshops conducted by the National Academy of Sciences (www.natonalacademies.org) in 1993 or the public meetings conducted by the Institute of Medicine (www.iom.edu) in 1996. A model that could be considered is a summit on EOL care similar to the summit on Access Block in EDs to be sponsored by the Victorian Government in September 2008. While there are obvious differences between the two challenges, they are both assuming increasing importance and are both affected by many issues which are outside the direct influence of where the problem eventually is played out, ie in the ED in the case of access block or the management of death and dying in the ICU. As with the summit on access block, it would need to involve many different people and groups, eg government, health care workers and their professional groups, lawyers, ethicists,

the community and the media in order to facilitate the discourse which needs to occur within society.

The media is an important determinant of patient's expectations around what modern medicine (in this case, intensive care), can offer. Sometimes it can have a positive effect, such as in the case of an extremely well informed article[4] which examines the contrast between 70% of Americans wanting to die at home and the reality of more than one-third spending at least 10 days in an ICU. On the other hand, when policymakers try to encourage a more proactive approach it can be reported as a headline - *'tick-the-box*' if you want to die[5], the inference being that the government is trying to save money, not meet the wishes of people. Another confounder is articles inferring that we may soon be able to live forever[6]. On the other hand, Stephen Leeder[7] from Sydney University encourages society to think about 'when to stop' aggressive medical care. It is anticipated that EOL issues will generate aggressive public debate and extensive media coverage. It is important that the profession of intensive care be encouraged to play a leading and informed role in this debate.

It may be that intensive care physicians and their organisations could take more of a leadership role in working more closely with the media in more accurately defining just what intensive care and modern medicine can offer and where its limitations are. The American Institute of Health established a committee on Care at the End-of-Life[8]. They published seven recommendations and a whole Community Model for Care at the End-of-Life. Recommendations included more public debate; multidisciplinary research institutes, working with society and reporting to government; the expansion of palliative care services; a more comprehensive undergraduate and postgraduate curriculum for health care workers; and a symptom-orientated care plan at EOL.

NSW Health could also consider establishing a centre for analysing and solving the increasing issues that society will be facing around death and dying.

As with many initiatives around resolving conflict in EOL issues, there is little in the way of evaluation and almost no robust research.

REFERENCES

1. Tolle SW. Care of the dying: Clinical and financial lessons from the Oregon experience. *Annals of Internal Med* 1998;**128**(7):567-568.

2. Dunn PM, Schmidt TA, Carley MM, Donius M, Weinstein MA, Dull VT. A method to communicate patient preferences about medically indicated life-sustaining treatment in the out-of-hospital setting. *Journal of the American Geriatrics Society* 1996;**44**:785-791.

3. Weinberg JE, Cooper MM, (eds). The Dartmouth Atlas of Health Care 1998. Chicago: *American Hospital Publishing*; 1998; pp 81-106.

4. *Time Magazine*. 18th September 2000

5. *Daily Mail*. Monday 13th December 2004.

6. *The Australian Financial Review*. 29th-31st October 2004.

7. Leeder S. The key is knowing when to stop. *Sydney Morning Herald*, 31st January 2007.

8. Field MJU, Cassel CK (eds). Approaching Death. Improving Care at the End-of-Life. Washington DC: *National Academy Press*, 1997.

FOCUSING ON THE REVIEW QUESTIONS

We have provided detailed answers for the questions posed by NSW Health. On occasions, we have merged answers for several questions when they overlapped.

Identifying The Causes Of The Conflicts

Question 1 - **What Factors are Known to Contribute to Disputes Arising Between Family Members and Treating Clinical Teams About the Withholding or Withdrawal of Life-Sustaining Treatment?**

There is a vast literature exploring factors contributing to disputes between family members and treating clinical teams. The most discussed issues are communication or lack of it[1-4]; lack of cultural competency in EOL care[5-10]; lack of education and training around ethical dilemmas during EOL care[2,11-14]; differences in personal values and beliefs; the effects of different cultural and religious backgrounds[5-7,15,17]; institutional barriers such as the lack of guidelines and practical policies; and the lack of effective mediating and negotiating mechanisms[18-21]. Other issues possibly contributing to conflict include misconceptions and unrealistic expectations around new medical technology; underlying family conflicts[20,22-26]; mistrust and relationship deterioration between the family and the medical team; conflicts within the medical team (between doctors or between doctors and nursing staff)[25-32] as well as moral distress and burn-out of staff members[33-43].

Effective communication is probably the most important contributing factor in the prevention of EOL conflicts[44-71]. Much of the literature shows that the expectations and goals of the family members, patients and doctors are poorly understood and often discordant. Patients often do not understand nor recall the important clinical and prognostic information that doctors believed they have conveyed. Moreover, doctors have inadequate training in ethics and general aspects around EOL care[13,72-78].

A recent systematic review[79] looked at 51 studies and found that there was a significant discordance between patients/caregivers and health professionals regarding information they believed had been given. More importantly, there was a large discrepancy between the understanding of patients and the health professionals' perceptions of what they thought the patient's understanding and awareness was. The same study found that health professionals often underestimated the patient's need for information. We will discuss specific patient groups, such as those based on ethnicity and religion, under the next question.

Question 2 - Are There Specific Groups Where Conflicts Arise More Frequently? Why?

Many societies are increasingly becoming multiethnic and multicultural. The diversity poses challenges to health care professionals because there is often little understanding of the cultural needs of patients and family and how cultural factors influence their attitudes and beliefs towards illness, suffering and death. Sometimes, the beliefs and customs of patients may appear contradictory to that practiced by Western Medicine. In particular, when doctors have ingrained values that are inconsistent with the patient's cultural background, there is a risk of misunderstanding and conflict[6,80,81].

Carey and Cosgrove.(2006)[6] provided an in-depth discussion about cultural issues surrounding EOL care. They urged care providers to understand cultural differences and to cultivate cultural sensitivity and competency. They also emphasised the importance of spirituality and different EOL customs. Apart from patients' beliefs, spiritual needs and customs, care providers should also try to understand factors such as how to handle the body after death as well as ideas around organ donation and autopsy. They provided a summary of cultural issues surrounding EOL care that is presented below (Table 1).

Certain sub-groups such as patients with cancer[47,82-91] have had significant greater proportion of coverage in the literature. Other patient groups such as infants and children[52,92-95], patients with dementia or other mental problem[96-104], patients on renal dialysis or with renal failure[105-110], and patients with serious co-morbidities[56,111-115] seem to be also covered to a certain degree less than cancer.

Evidence for Effective Proactive Measures to Prevent Disputes Arising

Question 3 - What Proactive Measures Have Been Used to Mitigate Against the Likelihood of Disputes Arising?

Many measures have been adopted as proactive measures to prevent disputes/conflicts arising. From the literature we searched, 15 quantitative studies were selected; each had reasonable quality in terms of its design and execution and are summarised in Table 2. The intervention models adopted in these studies include training in communication, family meetings, proactive ethics consultations, proactive palliative care, structured daily goals, limited-time trial of treatment, implementation of locally tailored guidelines and advanced care planning. Note that these strategies/models are not necessarily exclusive. For example, most studies evaluating ethics consultations have also included improving communication skills in dealing with complex ethical issues as well as family meetings and the use of advanced care planning.

The importance of improving the competency of communication and relational skills during the EOL care has been advocated by many authors[22;44-46,50,92,93,129-135]. Von Gunten et al[136] proposed a seven step communication model:

1. Prepare for the discussion.
2. Establish what the patient (and family) knows.
3. Determine how information is to be handled.
4. Delver the information.
5. Respond to emotions.
6. Establish goals for care and treatment priorities.
7. Establish a plan.

A recent systematic review[53] found the patient and family caregivers have a high demand for information during all stages of their disease. Thus, effective communication would seem to be an important component in preventing disputes and delivering patient-centred care. Communication can be divided into different levels:

1. ***Personal communications skills***: such as dealing with the patient and their families in breaking bad news and in discussing complex EOL issues with other members of the medical team.

2. ***Unit level***: such as the structure and system in place in the ICU for initiating and facilitating family meetings; setting-up standard forms for withdrawing of life-sustaining treatment; standard daily care plan forms; and electronic medical records in nursing homes.

3. ***System level***: such as proactive palliative care, palliative care outreach service, ethics consultations, intensive interdisciplinary communication interventions with a time-limited trial; multidisciplinary intervention; implementation of guidelines; and local policies.

Question 4 - **How Successful Have These Measures Been in Avoiding Conflict and Why?**

Question 5 - **Do These Proactive Measures Have Differential Impacts Based on Patient Groups?**

Question 6 - **What Factors Have Been Identified as Barriers or Facilitators to Implementing Proactive Measures?**

As these questions overlap, we are addressing them together. While there is some emerging evidence in the literature supporting the effectiveness of various strategies, unfortunately the evidence-base remains sparse and inadequate. Moreover, the strategies often have multiple components, making it difficult to determine the

principle contributor or combination of components which contributed to the results. There is very little high level evidence, if any, which identify sub-groups of patients who may benefit from particular interventions, as the majority of studies only had small to medium sample sizes with insufficient power to make valid conclusions. These studies were also not large enough to test the interaction effect of the intervention (that is, if the intervention works differently on different patient populations). As each study had its particular inclusion criteria; stated composition of patients and clinicians; and conducted within a particular setting, the effectiveness of such interventions should be interpreted within these contextual parameters and caution should be exercised in generalising the results to other settings. A summary of results is outlined below with key results presented in Table 2.

Effectiveness of the Techniques in Dealing with Personal Communication Skills

There are many studies emphasising the importance of effective communication in dealing with the issues at the EOL[45-46,48-55,61]. Back and Arnold[32] provided a concise and insightful discussion abut the common pitfalls in dealing with conflict in caring for the critically ill. They described behaviours that should be avoided when dealing with conflict, including:

- Avoiding or denying conflict.
- Assuming that you know the whole story.
- Repeatedly trying to convince the other party about the correctness of your own view.
- Assuming you know the other party's intentions.
- Holding the other party responsible for resolving issues.
- Assuming that the issue can be settled rationally or based on evidence.
- Declaring other views as ethically questionable.
- Using anger or sarcasm as coercive threats.
- Making decisions or statements in the heat of the moment.

Based on successful methods used in other areas, they suggested using communication strategies such as active listening, self-disclosure, explanations, empathising, reframing and brainstorming (See Table 3 for a more detailed explanation of these techniques and some useful phrases that could be used).

A recent review focuses on the evidence-base of personal communication strategies and cultural issues when delivering bad news and discussing advanced care planning. The Strength of Recommendation Taxonomy (SORT) was used to grade the level of evidence of specific communication recommendations summarised in Tables 2–4. SORT is a measure of the quality of patient outcome orientated evidence: 'A' level grading represents consistent evidence from two or more high quality studies, including randomised controlled trials, cohort studies and systematic reviews; 'B' level evidence represents inconsistent or lesser quality studies, including cohort studies and case series; and 'C' is evidence based on expert opinion or general practice.

It appears that the majority of recommendations are based on expert opinion. However, this does not necessarily mean such recommendations or techniques are invalid as most have a long and rich history in social science and psychology. Nevertheless, most recommendations are based on face value.

Strategies and Models For Improving Unit Level and System Level Communication and Preventing Conflicts

Family Meetings (both formal and informal, regular and irregular)

Three research groups have formally tested the effectiveness of family meetings in improving EOL issues. Lilly and colleagues[61,67] examined an 'intensive communication intervention' model that included four key components:

1. Proactive identification of patients who may have a low chance of survival and who were more likely to encounter ethical issues during their ICU stay according to the following pre-specified criteria: a predicted ICU LOS >5 days; a predicted 25% or higher mortality rate as estimated by the attending physician; or a change in functional status that was potentially irreversible.

2. Initiating formal multidisciplinary meetings with families of patients within 72 hours of admission to the ICU. Such meetings were carefully prepared and structured and included treatment plans and agreed 'milestones' on which success or failure of the treatment plan would be judged. This would facilitate a possible shift from 'cure' care to 'comfort' care.

3. Effective communication of the agreed timeframes and 'milestones' to the treating team and other involved clinicians.

4. Weekly multidisciplinary reviews of cases with the team consisting of attending physicians, nurses, social workers, rehabilitation facility providers and relevant others.

The studies showed that the intervention group had significantly reduced ICU LOS as well as increasing the satisfaction of patients and the families of non-surviving patients as well as reducing mortality in ICU.

Ahrens et al[120] adopted a similar proactive screening process in identifying at-risk patients. The study used a different set of criteria and instituted daily communication with families of the patients by a team consisting of both physicians and nurses. The study also included extensive education of all medical and nursing staff in ICU. It showed a reduced ICU and hospital LOS as well as reduced fixed and variable costs amongst the intervention group in comparison with the control group.

Burns and colleagues[121] conducted a study starting with the screening of the patients who had a high risk of conflict using a four question tool. The screenings

were conducted by a social worker using a structured interview with patient's families and patients, if they were capable of participating. The social worker then met with the clinical team on rounds the next morning and provided feedback to the team regarding findings from the interview. The clinical team made decisions including:

- One-off family meetings.
- Regular family meetings.
- A one-off ethics consult.
- Regular ethics consults.
- A one-off social services consult.
- Regular social services consults.
- A pain consult.
- Pastoral services.
- A second opinion.
- Others and no action.

The study shown increased likelihood of forgoing resuscitation, as well as an increased rate of choosing either comfort-care or continuing an aggressive care treatment plan. However, the study shown no significant changes in satisfaction with the care provided; the amount of information provided; nor in the involvement of family in decision making.

Limited-Time Trial

The concept of the limited-time trial has been discussed and advocated by experts and is recommended in the NSW guidelines. Yet, there is little solid evidence demonstrating its effectiveness apart from Lilly et al's two well conceived trials (although they were non-randomised)[61,67]. By incorporating the 'milestones' of the treatment care plan into the family meetings, it actually acted as a variant of the 'limited-time trial' described by Lee at al[137]. The combination of both family meetings and consensus between the caring team and family members allowed the subsequent session to begin with a discussion of the medical options in the setting of a failing care plan. It allowed clinicians to follow a plan rather than delivering emotionally laden bad news. It also allowed time for the family to adjust to the situation and accept that medical technology may sometimes be ineffective. Thus the discussion could more easily shift from 'cure' to 'comfort' care.

Daily Team Consensus Procedure (Structured daily goals)

As part of improving communication among medical teams as well as between medical teams and patients and their families, Pronovost and colleagues[122] used a before and after design to study the effect of introducing a daily goal forms in the ICU. During the morning round, the respective care team – physicians, nurses, respiratory therapists and pharmacists completed the form for each patient. The form was signed by a fellow or attending physician. Three times a day, all team members reviewed the goals. The daily written goals included family communication

strategies, long term goals of care and, when appropriate, palliative care. The study showed a 50% reduction in the ICU LOS eight weeks after implementation and an increase in perceived communication by nurses and physicians both within the care team, and with patients and their families.

Proactive Palliative Care

Campbell and Guzman studied[118,119] the effect of proactive palliative care in an ICU. The studies applied similar frameworks to two different patient groups: one with end-stage dementia and another consisting of multisystem organ failure or global cerebral ischemia after cardiac arrest.   A nurse practitioner-directed multidisciplinary palliative care team screened the medical ICU census daily for any of the above patients. The team was involved in communicating prognostic news to the family; providing assistance in identifying the patients' advance directives or preferences; providing assistance with discussion of the treatment options with the patient's surrogate; implementing palliative care strategies when treatment goals changed to 'comfort measures only' and provision of consultation and education to the primary care team regarding palliative strategies.   If needed, family meetings were held by the palliative care team. The intervention arm showed reduced hospital LOS and time to establish of comfort care goals; decreased use of resources and reduced ICU LOS.

Pierucci et al[124] conducted a retrospective study with comparisons made between three groups of families of neonates and infants (<1 year old) at a children's hospital over a 4-year period. The three groups were:

1. Those patients who received a palliative care consultations (n=25).
2. Those who did not receive consultations.
3. The subset of group 2 who had a matching diagnosis to group 1.

The paediatric palliative care services consisted of two clinical nurse specialists and a physician medical director responding to requests for consultations. The nurses worked directly with the existing medical team and the families but reported to the supervising palliative care physician. The nurse made recommendations about the environment, advanced directive planning, medical interventions, provided emotional support to the families and assisted with grief and bereavement counselling. The palliative care physician was not involved directly in the management of patients but made recommendations and the patient's attending physician made decisions based on those recommendations. Once consulted, the palliative care staff followed the patient together with the treating medical teams for the duration of their admission. If the patient survived hospitalisation, the palliative care service participated in discharge planning and home care through consultation with a home care agency. Palliative care staff also helped with funeral arrangements and bereavement counselling where necessary. Infants who received consultations had fewer days in the ICUs, decreased number of laboratory tests, a lower rate of central line and feeding tube insertions, decreased vasopressor and muscle relaxant use, decreased

mechanical ventilation, a lower rate of CPR and a decreased number of radiological tests. Their families had more frequent referrals for chaplains and social services. There was also an increased consultation rate from 5% to 38% over three years.

Proactive Ethics Consultations

One of the problems with interpreting the use of ethics consultations is related to how the word is defined and what is the function of the consultation. We have adopted the following definition: "An ethics consultation is a service provided by an individual consultant, team or committee to address ethical issues involved in a specific clinical case. Its central purpose is to improve the process and outcomes of patient care by helping to identify, analyse and resolve ethical problems."

The most significant research in studying the effect of proactive ethics consultations was done by Schneiderman et al[117,123,126,138,139] and Dowdy et al[127]. Schneiderman et al conducted both a single site[117,126] and multi-site[123] randomised controlled trial, showing that ethics consultations are associated with reductions in hospital and ICU LOS as well as in life-sustaining treatments for those patients who died in hospital. Moreover, the study showed that ethics consultations in the ICU were well received by the majority of healthcare providers. Patients and their surrogates thought it was helpful in addressing treatment conflicts. In a follow-up publication using the same multi-site trial data, Gilerm and Schneiderman et al[117] showed that the ethics consultations resolved conflicts that would have otherwise resulted in inappropriately prolonged, non-beneficial or unwanted treatments in the ICU and saved valuable resources. The model had a specific focus on conflicts within family, amongst providers or between providers and family. All of the interventions were provided by a trained and experienced medical ethics consultation service, not only skilled in facilitating communication but also knowledgeable in ethics and the law. The service was supported by an institutional ethics committee. Consultations attempted to be inclusive, educational, respectful of cultural values, and supportive of institutional efforts at quality improvement, including a reduction in resource utilisation.

Dowdy et al[127] conducted an earlier non-randomised trial in examining the effectiveness of a proactive ethics consultation intervention. The study specifically selected patients who had mechanical ventilation longer than four days. The applied proactive ethics consultations applied standardised questions, focused on communication and decision making issues and developed specific strategies for implementation by the care team. The consultation had both structured and unstructured dimensions. The consultation team consisted of two clinicians trained in clinical ethics.

Most of the experience with ethics consultation is from the USA but there are also initiatives from other countries, especially in Europe. The First International Summit on Clinical Ethics Consultation was held in Cleveland in 2003 and the Second International Conference on Clinical Ethics Consultation was held in Basel 2005[140]. In a thematic issue, "Research on clinical ethics and consultation" by Medical Health

Care and Philosophy in 2008, five studies (four from Europe and one from the USA) were included[140]. The studies covered a range of topics and focused on issues such as ethical difficulties around EOL decisions, experiences with newly developed or well established ethics consultation services and the expectations of physicians in various clinical fields who were unfamiliar with clinical ethics consultations[140]. A study[141] from Germany discussed ethical problems in intensive care and in EOL care and how there were many occasions where ethical consultations were considered to be necessary but were not always available. The study highlighted the problems in clinical decision making due to insufficient discrimination between the permissible and the prohibited forms of treatment limitation. A study from Norway[143] reported that clinicians were generally satisfied with ethics consultation services but preferred to be involved actively in the entire process. The study also reported obstacles and challenges of ethics consultations, in particular, the non-referral of cases to the ethics committee. This observation raised the issue of to what extent Norwegian physicians perceived the consultation as a threat to their authority. A study from the USA[124] specifically investigated the hypothesis that clinical staff may be afraid of the consequences of an ethics consultation. The data from a survey of nurses and social workers showed that fear of retaliation was somewhat prevalent but was not associated with a reduction in their willingness to request ethics consultation. Doctors from Bulgaria, a country that did not have any type of ethics consultations at the time of the study[144], reported similar ethical problems as those in other countries and had a positive attitude towards the prospect of ethics consultations. A Dutch clinic reported the process and results of an educational approach they termed '*moral case deliberation*'[145].

In summary, there is increasing interest in using ethics consultation for preventing and resolving disputes during the EOL. It may improve overall quality of life and well being of patients and their surrogates and perhaps also save valuable resources[145-151]. The strongest evidence is from the three trials cited above (Table 2). Their generalisation to other settings and cultures has yet to be confirmed. Furthermore, the studies showed that effectiveness depended on a well trained and experienced ethics consultation team which was often backed by a full ethics committee in the institutions. It is not certain if the same improvement would be achieved in hospitals with a less developed ethics structure.

Advance Care Planning (including advance directives)

Many authors and experts have advocated the use of the advance care planning, especially advance directives[98,100,101,116,152-160]. Advance directives, a kind of advance care planning, specifically address medical care. Instructional advance directives, or 'living wills,' issue treatment instructions while proxy advance directives or 'durable powers of attorney' name proxies to make medical decisions on a patient's behalf. However, the evidence supporting the use of the advance directives for resolving conflicts during EOL care is sparse[161]. Most criticism of advanced directives is aimed at the flawed execution of a sound concept[101,156-158,161]. However, some suggest that the concept is fundamentally flawed in simply promising more

control over future care than is possible[161,162]. It was suggested that medical crises could not be predicted in detail, making most prior instructions difficult to adapt, irrelevant or even misleading.

There are also practical limitations in relying on advance directives for dealing with conflicts during the EOL. In Japan, about 10% of patients have some sort of advance directives[163]. A recent study found that only 23,000 Spanish citizens had an advance directive[153]. During the EOL stage, few patients have the full intellectual capacity to make decisions on their own. Using a surrogate, as specified in an advance directive, has its limitations. Some studies have shown that patient's wishes were often not accurately presented[164,165]. Doctors and nurses and patients' surrogates often have to make decisions regarding rapid changes of the patients' physical conditions by balancing between accepted medical practice and the best interests of the patients. Studies show that it is quite common for existing advanced directives to be overridden or ignored by doctors[128,166,167]. The NIH State-of-Science Report (2004)[168] also concludes that

> *"Encouragement to initiate advance directives (i.e., legal documents, such as living wills and health care powers of attorney) alone, have not been shown to improve outcomes among individuals with diseases other than dementia; however, the reasons for this are not well-known".*

Therefore, it was recommended that instead of focusing on completing advance directives, advanced care planning should prepare patients and families in more general terms for future medical crises[161].

As previous studies have shown (see Table 2), advanced care planning could be part of the components of either proactive palliative care and ethics consultations which have shown effectiveness in preventing and resolving conflicts.

Improving Communication Amongst Clinicians

Researchers have also examined the effect of using standardised communication tools in improving the quality of care during the EOL[169-172]. Bomba and Vermilyea[173] discussed the impact of POLST and similar medical order forms. The POLST provided explicit direction about resuscitation status if patients are pulseless and apnoeic. Other interventions that patients may or may not want are also included in the directions. Research in Oregon, in the USA, has indicated that the POLST paradigm program conveys patients' preferences accurately and is more likely to be followed by the medical profession than traditional advance directives alone.

Treece et al[174] conducted a survey on doctors' and nurses' satisfaction level after introducing a 'withdrawal of life support order form' to improve quality of EOL care in

the ICU and found a high approval rate.   The research team included the form in an intervention aiming for integrating palliative and critical care[175]. This intervention has five components:

1. Educating critical care clinicians regarding the principles and practice of palliative care in the ICU.
2. Providing role models in the form of local champions for promoting attitudinal change.
3. Academic detailing of nurses and physicians to identify and address local barriers to improving EOL care.
4. Providing feedback of local quality improvement data.
5. Providing system supports, including a palliative care order form, family information pamphlets, and other system supports for providing palliative care in the ICU.

Hefferner et al[176] conducted an earlier study that showed the effect of a procedure specific "Do Not Resuscitate" (DNR) order on the communication of the treatment limitations during the EOL. However, despite promising results for various models, the landmark SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) study showed no effect of the study outcomes and no improvement of care quality[109]. The study adopted a randomised trial design and was designed to examine whether physicians, hospital staff, critically ill hospitalised patients and families would benefit from an enhanced communication intervention. The study outcomes included patient and physician agreement on preferences; incidence or time of written DNR orders; days spent in ICU receiving mechanical ventilation or being comatosed before death; level of reported pain and reduction in use of hospital resources. In the intervention group, liaison nurses were trained to improve EOL communication by having multiple contacts with patients, families, physicians, and hospital staff to elicit preferences, facilitate advanced care planning, patient-physician communication and encourage pain management. Multiple explanations[177] were offered for its lack of the effectiveness, including:

- Poor implementation.
- False dichotomisation of DNR decisions.
- Insensitivity of the outcome measures.
- Lack of clear and unambiguous directions.
- Ignoring nurses.
- Ineffective information presentation.
- Study time too short.
- Flawed conceptual model.
- Irrelevant, because usual care is not seriously flawed.
- No nurse involvement in the formation of the study[178].
- Failure to take into account the local culture and organisational context[179].
- Failure to address conflicts within patients' families and surrogates, between family and care team and within the care team[117].

Other Emerging System Interventions: Medical Emergency Teams and the Integration Between the Hospitalist and Palliative Care

Rapid Response Systems such as the MET concept[180,181]) are becoming increasingly employed to identify and respond to seriously ill patients. Often the MET system has to deal with patients who are dying as part of a normal and totally predictable process, where further active treatment would be futile. The reasons are many but include a general reluctance to discuss dying amongst many clinicians and sometimes just an inability to diagnose dying[182]. Thus the response teams, usually as an outreach of intensive care have, in many cases, become the surrogate dying team, often having to talk to relatives and explain to the home medical team that there is little more to offer in the way of active management.

The data from a large cluster randomised controlled trial including 23 Australian hospitals showed that the MET hospitals issued many more not-for-resuscitation orders (NFR) than the controls hospitals when called to treat patients Thus, the implication that a MET system may act like a NFR team on patients could be further explored. More importantly, the impact of a MET system on the incidence of NFR recordings occurred outside ICUs. Thus, it presents a unique opportunity for raising EOL issues with families or the care team for those patients where further active management would be futile[183].

The specialty of hospitalists is rapidly growing in the USA and Canada. Hospitalists are usually doctors trained in the general medical care of hospitalised patients. Hospitalists manage patients throughout the continuum of hospital care, many of whom will die in hospital. Hospitalists are often the primary deliverer of palliative care. Researchers from the USA suggest that because of their continuing presence, hospitalists may afford unique opportunities for dying patients and their families, addressing issues such as physical symptoms; emotional and spiritual distress; enhanced interdisciplinary communication and involvement of hospital-based health professionals. This leads to greater integration between palliative care and hospitalists[184].

Systematic Review of Randomised Controlled Trials (RCTs) Involving the Organisation of Care at the EOL

Thomas et al[185] (2006) conducted a systematic review on published randomised controlled trials about the organisation of care at the EOL by searching nine databases. The review included 23 RCTs that tried to summarise the effect of palliative care on three major themes:

- Dedicated community teams; quality of life; on the management of symptoms; satisfaction with care; the duration of the palliative period and on the place of death.
- Specific interventions — advanced planning of care for the EOL; patient-held records; providing quality of life data to patients and physicians; grief

   counselling for relatives; palliative care education for nurses and palliative care for patients with dementia.
- The costs of palliative care compared to conventional care.

The authors found it was difficult to synthesise an accurate overview of the state of science around EOL issues because the RCTs were conducted in different countries and health systems, with varying terminal illnesses and circumstances of dying and spanning approximately 20 years of time.   However, it appears that community or home-based EOL care compares favourably with more traditional or conventional hospital-based and episodic medical care in improving symptoms and in the opinions of patients and caregivers. The cost-effectiveness of the palliative care strategies reviewed was not clear, given the limitations of the methodology of the studies.

One of the findings consistent across reviews in palliative care[186-188], is that the evidence-base is sparse and research methodology of the published studies is generally poor.   There is a great need for sound research in providing the policy relevant evidence.

The National Institutes of Health (2004) State-of-the-Science Conference on Improving End-of-Life Care identified five key questions and provisional answers[168] (we state their questions verbatim and copy parts of their answers):

1. What defines the transition to EOL? They stated that it is uncommon to be able to clearly identify the EOL for an individual. It is difficult to predict accurately an individual's time of death and there are several transitions that may involve co-morbidities and frailty.
2. What outcome variables are important indicators of the quality of the EOL experience for the dying person and for the surviving ones? Measuring the association between EOL care and the quality of life could be strengthened by clear definitions and consistent measurements of quality of life.
3. What patient, family and health care system factors are associated with improved or worsened outcomes? Research is based on small samples and narrowly defined populations, with assessment and management of symptoms most thoroughly studied in patients with cancer.
4. What processes and interventions are associated with improved or worsened outcomes? A detailed list of areas of research and a critique of problems in research designs is presented.
5. What are the future research directions for improving EOL care?

Some suggested ways forward are to:

- Develop conceptual models to guide a full range of systematic research.
- Operationalise definitions of EOL and palliative care.
- Create a researchers' network and well-defined cohorts of patients.
- Develop a consensus on the minimum set of measures for EOL domains.

- Categorise measures by sources of information, level of information and cognitive requirements.
- Test measurement tools across disease, ethnicity, age, gender and cultural groups.
- Improve information from proxies.
- Develop instruments that minimise the burden of response for patients and families.
- Pay attention to ethical issues, such as the concept of a good death.
- Enlist patients at the beginning of a serious illness to obtain their comments on their health care throughout the period of illness.
- Explore the manner in which individual, family and health care system factors affect outcomes.
- Identify patient preferences.
- Conduct multicentre studies with appropriate power computations to test different interventions.
- Identify the needs of surviving loved ones.

Evidence of Effective Dispute Resolution Techniques to Resolve Conflicts

Question 7 **- What Dispute Resolution Measures have been Deployed to Resolve the Conflicts? (eg Professional Mediators Based Within Hospitals, Ethics Committees, Courts).**

The resolution measures that have been employed to resolve the conflicts involve mediators (could be either within or outside the hospitals), palliative care services or ethics consultation services (both by individual consultant, a team or ethics committee). Other measures involve legal procedures or options such as expert determination, tribunals and court hearings.

Question 8 **- How Successful have these Measures been in Resolving the Conflict and Why?**

Mediators, Palliative Care Consultation and Ethics Consultations

It is difficult from available research to distinguish proactive measures to prevent the conflicts from those measures used to directly resolve conflicts. Perhaps the measures that are effective in preventing the conflicts (such as proactive palliative care consultation and proactive ethics consultations) are also effective for resolving the conflicts. As timely and intensive communication amongst all parties is an integral part of dealing with issues during the EOL, models and strategies that are deemed useful in preventing conflicts are also likely to be useful in directly resolving conflicts.

In practice and, as discussed previously, the family meetings, ethics consultation and palliative care services may have already played a mediator's role during the

consulting process[117,127,139]. The presence of bioethicists during family meetings may be helpful in resolving conflicts between patients, their surrogates and the care team[147,189-192].   Based on a qualitative study, Watkins et al[147] found that bioethicists tended to employ elements of the 'rational choice' model at particular turning points in the decision making process in order to achieve pragmatic goals. Bioethicists also function as a 'mediator' to create consensus between family and staff and provide sympathy and comfort to distressed family members. In general, bioethicists support staff during the mediation, using a context-dependent approach. Apart from being a 'consultant' or 'mediator', bioethicists often play a third role as a 'persuader,' in order to negotiate difficult areas of EOL decision making[147].

There is little research regarding what type of mediators or consultants would be most effective during the consultation. The mediators could be part of the ethics consultation service or palliative care service either located within or outside hospitals. The mediators could be bioethicists, doctors, nurses or social workers, specifically trained in bioethics and negotiating, or outside mediators specialising in conflict resolution. The trials[123,126,127] showing effectiveness often employed consultants who were doctors or nurses with special training in bioethics and negotiating.

Legal Procedures or Options Such as Expert Determination, Tribunals and Court Hearings

This question is discussed in detail elsewhere (page 36-50).

Question 9 - Do these Dispute Resolution Measures have Differential Impacts Based on Patient Group?

There is a scarcity of studies in this area. We have provided discussion of the studies that tested the effectiveness of these models previously (see Table 2).   One noteworthy point when interpreting these results is that each study was conducted amongst specific study populations. Thus the effectiveness, if any, should not be generalised to other patient populations without qualification. Moreover, such effectiveness on the specific patient populations was also bounded by the organisational culture and contextual parameters among which the study was conducted.

Question 10 - What Factors have been Identified as Barriers or Facilitators of Implementing Dispute Resolution Techniques?

We have summarised results from selected studies in Table 2. For each study we have tried to present the successful features of the models and to identify successful factors in the implementation process.   Given the large array of the models described and small number of the studies involved in each model, it is difficult to provide a general summary of the barriers or facilitators of implementing these

interventions. Moreover, the studies often provided inadequate information regarding the implementation for all the components involved, making it difficult to infer from the published studies what are the barriers or facilitators. Nevertheless, it appears that the interventions that have been most effective may share some common features:

- They often adopted a multidisciplinary approach with nurses and allied health worker as active participants.
- They often had a proactive component: actively identifying patients at risk of having EOL problems and integrating 'acute care' with 'comfort care' earlier.
- The decision making process was nether patient or surrogate-centred nor doctor-centred; it was a shared process.
- The communication strategy was comprehensive, intensive and timely (often daily) and patient-focused.
- The interventions often had multiple components such as family meetings, daily communications, proactive palliative care or ethics consultations and limited-time trials.

Although less explicit, the successful interventions often can be inferred as having champions leading local initiatives and having a wider consultation and collaborative process. The successful interventions often had a clear goal, were practical and achievable with a system tailored to local organisational structure and culture.

REFERENCES

1. Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D et al. What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal* 2006; 174(5):627-633.

2. Song M, Sereika SM. An evaluation of the Decisional Conflict Scale for measuring the quality of end-of-life decision making. *Patient Education & Counseling* 2006; 61(3):397-404.

3. Kirchhoff KTS. Caring for the family of the critically ill patient. *Critical Care Clinics* 2004; 20(3):453-466.

4. Thompson BT, Cox P, Antonelli M, Carlet J, Cassell J, HIll N et al. Challenges in End-of-Life Care in the ICU: Statement of the 5th international consensus conference in critical care: Brussels, Belgium, April 2003: Executive summary. *Critical Care Medicine* 2004; 32(8):1781-1784.

5. Bito S, Matsumura S, Singer MK, Meredith LS, Fukuhara S, Wenger NS. Acculturation and end-of-life decision making: comparison of Japanese and Japanese-American focus groups. Bioethics 2007; 21(5):251-262.

6. Carey SM, Cosgrove JF. Cultural issues surrounding end-of-life care. Current Anaesthesia and Critical Care 2006; 17(5):263-270.

7. Giger JN, Davidhizar RE, Fordham P. Multi-cultural and multi-ethnic considerations and advanced directives: developing cultural competency. Journal of cultural diversity 2006; 13(1):3-9.

8. Hsin DH, Macer D. Comparisons of life images and end-of-life attitudes between the elderly in Taiwan and New Zealand. The journal of nursing research : JNR 2006; 14(3):198-208.

9. Sinclair S, Raffin S, Pereira J, Guebert N. Collective soul: the spirituality of an interdisciplinary palliative care team. Palliative & supportive care 2006; 4(1):13-24.

10. Tang S, Liu T, Lai M, Liu L, Chen C, Koong S. Congruence of knowledge, experiences, and preferences for disclosure of diagnosis and prognosis between terminally-ill cancer patients and their family caregivers in Taiwan. Cancer Investigation 2006; 24(4):360-366.

11. Gross ML. Medical ethics education: To what ends? Journal of Evaluation in Clinical Practice 2001; 7(4):387-397.

12. Huei YW, Malik FA, Higginson IJ. End of life content in geriatric textbooks: What is the current situation? BMC Palliative Care 2006; 5(art. no. 5.).

13. Ross DD, Shpritz D, Hull MM, Goloubeva O. Long-term evaluation of required coursework in palliative and end-of-life care for medical students. Journal of Palliative Medicine 2005; 8(5):962-974.

14. Winchester TA. Teaching communication skills to nursing home certified nursing assistants. Geriatric Nursing 2003; 24(3):178-181.

15. Cheng BK. Cultural clash between providers of majority culture and patients of Chinese culture. Journal of Long Term Home Health Care 1997; 16(2):39-43.

16. Feldman MDZ. Chinese and U.S. Internists adhere to different ethical standards. Journal of General Internal Medicine 1999; 14(8):469-473.

17. Koenig BAG. Understanding cultural difference in caring for dying patients. Western Journal of Medicine 1995; 163(3):244-249.

18. Lanken PN, Terry PB, DeLisser HM, Fahy BF, Hansen-Flaschen J, Heffner JE et al. An official American thoracic society clinical policy statement: Palliative care for patients with respiratory diseases and critical illnesses. American Journal of Respiratory and Critical Care Medicine 2008; 177(8):912-927.

19. O'Mahony S, McHenry J, Snow D, Cassin C, Schumacher D, Selwyn PA. A review of barriers to utilization of the medicare hospice benefits in urban populations and strategies for enhanced access. Journal of Urban Health 2008; 85(2):281-290.

20. Arnold EM, Artin KA, Griffith D, Person JL, Graham KG. Unmet needs at the end of life: Perceptions of hospice social workers. Journal of Social Work in End-of-Life and Palliative Care 2007; 2(4):61-83.

21. Nelson JE, Angus DC, Weissfeld LA, Puntillo KA, Danis M, Deal D et al. End-of-life care for the critically ill: A national intensive care unit survey. Critical Care Medicine 2006; 34(10):2547-2553.

22. Planalp S, Trost MR. Communication issues at the end of life: Reports from hospice volunteers. Health Communication 2008; 23(3):222-233.

23. Adershed B, Werkander H. Next of kin's feelings of guilt and shame in end-of-life care. Contemporary Nurse 2007; 27(1):61-72.

24. Burt RA. Law's effect on the quality of end-of-life care: lessons from the Schiavo case. Critical Care Medicine 2006; 34(11):S348-S354.

25. Kramer BJ, Boelk AZ, Auer C. Family conflict at the end of life: Lessons learned in a model program for vulnerable older adults. Journal of Palliative Medicine 2006; 9(3):791-801.

26. Wojtasiewicz ME. Damage compounded: disparities, distrust, and disparate impact in end-of-life conflict resolution policies. American Journal of Bioethics 2006; 6(5):8-12.

27. Kopelman AE. Understanding, avoiding, and resolving end-of-life conflicts in the NICU. Mount Sinai Journal of Medicine 2006; 73(3):580-586.

28. Dubler NN. Conflict and consensus at the end of life. Hastings Center Report 2005; 35(SPEC. ISS.).

29. Cherny NI. Palliative care in situations of conflict: Lessons from Jerusalem. American Journal of Hospice and Palliative Medicine 2006; 23(6):469-474.

30. Bloche MG. Managing conflict at the end of life. New England Journal of Medicine 2005; 352(23):2371-2373.

31. Back AL, Arnold RM. Dealing with conflict in caring for the seriously ill: "It was just out of the question". Journal of the American Medical Association 2005; 293(11):1374-1381.

32. Ashby MAK. Resolving conflict in end-of-life care. Medical Journal of Australia 2005; 183(5):05.

33. Catlin A, Armigo C, Volat D, Vale E, Hadley MA, Gong W et al. Conscientious objection: a potential neonatal nursing response to care orders that cause suffering at the end of life? Study of a concept. Neonatal network : NN 2008; 27(2):101-108.

34. Chiu PPL, Hilliard RI, Azzie G, Fecteau A. Experience of moral distress among pediatric surgery trainees. Journal of Pediatric Surgery 2008; 43(6):986-993.

35. Pendry PS. Moral distress: recognizing it to retain nurses. Nursing Economics 2007; 25(4):217-221.

36. Ferrell BR. Understanding the moral distress of nurses witnessing medically futile care. Oncology Nursing Forum 2006; 33(5):922-930.

37. Frederich MES. Physician-nurse conflict: Can nurses refuse to carry out doctor's orders? Journal of Palliative Medicine 2002; 5(1):155-158.

38. Jezuit DL. The phases of suffering experienced by critical care nurses in association with difficult end-of-life situations [[Dissertation] Chicago: Rush University, College of Nursing; 2001.

39. Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. Journal of Advanced Nursing 2001; 33(6):707-715.

40. Perrin KO. How do intensive care unit (ICU) nurses interact with physicians to facilitate discussion of patients' preferences about resuscitation? PhD Dissertation (110p): Union Institute; 2001.

41. Krishnasamy M. Nursing, morality, and emotions: Phase I and phase II clinical trials and patients with cancer. Cancer Nursing 1999; 22(4):251-259.

42. James V, Field D. Who has the power? Some problems and issues affecting the nursing care of dying patients. European Journal of Cancer Care 1996; 5(2):73-80.

43. Bennett L, Duke J. Research note: decision-making processes, ethical dilemmas and models of care in HIV/AIDS health care provision. Sociology of Health & Illness 1995; 17(1):109-119.

44. Bradley CT, Brasel KJ. Core competencies in palliative care for surgeons: Interpersonal and communication skills. American Journal of Hospice and Palliative Medicine 2008; 24(6):499-507.

45. Mahmood-Yousuf K, Munday D, King N, Dale J. Interprofessional relationships and communication in primary palliative care: Impact of the Gold Standards Framework. British Journal of General Practice 2008; 58(549):256-263.

46. Ngo-Metzger Q, August KJ, Srinivasan M, Liao S, Meyskens J. End-of-life care: Guidelines for patient-centered communication. American Family Physician 2008; 77(2):167-174.

47. Rose JH, Radziewicz R, Bowman KF, O'Toole EE. A coping and communication support intervention tailored to older patients diagnosed with late-stage cancer. Clinical Interventions in Aging 2008; 3(1):77-95.

48. Wilkinson S, Perry R, Blanchard K, Linsell L. Effectiveness of a three-day communication skills course in changing nurses' communication skills with cancer/palliative care patients: A randomised controlled trial. Palliative Medicine 2008; 22(4):365-375.

49. Wittenberg-Lyles EM, Goldsmith J, Sanchez-Reilly S, Ragan SL. Communicating a terminal prognosis in a palliative care setting: Deficiencies in current communication training protocols. Social Science and Medicine 2008; 66(11):2356-2365.

50. Back AL, Arnold RM, Baile WF, Fryer-Edwards KA, Alexander SC, Barley GE et al. Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. Archives of Internal Medicine 2007; 167(5):453-460.

51. Fischer GS, Arnold RM. Feasibility of a brief workshop on palliative care communication skills for medical interns. Journal of Palliative Medicine 2007; 10(1):19-23.

52. Hsiao JL, Evan EE, Zeltzer LK. Parent and child perspectives on physician communication in pediatric palliative care. Palliative and Supportive Care 2007; 5(4):355-365.

53. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S et al. A Systematic Review of Prognostic/End-of-Life Communication with Adults in the Advanced Stages of a Life-Limiting Illness: Patient/Caregiver Preferences for the Content, Style, and Timing of Information. Journal of Pain and Symptom Management 2007; 34(1):81-93.

54. Sanchez-Reilly SE, Wittenberg-Lyles EM, Villagran MM. Using a pilot curriculum in geriatric palliative care to improve communication skills among medical students. American Journal of Hospice and Palliative Medicine 2007; 24(2):131-136.

55. Workman S. A communication model for encouraging optimal care at the end of life for hospitalized patients. QJM 2007; 100(12):791-797.

56. Engelberg R, Downey L, Curtis JR. Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care. Journal of Palliative Medicine 2006; 9(5):1086-1098.

57. Sorensen R, I. Integrating patients' nonmedical status in end-of-life decision making: Structuring communication through 'conferencing'. Communication and Medicine 2006; 3(2):185-196.

58. Tulsky JA. Beyond advance directives. Importance of communication skills at the end of life. Journal of the American Medical Association 2005; 294(3):359-365.

59. Auerbach AD, Pantilat SZ. End-of-life care in a voluntary hospitalist model: Effects on communication, processes of care, and patient symptoms. American Journal of Medicine 2004; 116(10):669-675.

60. Haq C, Steele D, Marchand L, Seibert C, Brody D. Integrating the Art and Science of Medical Practice: Innovations in Teaching Medical Communication Skills. Family Medicine 2004; 36(SUPPL.):S43-S50.

61. Lilly CM, Sonna LA, Haley KJ, Massaro AF. Intensive communication: Four-year follow-up from a clinical practice study. Critical Care Medicine 2003; 31(5 SUPPL.):S394-S399.

62. Aronson SG, Kirby RW. Improving knowledge and communication through an advance directives objective structured clinical examination. Journal of Palliative Medicine 2002; 5(6):916-919.

63. Curtis JR, Patrick DL, Shannon SE, Treece PD, Engelberg RA, Rubenfeld GD. The family conference as a focus to improve communication about end-of-life care in the intensive care unit: Opportunities for improvement. Critical Care Medicine 2001; 29(2 SUPPL.):N26-N33.

64. Ditto PH, Danks JH, Smucker WD, Bookwala J, Coppola KM, Dresser R et al. Advance directives as acts of communication: A randomized controlled trial. Archives of Internal Medicine 2001; 161(3):421-430.

65. Azoulay E, Chevret S, Leleu G, Pochard F, Barboteu M, Adrie C et al. Half the families of intensive care unit patients experience inadequate communication with physicians. Critical Care Medicine 2000; 28(8):3044-3049.

66. Fins JJ, Solomon MZ. Communication in intensive care settings: The challenge of futility disputes. Critical Care Medicine 2001; 29(2 SUPPL.):N10-N15.

67. Lilly CM, De Meo DL, Sonna LA, Haley KJ, Massaro AF, Wallace RF et al. An intensive communication intervention for the critically Ill. American Journal of Medicine 2000; 109(6):469-475.

68. Curtis JR, Patrick DL, Caldwell E, Greenlee H, Collier AC. The quality of patient-doctor communication about end-of-life care: A study of patients with advanced AIDS and their primary care clinicians. AIDS 1999; 13(9):1123-1131.

69. Field DC. Communication and awareness about dying in the 1990s. Palliative Medicine 1999; 13(6):459-468.

70. Haidet P, Hamel MB, Davis RB, Wenger N, Reding D, Kussin PS et al. Outcomes, preferences for resuscitation, and physician-patient communication among patients with metastatic colorectal cancer. American Journal of Medicine 1998; 105(3):222-229.

71. Kaufert JM, Putsch RW. Communication through interpreters in healthcare: ethical dilemmas arising from differences in class, culture, language, and power.[see comment]. [Review] [47 refs]. Journal of Clinical Ethics 1997; 8(1):71-87.

72. Klaristenfeld DD, Harrington DT, Miner TJ. Teaching palliative care and end-of-life issues: A core curriculum for surgical residents. Annals of Surgical Oncology 2007; 14(6):1801-1806.

73. Fischer SM, Egan K, Kassner C, Kutner JS. Healthcare professional education: A unique role for hospices. American Journal of Hospice and Palliative Medicine 2005; 22(1):32-40.

74. Curtis JR. Communicating about end-of-life care with patients and families in the intensive care unit. Critical Care Clinics 2004; 20(3):363-380.

75. Montagnini M, Varkey B, Duthie J. Palliative care education integrated into a geriatrics rotation for resident physicians. Journal of Palliative Medicine 2004; 7(5):652-659.

76. Reilly JM, Ring J. An End-of-life Curriculum: Empowering the Resident, Patient, and Family. Journal of Palliative Medicine 2004; 7(1):55-62.

77. Robinson K, Sutton S, Von Gunten CF, Ferris FD, Molodyko N, Martinez J et al. Assessment of the education for physicians on end-of-life care (EPEC[TM]) project. Journal of Palliative Medicine 2004; 7(5):637-645.

78. Ross DD, Shpritz D, Alexander CS, Carter K, Edelman MJ, Friedley N et al. Development of required postgraduate palliative care training for internal medicine residents and medical oncology fellows. Journal of Cancer Education 2004; 19(2):81-87.

79. Hancock K, Clayton JM, Parker SM, Walder S, Butow PN, Carrick S et al. Discrepant Perceptions About End-of-Life Communication: A Systematic Review. Journal of Pain and Symptom Management 2007; 34(2):190-200.

80. Mazanec P, Tyler MK. Cultural considerations in end-of-life care: how ethnicity, age, and spirituality affect decisions when death is imminent. The American journal of nursing 2003; 103(3):50-58.

81. Rao AS, Desphande OM, Jamoona C, Reid CM. Elderly Indo-Caribbean Hindus and end-of-life care: A community-based exploratory study. Journal of the American Geriatrics Society 2008; 56(6):1129-1133.

82. Ahmed N. Supportive care for patients with gastrointestinal cancer. Cochrane Database of Systematic Reviews 2004; 3:Art. No.: CD003445.

83. Bakitas M, Ahles TA, Skalla K, Brokaw FC, Byock I, Hanscom B et al. Proxy perspectives regarding end-of-life care for persons with cancer. Cancer 2008; 112(8):1854-1861.

84. Curiale V. Home-based palliative care for adults with cancer. Cochrane Database of Systematic Reviews 2007; 2:Art. No.:CD006510.

85. Fairchild A, Goh P, Sinclair E, Barnes EA, Ghosh S, Danjoux C et al. Has the Pattern of Practice in the Prescription of Radiotherapy for the Palliation of Thoracic Symptoms Changed Between 1999 and 2006 at the Rapid Response Radiotherapy Program? International Journal of Radiation Oncology Biology Physics 2008; 70(3):693-700.

86. Ke LS, Chiu TY, Lo SS, Hu WY. Knowledge, attitudes, and behavioral intentions of nurses toward providing artificial nutrition and hydration for terminal cancer patients in Taiwan. Cancer Nursing 2008; 31(1):67-76.

87. Sato K, Miyashita M, Morita T, Sanjo M, Shima Y, Uchitomi Y. Quality of end-of-life treatment for cancer patients in general wards and the palliative care unit at a regional cancer center in Japan: A retrospective chart review. Supportive Care in Cancer 2008; 16(2):113-122.

88. Sola I. Non-invasive interventions for improving well-being and quality of life in patients with lung cancer. Cochrane Database of Systematic Reviews 2004; 4:Art. No.:CD004282.

89. Eliott JA, Olver IN. The implications of dying cancer patients' talk on cardiopulmonary resuscitation and do-not-resuscitate orders. Qualitative Health Research 2007; 17(4):442-455.

90. Fadul N, Elsayem A, Palmer JL, Zhang T, Braiteh F, Bruera E. Predictors of access to palliative care services among patients who died at a comprehensive cancer center. Journal of Palliative Medicine 2007; 10(5):1146-1152.

91. Gilbert T, Wilkinson T, Crudgington S. Supporting people with intellectual disability in the cancer journey: The 'Living with cancer' communication pack. European Journal of Oncology Nursing 2007; 11(4):357-361.

92. Carnevale FA. Examining parental communication in pediatric critical care. Pediatric Critical Care Medicine 2008; 9(1):113-114.

93. Feudtner C. Collaborative Communication in Pediatric Palliative Care: A Foundation for Problem-Solving and Decision-Making. Pediatric Clinics of North America 2007; 54(5):583-607.

94. Angus DC, Barnato AE, Linde-Zwirble WT, Weissfeld LA, Watson RS, Rickert T et al. Use of intensive care at the end of life in the United States: An epidemiologic study. Critical Care Medicine 2004; 32(3):638-643.

95. Kunin H. Ethical issues in pediatric life-threatening illness: Dilemmas of consent, assent, and communication. Ethics and Behavior 1997; 7(1):43-57.

96. Maust DT, Blass DM, Black BS, Rabins PV. Treatment decisions regarding hospitalization and surgery for nursing home residents with advanced dementia: The CareAD Study. International Psychogeriatrics 2008; 20(2):406-418.

97. Ouldred E, Bryant C. Dementia care. Part 3: end-of-life care for people with advanced dementia. British journal of nursing (Mark Allen Publishing) 2008; 17(5):308-314.

98. Triplett P, Black BS, Phillips H, Richardson Fahrendorf S, Schwartz J, Angelino AF et al. Content of advance directives for individuals with advanced dementia. Journal of Aging and Health 2008; 20(5):583-596.

99. Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I. Effectiveness of specialized palliative care: A systematic review. JAMA - Journal of the American Medical Association 2008; 299(14):1698-1709.

100. Ambrosini DL, Crocker AG. Psychiatric advance directives and the right to refuse treatment in Canada. Canadian Journal of Psychiatry 2007; 52(6):397-402.

101. Kim MM, Van Dorn RA, Scheyett AM, Elbogen EE, Swanson JW, Swartz MS et al. Understanding the personal and clinical utility of psychiatric advance directives: A qualitative perspective. Psychiatry 2007; 70(1):19-29.

102. Nemeth A. Communication key to quality care of dementia patients at end of life. Geriatrics and Aging 2007; 10(8):541.

103. Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: Developing and assessing the Disability Distress Assessment Tool (DisDAT). Journal of Intellectual Disability Research 2007; 51(4):277-292.

104. Bambauer KZ, Zhang B, Maciejewski PK, Sahay N, Pirl WF, Block SD et al. Mutuality and specificity of mental disorders in advanced cancer patients and caregivers. Social Psychiatry and Psychiatric Epidemiology 2006; 41(10):819-824.

105. Patel SS, Holley JL. Withholding and withdrawing dialysis in the intensive care Unit: Benefits derived from consulting the renal physicians association/American Society of nephrology clinical practice guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis. Clinical Journal of the American Society of Nephrology 2008; 3(2):587-593.

106. Holley JL. Palliative Care in End-Stage Renal Disease: Illness Trajectories, Communication, and Hospice Use. Advances in Chronic Kidney Disease 2007; 14(4):402-408.

107. Cohen LM, Germain MJ, Poppel DM. Practical Considerations in Dialysis Withdrawal: "To Have That Option is a Blessing". Journal of the American Medical Association 2003; 289(16):2113-2119.

108. Perry E, Swartz J, Kelly G, Brown SL, Swartz RD. Palliative care in chronic kidney disease: peer mentoring program personalizes advance directives discussions. Nephrology news & issues 2003; 17(8):28-31.

109. Moss AH. Recommendations regarding conflict resolution and forgoing dialysis in special patient populations. Nephrology News & Issues 15(13):51-4, 2001.

110. Conneen S, Tzamaloukas AH, Adler K, Keller LK, Bordenave K, Murata GH. Withdrawal from dialysis: Ethical issues. Dialysis and Transplantation 1998; 27(4):200+202-204+207-209+224.

111. Goodridge D, Duggleby W, Gjevre J, Rennie D. Caring for critically ill patients with advanced COPD at the end of life: A qualitative study. Intensive and Critical Care Nursing 2008; 24(3):162-170.

112. Ram FSF. Non-invasive positive pressure ventilation for treatment of respiratory failure due to exacerbations of chronic obstructive pulmonary disease. Cochrane Database of Systematic Reviews 2005; 1:Art. No.:CD004360.

113. Curtis JR, Engelberg RA, Wenrich MD, Au DH. Communication about palliative care for patients with chronic obstructive pulmonary disease. Journal of Palliative Care 2005; 21(3):157-164.

114. Knauft E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. Chest 2005; 127(6):2188-2196.

115. Nielson CP, Connolly MJ. Respiratory critical care in the elderly. Is it worthwhile? CME Journal Geriatric Medicine 2003; 5(1):3-10.

116. Mengual RP, Feldman MJ, Jones GR. Implementation of a novel prehospital advance directive protocol in southeastern Ontario. Canadian Journal of Emergency Medicine 2007; 9(4):250-259.

117. Gilmer T, Schneiderman LJ, Teetzel H, Blustein J, Briggs K, Cohn F et al. The costs of nonbeneficial treatment in the intensive care setting. Health Affairs 2005; 24(4):961-971.

118. Campbell ML, Guzman JA. A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia. Critical Care Medicine 2004; 32(9):1839-1843.

119. Campbell ML, Guzman JA. Impact of a proactive approach to improve end-of-life care in a medical ICU. Chest 2003; 123(1):266-271.

120. Ahrens T, Yancey V, Kollef M. Improving family communications at the end of life: Implications for length of stay in the intensive care unit and resource use. American Journal of Critical Care 2003; 12(4):317-324.

121. Burns JP, Mello MM, Studdert DM, Puopolo AL, Truog RD, Brennan TA. Results of a clinical trial on care improvement for the critically ill. Critical Care Medicine 2003; 31(8):2107-2117.

122. Pronovost P, Berenholtz S, Dorman T, Lipsett P, Simmonds T, Haraden C. Improving communication in the ICU using daily goals. Journal of Critical Care 2003; 18(2):71-75.

123. Schneiderman L, Gilmer T, Teetzel H, et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. Journal of the American Medical Association 2003; 290:1166-1172.

124. Pierucci R, Kirby R, Leuthner S. End-of-life care for neonates and infants: The experience and effects of a palliative care consultation service. Pediatrics 2001; 108:653-660.

125. Holzapfel L, Demingeon G, Piralla B, Biost L, Nallett B. A four-step protocol for limitation of treatment in terminal care. An observational study in 475 intensive care unit patients. Intensive Care Medicine 2002; 28(9):1309-1315.

126. Schneiderman I, Gilmer T, Teetze H. Impact of ethics consultations in the intensive care setting: a randomized, controlled trial. Critical Care Medicine 2000; 28:3920-3924.

127. Dowdy MD, Robertson C, Bander JA. A study of proactive ethics consultation for critically and terminally ill patients with extended lengths of stay. Critical Care Medicine 1998; 26(2):252-259.

128. SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). JAMA 1995; 274:1591-1598.

129. Angelos P, Kapadia MR. Physicians and cancer patients: communication and advance directives. Cancer treatment and research 2008; 140:13-28.

130. Lowey SE. Communication between the nurse and family caregiver in end-of-life care: A review of the literature. Journal of Hospice and Palliative Nursing 2008; 10(1):35-48.

131. Owen R, Jeffrey D. Communication: Common challenging scenarios in cancer care. European Journal of Cancer 2008; 44(8):1163-1168.

132. Barclay JS, Blackhall LJ, Tulsky JA. Communication strategies and cultural issues in the delivery of bad news. Journal of Palliative Medicine 2007; 10(4):958-977.

133. Biola H, Sloane PD, Williams CS, Daaleman TP, Williams SW, Zimmerman S. Physician communication with family caregivers of long-term care residents at the end of life. Journal of the American Geriatrics Society 2007; 55(6):846-856.

134. Brownlee A, Palovcak M. The role of augmentative communication devices in the medical management of ALS. NeuroRehabilitation 2007; 22(6):445-450.

135. Bushinski RL, Cummings KM. Practices of effective end-of-life communication between nurses and patients/families in two care settings. Creative nursing 2007; 13(3):9-12.

136. Von Gunten CF, Ferris FD, Emanuel LL. Ensuring competency in end-of-life care: Communication and relational skills. Journal of the American Medical Association 2000; 284(23):3051-3057.

137. Lee D, Swinburne A, Fedullo A, et al. Withdrawing care: Experience in a medical intensive care unit. Journal of the American Medical Association 1994; 271:1358-1361.

138. Schneiderman LJ. Ethics consultation in the intensive care unit. Current Opinion in Critical Care 2005; 11(6):600-604.

139. Schneiderman LJ. Effect of ethics consultations in the intensive care unit. Critical Care Medicine 2006; 34(11 SUPPL.):S359-S363.

140. Reiter-Theil S, Agich GJ. Research on clinical ethics and consultation. Introduction to the theme. Medicine, Healthcare and Philosophy 2008; 11(1):3-5.

141. Beck S, van de Loo A, Reiter-Theil S. 'A "little bit illegal": Withholding and Withdrawing of Mechanical Ventilation in the Eyes of German Intensive Care Physicians'. Medicine, Health Care and Philosophy 2008; 11(1):7-16.

142. Foerde R, Pedersen R, Akre V. 'Clinicians' Evaluation of Clinical Ethics Consultations in Norway: A Tool for Quality Improvement'. Medicine, Health Care and Philosophy 2008; 11(1):17-25.

143. Danis M, Farrar A, Grady C, Taylor C, O'Donnell P, Soeken K et al. Does fear of retaliation deter requests for ethics consultation? Medicine, Healthcare and Philosophy 2008; 11(1):27-34.

144. Aleksandrova S. 'Survey on the Experience in Ethical Decision-Making and Attitude of Pleven University Hospital Physicians towards Ethics Consultation'. Medicine, Health Care and Philosophy 2008; 11(1):35-42.

145. Molewijk B, Verkerk M, Milius H, Widdershoven G. Implementing moral case deliberation in a psychiatric hospital: Process and outcome. Medicine, Healthcare and Philosophy 2008; 11(1):43-56.

146. Kelso CM, Lyckholm LJ, Coyne PJ, Smith TJ. Palliative care consultation in the process of organ donation after cardiac death. Journal of Palliative Medicine 2007; 10(1):118-126.

147. Watkins LT, Sacajiu G, Karasz A. The role of the bioethicist in family meetings about end of life care. Social Science and Medicine 2007; 65(11):2328-2341.

148. Orr RD. Clinical ethics consultation: to intubate or not to intubate--Part 1 of a series. Today's Christian doctor : the journal of the Christian Medical & Dental Society 2006; 37(3):30-31.

149. Boyle DK, Miller PA, Forbes-Thompson SA. Communication and end-of-life care in the intensive care unit: Patient, family, and clinician outcomes. Critical Care Nursing Quarterly 2005; 28(4):302-316.

150. Curtis JR. Interventions to improve care during withdrawal of life-sustaining treatments. Journal of Palliative Medicine 2005; 8(SUPPL. 1):S116-S131.

151. Fine RL, Whitfield JM, Carr BL, Mayo TW. Medical futility in the neonatal intensive care unit: Hope for a resolution. Pediatrics 2005; 116(5):1219-1222.

152. Marshall R. Advance care directives for people with spinal cord injury: A neglected need. Topics in Spinal Cord Injury Rehabilitation 2008; 13(3):45-52.

153. Simon-Lorda P, Tamayo V, Barrio-Cantalejo IM. Advance directives in Spain. Perspectives from a medical bioethicist approach. Bioethics 2008; 22(6):346-354.

154. Wolf Bosek MS, Ring ME, Cady RF. Do psychiatric advance directives protect autonomy? JONA's Healthcare Law, Ethics, and Regulation 2008; 10(1):17-26.

155. Roessel LL. Protect your patients' rights with advance directives. The Nurse practitioner 2007; 32(8):38-43.

156. Bullock K. Promoting advance directives among African Americans: A faith-based model. Journal of Palliative Medicine 2006; 9(1):183-195.

157. Elbogen EB, Swartz MS, Van Dorn R, Swanson JW, Kim M, Scheyett A. Clinical decision making and views about psychiatric advance directives. Psychiatric Services 2006; 57(3):350-355.

158. Furman CD, Head B, Lazor B, Casper B, Ritchie CS. Evaluation of an educational intervention to encourage advance directive discussions between medicine residents and patients. Journal of Palliative Medicine 2006; 9(4):964-967.

159. Harvey M. Advance directives and the severely demented. Journal of Medicine and Philosophy 2006; 31(1):47-64.

160. Lotjonen S. Medical research on patients with dementia - The role of advance directives in European legal instruments. European Journal of Health Law 2006; 13(3):235-261.

161. Perkins HS. Controlling death: The false promise of advance directives. Annals of Internal Medicine 2007; 147(1):51-57.

162. Teno JM. Advance directives: Time to move on. Annals of Internal Medicine 2004; 141(2):159-160.

163. Miyata H, Shiraishi H, Kai I. Survey of the general public's attitudes toward advance directives in Japan: How to respect patients' preferences. BMC Medical Ethics 2006; 7:Art. No.:11.

164. Fischer GS, Tulsky JA, Rose M, Siminoff L. Patient knowledge and physician afer discussion of advanced directives. Journal of General Internal Medicine 1998; 13:447-454.

165. Seckler A, Meier DE, Mulvihill M, Cammer Paris B. Substituted judgment: how accurate are proxy predictions? Annals of Internal Medicine 1991; 115:92-98.

166. Galambos C. Preserving end-of-life autonomy: the Patient Self-Determination Act and the Uniform Health Care Decisions Act. Health & Social Work 1998; 23:275-281.

167. Volicer L, Cantor M, Derse AR, Edwards D, Prudhomme A, Gregory D et al. National Ethics Committee of The Veterans Health Administration. Advanced care planning by proxy for residents of long-term care facilities who lack decision-making capacity. Journal of the American Geriatrics Society 2002; 50:761-767.

168. National Institute of Health. National Institutes of Health State-of-the-Science Conference: Statement on Improving End-of-Life Care. 2004. http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm, NIH. Ref Type: Report

169. Eliott JA, Olver IN. Perceptions of "Good Palliative Care" orders: A discursive study of cancer patients' comments. Journal of Palliative Medicine 2003; 6(1):59-68.

170. Tilden VP, Nelson CA, Dunn PM, Donius M, Tolle SW. Nursing's perspective on improving communication about nursing home residents' preferences for medical treatments at end of life. Nursing Outlook 2000; 48(3):109-115.

171. Heffner JE, Barbieri C, Fracica P, Brown LK. Communicating do-not-resuscitate orders with a computer-based system. Archives of Internal Medicine 1998; 158(10):1090-1095.

172. Tolle SW, Tilden VP, Nelson CA, Dunn PM. A prospective study of the efficacy of the physician order form for life-sustaining treatment. Journal of the American Geriatrics Society 1998; 46(9):1097-1102.

173. Bomba PA, Vermilyea D. Integrating POLST into palliative care guidelines: A paradigm shift in advance care planning in oncology. JNCCN Journal of the National Comprehensive Cancer Network 2006; 4(8):819-829.

174. Treece PD, Engelberg RA, Crowley L, Chan JD, Rubenfeld GD, Steinberg KP et al. Evaluation of a standardized order form for the withdrawal of life support in the intensive care unit. Critical Care Medicine 2004; 32(5):1141-1148.

175. Treece PD, Engelberg RA, Shannon SE, Nielsen EL, Braungardt T, Rubenfeld GD et al. Integrating palliative and critical care: Description of an intervention. Critical Care Medicine 2006; 34(11 SUPPL.):S380-S387.

176. Heffner J, Barbieri C, Casey K. Procedure-specific-do-not-resuscitate orders. Effect on communication of treatment limitations. Archives of Internal Medicine 1996; 156:793.

177. Lynn J, DeVries K, Arkes H, et al. Ineffectiveness of the SUPPORT Intervention: review of explanations. Journal of the American Geriatrics Society 2000; 48:s206-s213.

178. Baggs JG. End-of-life care for older adults in ICUs. Annual review of nursing research 2002; 20:181-229.

179. Hakim RB, Teno JM, Harrell J, Knaus WA, Wenger N, Phillips RS et al. Factors Associated with Do-Not-Resuscitate Orders: Patients' Preferences, Prognoses, and Physicians' Judgments. Annals of Internal Medicine 1996; 125(4):284-293.

180. Lee A, Bishop G, Hillman KM, Daffurn K. The Medical Emergency Team. Anaesth Intensive Care 1995; 23(2):183-186.

181. Hillman K, Chen J, Cretikos M, Brown D, Bellomo R, Doig G et al. Introduction of medical emergency team (MET) system - a cluster-randomised controlled trial. Lancet 2005; 365:2091-2097.

182. Jones DA, McIntyre T, Baldwin I, Mercer I, Kattula A, Bellomo R. The medical emergency team and end-of-life care: a pilot study. Crit Care Resusc 2007; 9(2):151-156.

183. Chen J, Flabouris A, Bellomo R, Hillman K, Finfer S, et al. The Medical Emergency Team System and Not-for-Resuscitation Orders: Results from the MERIT study. Resuscitation 2008; In press.

184. Muir JCA. Palliative care and the hospitalist: An opportunity for cross-fertilization. American Journal of Medicine 2001; 111(9 SUPPL. 2):10S-14S.

185. Thomas RE, Wilson D, Sheps S. A literature review of randomized controlled trials of the organization of care at the end of life. Canadian Journal on Aging 2006; 25(3):271-293.

186. Morrison RS. Palliative care outcomes research: The next steps. Journal of Palliative Medicine 2005; 8(1):13-16.

187. Piggott M, McGee H, Feuer D. Has CONSORT improved the reporting of randomized controlled trials in the palliative care literature? A systematic review. Palliative Medicine 2004; 18(1):32-38.

188. Rinck GC, Van Den Bos GAM, Kleijnen J, De Haes HJCJ, Schade? E, Veenhof CHN. Methodologic issues in effectiveness research on palliative cancer care: A systematic review. Journal of Clinical Oncology 1997; 15(4):1697-1707.

189. Buchanan SF, Desrochers JM, Henry DB, Thomassen G, Barrett PH, Jr. A mediation/medical advisory panel model for resolving disputes about end-of-life care. Journal of Clinical Ethics 2002; 13(3):188-202.

190. DuVal G, Sartorius L, Clarridge B, Gensler G, Danis M. What triggers requests for ethics consultations? Journal of Medical Ethics 2001; 27(SUPPL, 1):i24-i29.

191. Kovach KK. Neonatology life and death decisions: can mediation help? Capital University Law Review 2000; 28(2):251-292.

192. Orr RD, deLeon DM. The role of the clinical ethicist in conflict resolution. [Review] [21 refs]. Journal of Clinical Ethics 2000; 11(1):21-30.

Appendix

TABLE 1
RELIGIOUS BELIEFS AND ATTITUDES REGARDING DEATH

FAITH	GENERAL BELIEFS	BELIEFS REGARDING CARE OF DYING	HANDLING AND PREPARATION OF THE BODY	ATTITUDES TOWARDS ORGAN DONATION/AUTOPSY
Buddhism	No single God but many Gods acknowledged, although all lesser beings than Buddha. Belief in rebirth and that the present life influences the next. Following the teachings of Buddha brings them closer to Nirvana.	Time for meditation which brings enlightenment. Patient may be reluctant to take medication that clouds the mind or impairs meditation. May appreciate a visit from a Buddhist monk/sister. Generally calm and accepting of death.	Incense may be lit in the room. The family may choose to wash the body. Cremation is usual.	Usually no objection to post mortem. No consensus regarding organ donation.
Hindu	Three supreme Gods worshipped along with numerous others. Belief in a soul that needs to be freed to join the supreme being. Believe in reincarnation. Different sects have different beliefs.	Ritual of washing gives physical and spiritual cleanliness but modesty should be preserved. Time for prayer and meditation important. Pictures, beads or charms may be kept close to the patient. Water from the River Ganges may be given. A Hindu priest may tie a thread around the wrist or neck which should not be removed.	Non-Hindus may touch the body if it is wrapped in a sheet or if they wear gloves. The family may wish to wash the body and have it placed on the floor while incense burns. All are cremated as soon as possible.	No objection to organ donation. Post mortems generally objected to as considered disrespectful, unless legally necessary.

FAITH	GENERAL BELIEFS	BELIEFS REGARDING CARE OF DYING	HANDLING AND PREPARATION OF THE BODY	ATTITUDES TOWARDS ORGAN DONATION/AUTOPSY
Islam	Believe in one God, Allah. Believe in life after death and resurrection of the body. Judgement by God according to a person's deeds and delivers him to heaven or hell. Five religious duties are: faith, prayer, alms giving, fasting and pilgrimage to Mecca.	Family and friends provide emotional support. Prayer is said 5 times daily facing Mecca. The face of a dying person should be turned towards Mecca. Readings from the Koran may be said close to death. The patient may wish a religious leader to visit. Modesty should be preserved.	Non-Muslims touching the body after death should wear gloves. The head is turned to the right and facing towards Mecca. The family may wish to wash the body themselves. Muslims are buried as soon as possible after death.	Organ donation is acceptable. Autopsy only permissible for legal or medical reasons.
Judaism	Believe in one God, an afterlife and physical resurrection of the dead. Strong sense of the value of human life. Different groups: Orthodox-traditional, non-Orthodox – make religious observance fit into modern society.	No last rites but a visit from a Rabbi may be requested. Psalms and prayers are recited by the patient and family. Powerful grip on life can produce ambivalence to a dying person.	Traditionally, the body is left for 8 min with a feather over the nose and mouth to confirm death. The jaw is then bound and the arms placed by the side. This may be performed by the family. The body is placed on the floor, feet towards the door with a candle at the head. The body should not be moved on the Sabbath but this is rarely practicable. The body should not be left alone. Funeral occurs as soon as possible. Orthodox Jews are buried, non-Orthodox Jews may be cremated.	Post mortem resisted by Orthodox Jews unless ordered by civil authorities. Organ donation frowned on in most cases. Non-Orthodox Jews have more relaxed attitudes.
FAITH	GENERAL BELIEFS	BELIEFS REGARDING CARE OF DYING	HANDLING AND PREPARATION OF THE BODY	ATTITUDES TOWARDS ORGAN DONATION/AUTOPSY

| Sikhism | Believe in one God. Individuals, by doing good find the route to salvation. Believe in reincarnation and a path towards perfection. Strong community aspect. Wear 5 symbols of Sikhism: Kesh - uncut hair; Kangha - comb; Kara – steel bangle; Kirpan - symbolic dagger; Kaccha, - long under-shorts. | Near death, the family pray at the bedside and read from the holy book. Some may prefer to pray privately. Tend not to be afraid of death because of the doctrine of reincarnation. | Non-Sikhs may touch the body but the family may wish to prepare the body themselves in which case the body should be wrapped in a plain sheet. The family will wash and dress the body. The 5 K's should be left intact. Apart from neonates, all are cremated, and should be performed as soon as possible after death. | No objections to organ donation. No objections to post mortem. |

(Note: adopted from Carey SM, Cosgrove JF. Cultural issues surrounding end-of-life care. Current Anaesthesia and Critical Care. 2006;17:263-270.)

TABLE 2
THE SELECTIVE MOST RELEVANT STUDIES WITH DATA

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURE	OUTCOMES	FEATURES OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Mengual et al 2007 Canada [116]	Prospective observational study (n=86).	Pre-hospital do not resuscitate (DNR) protocol that allows paramedics to honour verbal and non-standard written DNR requests on all patients with a previous cardiac arrest.	The mean paramedic comfort was rated 4.9 on a 5-point Likert scale (5=very comfortable); 98% of the surrogate decision makers (SDM) reported comfort in withholding cardio-pulomary resuscitation (CPR), with paramedic care in all cases.	A paramedic may withhold or withdraw resuscitative efforts if ▪ A DNR order is present and the patient has been identified. ▪ In the absence of a written DNR, a legally recognised SDM is present and states that the patient expressed a desire not to be resuscitated in this type of circumstance or presents reasons why the patient should not be resuscitated. ▪ The paramedic has no concerns about the appropriateness of withholding resuscitation.	▪ A broad consultative process among stakeholders before the implementation. ▪ Initial 2 hour didactic session and continuing education was provided. ▪ Training included discussion of patient autonomy. ▪ *The Heath Care Consent Act* (HCCA), methods of initiating DNR discussion. ▪ Identification of legally recognised SDMs, death notification and completion of survey questionnaires after a cardiac arrest. ▪ Multiple attempts were made to contact every SDM, including the use of telephone directories, internet search engines as well as contacting the family physicians of the deceased.	Such a model appears to be feasible and acceptable for pre-hospital settings and could be considered as a pilot test in NSW.
PAPER	STUDY	MODEL OF	OUTCOMES	FEATURES OF	IMPLEMENTATION	COMMENTS

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURE	OUTCOMES	FEATURES OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Gilmer and Schneiderman et al 2005 USA[117]	Randomised controlled trial with intervention group (n=156) and control group (n=144) in ICUs of 6 hospitals, part of a previously reported multi-centre trial by Schneiderman (2003)	▪ Identifying patients who had value-based treatment conflicts (eg disputes regarding CPR status; intubate or extubate; aggressive life saving efforts versus comfort care; whether treatments were in the patient's best interest; absence of a qualified surrogate; or conflicts amongst family as to who should serve as surrogate). ▪ Enacting proactive ethics consultation to improve communication and decision making.	▪ Ethic consultations were associated with reductions in hospital days and treatment costs amongst patients who did not survive to hospital discharge. ▪ Ethics consultations resolved conflicts that may have been inappropriately prolonged, non-beneficial or unwanted treatments in the ICU instead of focusing on more appropriate comfort care.	▪ Specifically addressed the conflicts within the family, amongst providers, or between providers and the family. ▪ All interventions were provided by a trained, experienced medical ethics consultation service, not only skilled in facilitating communication but also knowledgeable in ethics and the law and officially backed by an institutional ethics committee. The ethics consultations had tried to ensure that the process of decision making is inclusive, educational, respectful of cultural values and supportive of institutional efforts at quality improvement and appropriate resource utilisation.	Adopted a general process model of ethics consultation: ▪ Medical review: reviewing medical records and interviewing those who were involved. ▪ Ethical diagnosis by the ethics consultant(s): framing issues and drawing upon relevant supporting material. ▪ Recommending action plans: measures for further meetings to improve communication (sharing information, dealing with emotional discomfort and grieving as well as correcting mis-understanding) ranging from team-only meetings with selected participants to a formal conference involving the full ethics committee. ▪ Documentation of the consultation in the patient's medical record. ▪ Follow-up by ethics consultation(s) to provide ongoing support to the process.	An important paper in discussing the impact of the ethics consultation(s) on the cost of hospitalisation. It may have important implications for NSW.

	METHODS	PROACTIVE MEASURE		SUCCESSFUL MODELS	SUCCESS FACTORS	
Campbell and Guzman 2004[118] USA	Non-randomised retrospective comparison group (n=26) and prospective intervention group (n=26) in 1 medical ICU.	▪ Selecting patients with end-stage dementia. ▪ Proactive case finding by palliative care team. ▪ Assisting with family communication regarding prognosis and treatment options. ▪ Implementing palliative care measures as guided by care goals.	▪ Reduced hospital and ICU length of stay (LOS). ▪ Reduced time to establishment of DNR goals. ▪ Reduced use of non-beneficial resources.	The proactive interventions feature: ▪ Early involvement of palliative care services in the process of communicating prognostic news to the family. ▪ Assistance in identifying the patient's advance directives or preferences. ▪ Assistance with discussion of the treatment options with patient's surrogate. ▪ Implementation of palliative care strategies when treatment goals changed to 'comfort measures only'. ▪ Provision of consultation and education to the primary team regarding palliative care strategies.	▪ Active identification of the patient on admission day. ▪ Involving patient's surrogate or guardian in early meetings and communicating prognosis and clarifying needs. ▪ Recommending comfort orientated care and withdrawal of ventilation following the indicators suggested by the guideline. ▪ Discharge from ICU if death was not imminent. ▪ Continuing involvement in the care of the patient if the care goals change to comfort measures. ▪ Active symptom management and family support for dying patients.	Another study that pointed to the potential benefit of proactive palliative care. The model can be shaped for NSW.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURE	OUTCOMES	FEATURES OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Campbell & Guzman et al 2003[119] USA	Non-randomised retrospective comparison group (n=40) and prospective intervention group (n=41) in 1 medical ICU.	▪ Selecting patients with multisystem organ failure or global cerebral ischemia after cardiac arrest. ▪ Proactive case finding by palliative care team. ▪ Assisting with family communication regarding prognosis and treatment options. ▪ Implementing palliative care measures as guided by care goals. ▪ The palliative care service consists of a dedicated nurse practitioner and two rotating physicians (an internist and an intensivist).	▪ Reduced hospital LOS and time to establish comfort care goals. ▪ Decreased use of non-beneficial resources and reduced ICU LOS for multisystem organ failure patients.	The proactive interventions feature: ▪ Early involvement of the palliative care service in the process of communicating prognostic news to the family. ▪ Assistance in identifying the patient's advance directives or preferences. ▪ Assistance with discussion of the treatment options with patient's surrogate. ▪ Implementation of palliative care strategies when treatment goals changed to 'comfort measures only'. ▪ Provision of consultation and education to the primary team regarding palliative care strategies.	▪ Actively identifying patient on admission day. ▪ Involving patient's surrogate or guardian in early meetings and communicating prognosis and clarifying other needs. ▪ Recommending comfort-orientated care and ventilation withdrawal following indicators suggested by the guideline. ▪ Discharge from ICU if death was not imminent. ▪ Continuing involving in the care of the patient if care goals changed to comfort measures. ▪ Active symptom management and family support for dying patients.	A similar study to the previous one but using different patient groups, indicating possible effectiveness of the model to a general patient population.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Ahrens et al 2003 USA[120]	Non-randomised prospective intervention group (n=26) and comparison group (n=26) Setting: 1 medical ICU	Pre-screening of patients who met 2 out of the 6 inclusion criteria: ▪ AIDS. ▪ Conditions associated with an unacceptable quality of life (eg anoxia). ▪ Risk for death >80%. ▪ Lethal conditions. ▪ Mechanical ventilation > 3 days. ▪ Baseline New York Heart Association Class IV, Ejection Fraction<0.20); a daily medical update to families was provided by a communication team of physician and clinical nurse specialists.	▪ Shorter ICU and hospital LOS. ▪ Reduced fixed and variable costs.	▪ Multidisciplinary approach. ▪ Timely and daily update of care plan. ▪ Communication with the family.	▪ Identifying the barriers to effective communication (eg inadequate time, inconsistent use of multidisciplinary team, infrequency). ▪ Defining the specific roles of the physician and clinical nurse specialist. ▪ General education of all nurses on palliative care.	The patients included in the study were quite heterogeneous and the study was conducted in one ICU. The relevance of the model to NSW would need to be tested.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Burns et al 2003 USA[(121)]	Non-randomised prospective intervention study (n=172) and comparison group (n=701). Overall, 873 patients involved in a 2 stage study (phase 1: observational and phase 2: interventional). 7 ICUs were included in the study (3 medical and 4 surgical).	Four step intervention: ▪ Screening patients of high risk for conflict using the 4 question tool. ▪ Social workers performed a structured interview with the patient's surrogate (and patient if capable of participating). ▪ The social worker met with the clinical team on rounds the following morning and provided feedback to the team about the findings from the structured interview. ▪ The clinical team selected action plan from a list of recommendations made by the social worker.	▪ Increased likelihood of forgoing resuscitation. ▪ Increased incidence of choosing either comfort care only or aggressive care treatment plan. ▪ No significant changes in the level of satisfaction with the care provided, the amount of information provided, nor in involvement in decision making.	▪ Pro-active screening. ▪ Multidisciplinary approach involving social workers. ▪ Timely and daily. ▪ Wide-ranging options for clinical team including: one family meeting, regular family meetings, one ethics consult, regular ethics consults, social service consult, regular social service consults, pain consultation, pastoral services, second medical opinion, other/specify, and no action.	▪ Intervention was developed through a consultative process involving all stake-holders. ▪ No a priori assumptions and generalisations of what constitutes the 'appropriate' care for a given patient. ▪ Centred on reducing the conflict in decision making of any kind and to improve satisfaction with the care provided. ▪ The 4 step intervention was based on the consensus of local and national experts in the field.	The process of developing this 4 step model was sound. The model itself can be tailored to suit the local setting. The control group is not comparable with the intervention group due to the selection process. The results should be interpreted with caution.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Lilly, et al 2003 USA[61]	Non-randomised prospective intervention group (n=2361) and 2 control group. The 2 control groups were the follow up of the earlier study of Lilly et al (2000) intervention (n=396) and control group (n=134).	▪ Identifying patients who had a predicted ICU LOS >5 days; a predicted mortality of >25% as estimated by an attending physician; or a change in functional status that was potentially irreversible. ▪ Initiating a formal multidisciplinary meeting with families of patients within 72 hours of ICU admission.	▪ Reduced ICU LOS. ▪ Increased satisfaction with physician and nurse communication by surviving patients and families of non-surviving patients. ▪ Reduced ICU mortality.	▪ Proactive case-finding. ▪ Earlier involvement of families together with family meetings. ▪ Multidisciplinary approach. ▪ Limited-time trial approach: 'milestones' agreed by the family meeting. ▪ A formal consensus building process. ▪ An increase in the uniformity of the content of communications. ▪ A recognition of advanced supportive technology being prone to experiencing operational issues. ▪ A commitment by the attending physician to offer the option of providing earlier access to palliative care for dying patients.	▪ The family meeting was preceded by an assessment of the patient's medical condition, followed by communication with the primary care physician to review and agree about a recommended care plan, and review of any known advance directives. ▪ The formal meeting included the attending physician, nurse, junior medical officer, the patient's family (including the proxy), and, if possible, the patient. ▪ The meeting had 4 objectives: 1) to review medical facts and options for treatment; 2) to discuss the patient's perspectives on death and dying and other preferences; 3) to agree on the care plan; and most important, 4) to agree on criteria by which the success, or failure, of this care plan	The model description is very detailed and the sample size relatively large, adding further weight to the evidence base. Its emphasis on earlier family meetings with a limited-time trial and multidisciplinary approach is worthy of note. Highly valuable work and its relevance to NSW could be tested. Note that Lilly's previous study was the only study quoted in an international consensus paper.

				would be judged (a variant of limited-time trial). • A follow up meeting to review time frames. • Weekly multidisciplinary case reviews.	

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Pronovost et al 2003 USA[122]	▪ Prospective cohort study in a surgical oncology ICU. ▪ Patient sample size not specified. ▪ Not all at risk of death.	During multidisciplinary rounds each day a daily goals form was completed for each patient as well as a communication plan with the patient and family.	▪ 95% of nurses and residents reported understanding the goals of care at week 8 of the study in comparison with 10% at the baseline. ▪ One day less ICU LOS achieved. ▪ Perceived increase in communication by nurses and physicians.	▪ Multidisciplinary approach. ▪ Timely and daily. ▪ Involving nurses and residents. ▪ Consensus approach.	▪ Leadership and local champion. ▪ Ask staff to state the tasks to be completed as well as constructing a care plan and communication strategy. ▪ Interdisciplinary communication is more important than the specific tasks. ▪ Local culture and needs should be considered.	Many ICUs in the USA have adopted such a strategy. The rationale is intuitively appealing and the feasibility of similar tools could be trialled in NSW.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Schneiderman, et al 2003 USA[123]	Randomised controlled trial (n=278 for intervention group; n=273 for control) in adult ICUs in 7 hospitals.	▪ Identifying patients who had value-based treatment conflicts (eg disputes regarding CPR status, whether to intubate or extubate, the extent of aggressive life saving efforts versus comfort care; whether treatments were in the patient's best interest in the absence of a qualified surrogate, or conflicts among family as to who should serve as surrogate). ▪ Enacting proactive ethics consultation to improve communication and decision making.	▪ Increased decisions to forge life-sustaining treatments. ▪ Increased communication. ▪ Decreased ICU LOS for those patients who did not survive to discharge. ▪ No differences in mortality. ▪ High rate of satisfaction with the consultations between clinicians and family members.	▪ Specifically addressed the conflicts within the family, amongst providers, or between providers and the family. ▪ All interventions were provided by a trained, experienced medical ethics consultation service, not only skilled in facilitating communication but also knowledgeable in ethics and the law and officially backed by an institutional ethics committee. ▪ The ethics consultations tried to ensure that the process of decision making was inclusive, educational, respectful of cultural values and supportive of institutional efforts at quality improvement and appropriate resource utilisation.	Adopted a general process model of ethics consultation: ▪ Reviewing medical records and interviewing those who were involved. ▪ Ethics diagnosis by the ethics consultant(s): framing issues, drawing upon relevant supporting material; ▪ Recommendations for the next steps, including measures for further meetings to improve communication (sharing information, dealing with emotional discomfort and grieving, correcting misunderstandings) ranging from team only meetings with selected participants to a formal conference involving the full ethics committee. ▪ Documentation of the consultation in the patient's medical record. ▪ Follow-up by the ethics consultation(s) to provide ongoing support to the process.	Highly important and potentially relevant to NSW.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Pierucci, et al 2001 USA[124]	Retrospective observational study on neonates and infants (<1 year old) at one children's hospital. After reviewing the charts of 196 infants who died during a 4 year period, the infants were divided into 3 groups: those who received a palliative care consultation (group 1; n=25) and those who did not (group 2: n=171); Group 2a was defined as a subset of group 2 and who had a matching diagnosis to group 1(n=123).	The paediatric palliative care services provided in this hospital consisted of 2 clinical nurse specialists and a physician medical director, responding to the requests for consultations.	▪ 15 families had a palliative care consultation that resulted in a home death with home hospice services (not part of the main analysis). ▪ Increased rate of consultation from 5% in year 1994 to 38% in 1997. Infants who received consultations had fewer days in the ICU, blood draws, central line and feeding tubes insertions, vasopressor and muscle relaxant drug use, mechanical ventilation, CPR, and x-rays and their families had more frequent referrals for chaplain and	▪ The nurses worked directly with the existing medical team and the families but reported to the supervising palliative care physician. ▪ Making recommendations about the environment, advance directive planning, medical interventions. ▪ Providing emotional support to assist families cope with grief and bereavement. ▪ Palliative care physicians were not directly involved in the management of patients but made recommendations. ▪ The patient's attending physician made decisions based on the recommendations.	▪ Once consulted, palliative care staff follows the patient with the medical teams for the duration of the admission. ▪ If the patient survived the hospitalisation, the palliative care service participates in discharge planning and home care through consultation with a home care agency. ▪ Whether the patient dies at home or in the hospital, the palliative care staff often help with funeral arrangements and bereavement counselling. ▪ The same 2 nurse consultants provided the services during the 4 year study period.	The model achieved remarkable improvement. It also emphasised the continuum of the care even beyond the hospitalisation period. NSW Health may wish to explore the possibility of adopting such a model.

social services.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Holzapfelet al. 2002 USA[125]	Prospective observational study in 1 ICU with 475 consecutively admitted patients.	A 4-step protocol was designed to improve decision making regarding withholding and withdrawal of life-sustaining treatment.	▪ 17% (83/475) of patients had withholding and withdrawing of life-sustaining treatments and 88% (73/83) of them died. ▪ Mean ICU stay was 10 days from admission to withholding or withdrawing of life-sustaining treatment.	Structured protocol with 4 steps: Step 1: No limitation of care. Step 2: Patient designated DNR and vasopressor drugs limited to dopamine at a maximum dose of 20 ug/kg per min. Other therapies continued. Step 3: Active withdrawal of all therapy except comfort care. Step 4: same as group 3 except that minute ventilation was 5 1/min and dose of sedative and morphine was adjusted to achieve a score of 6 on the Ramsay sedation scale.	▪ The ICU staff made decisions regarding the level of the care based on the probability of death, quality of survival and family viewpoint. ▪ All ICU staff, the admitting physician and all family members have to agree with all procedures and changes in the level of the care. ▪ Allowing family enough time to consider proposals. ▪ Regular meetings with family with at least one physician and one nurse present. ▪ All family members are consulted regarding the procedures and no one person was specifically designated as	The study only measured limited outcomes and had no comparison group. Its relevance is less certain in NSW.

spokesman.
- Proper documentation in the patient record of decisions and discussion.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Lilly et al. 2000 USA[67]	Non-randomised prospective before-after study: intervention group (n=396) and control group (n=134) in 1 medical ICU among 530 consecutively admitted adult patients.	▪ Identifying patients who had a predicted ICU LOS >5 days, a predicted mortality of >25% as estimated by an attending physician, or a change in functional status that was potentially irreversible. ▪ Initiating formal multidisciplinary meetings with families of patients within 72 hours of ICU admission.	▪ Reduced ICU LOS. ▪ Earlier access to palliative care services. ▪ No increased mortality.	▪ Proactive case finding. ▪ Earlier involvement of families and family meetings. ▪ Multidisciplinary approach. ▪ Limited-time trial approach: 'milestones' agreed by the family meeting. ▪ A formal consensus building process. ▪ An increase in the uniformity of the content of communications. ▪ A recognition of advanced supportive technology as void when it was not working. ▪ A commitment by the attending physician to offer the option of providing earlier access to palliative care for dying patients.	▪ The family meeting was preceded by an assessment of the patient's medical condition, communication with the primary care physician about a recommended care plan, and review of any known advance directives. ▪ The formal meeting included the attending physician, nurse, junior medical officer, the patient's family (including the proxy), and if possible, the patient. ▪ The meeting had five objectives: 1) to review medical facts and options for treatment; 2) to discuss the patient's perspectives on death and dying, and other preferences; 3) to agree on care plan; and most important, 4)to agree on criteria by which the success or failure of the care plan would be judged (a variant of	The model emphasises intensive communication with the family within a limited-time trial using a multidisciplinary approach. The relevance for NSW could be tested.

| | | | | | limited-time trial); 5) a following meeting organised according to an agreed time frame. | |
| | | | | | ▪ Weekly multidisciplinary case review. | |

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Schneiderman, et al 2000 USA[126]	Randomised controlled trial (n=35 for intervention group; n=35 for control) in medical and paediatric ICUs in one hospital.	▪ Identifying patients who had value-based treatment conflicts (eg disputes regarding CPR status, decisions in regard to whether to intubate or extubate; aggressive life saving efforts versus comfort care). ▪ Enacting proactive ethics consultation to improve communication and decision making.	▪ Increased decisions to forge life-sustaining treatments. ▪ Increased communication. ▪ Decreased ICU LOS for those patients who did not survive to discharge. ▪ No differences in mortality. ▪ High rating of satisfaction with the consultations involving clinicians and family members.	▪ Specifically addressed any conflicts within the family, amongst providers, or between providers and the family. ▪ All of the interventions were provided by a trained, experienced medical ethics consultation service, not only skilled in facilitating communication but also knowledgeable in ethics and the law and officially backed by an institutional ethics committee. ▪ The ethics consultations had tried to ensure that the process of decision making is inclusive, educational, respectful of cultural values and supportive of institutional efforts at quality improvement and appropriate resource utilisation.	Adopted a general process: ▪ Medical review: reviewing medical records and interviewing those involved. ▪ Ethics diagnosis by the ethics consultant(s): framing issues, drawing upon relevant supporting material. ▪ Recommendations of next steps, including measures for further meetings to improve communication (sharing information, dealing with emotional discomfort and grieving and, addressing misunderstandings) ranging from team-only meetings with selected participants to a formal conference involving the full ethics committee. ▪ Documentation of the consultation in the patient's medical record. ▪ Follow-up by the ethics consultation(s) to provide ongoing support to model of ethics consultation. ▪ The process.	A very important model with solid theoretical foundation. However the sample size is quite small which limits generalisations.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
Dowdy, et al. 1998 USA[127]	Non-randomised prospective study with 1 intervention group (n=31) and 2 control groups (one with option of care time (n=31) and another with no intervention at all (n=37)) in 1 ICU.	▪ Selecting patients with >96 hours of continuous mechanical ventilation. ▪ Proactive ethics consultations to review care planning with care team applying standardised questions. ▪ Focusing the intervention on communication and decision making issues. ▪ Specific suggestions to the care team.	▪ Increased frequency and documentation of communications. ▪ Increased decisions to forgo life-sustaining treatments. ▪ Increased family members approval rating on consultations.	▪ A process-orientated intervention. ▪ Both 'counselling' and 'educational'. ▪ Proactive case-finding. ▪ Planning in advance for crises. ▪ Multidisciplinary communication and encouraging cooperation. ▪ Aiming for changing patterns of communication and decision making amongst physicians and all involved in the patient's care. ▪ The consultation is a consultee-centred process with both structured and unstructured dimensions. ▪ The consultation team consisted of 2 clinicians trained in clinical ethics.	Focus of consultation is on: ▪ Increasing dialogue between physicians and patients. ▪ Heightening attention to whatever is perceived as problematic. ▪ Encouraging questions. ▪ Helping persons to challenge one another. ▪ Removing obstacles to communication. ▪ Seeking the cooperation necessary to reach 'a mutually beneficial outcome from informed consensus or compromise'. ▪ Leadership buy-in.	A model with a sound theoretical foundation and conceptual framework but the sample size is small. The tenet of the model could be adopted and tested in NSW.

PAPER	STUDY METHODS	MODEL OF PROACTIVE MEASURES	OUTCOMES	FEATURE OF SUCCESSFUL MODELS	IMPLEMENTATION SUCCESS FACTORS	COMMENTS
SUPPORT principal investigators 1995 USA[128]	A study with both phase I: prospective observation (n=4301) and phase II: randomised controlled trial (n=4804; intervention vs control: 2652 vs 2152).	For the phase 2 trial: ▪ The patients were identified according to life-threatening diagnoses (any 1 or more of 9 diagnoses) such as acute respiratory failure, multisystem organ failure with sepsis, metastatic colon cancer. ▪ Physicians were provided with estimates of the patients' chances of 6 month survival daily. ▪ Specially trained nurses had multiple contacts with patient, family, physician, and hospital staff.	▪ No difference in patient and physician agreement on preferences between control and intervention groups. ▪ No difference in incidence or timing of written DNR. ▪ No difference in outcomes of days spent in ICU receiving mechanical ventilation or period of being comatosed before death, level of pain or use of hospital resources.	See next column regarding the possible explanations of why such an intervention was unsuccessful.	Multiple explanations offered for the failure to achieve positive outcomes: ▪ Was not implemented as designed. ▪ Falsely dichotomised DNR decisions. ▪ Did not focus on primary care physicians. ▪ Needed more sensitive outcome measures. ▪ Was not didactic enough. ▪ Nurses were often ignored. ▪ Information presentation was ineffective. ▪ Study time was not long enough. ▪ The conceptual model base was flawed. ▪ The usual care was not as bad as thought so the intervention was irrelevant. ▪ Nurses were not involved in the formulation of the study. ▪ Did not take into account local context	This was the largest study on improving communication and advance care planning. The study showed no significant improvement in any of the outcomes measured. Although multiple explanations were offered for the negative results, it demonstrated the difficulty in conducting a randomised control trial (RCT) on this topic. The study has more than 1340 citations (accessed in August 2008). Some would argue the conceptual base

					and culture. ■ Failure to address conflicts within the family, amongst providers, or between providers and the family.	of the model may be flawed.

TABLE 3
SUGGESTED TOOLS FOR ADDRESSING CONFLICT AT THE PERSONAL COMMUNICATION LEVEL

TOOL	USEFUL PHRASES
Active listening: Turn full attention to the speaker rather than focusing on your own concerns or on counterarguments and provide feedback showing that you have understood	"What I'm hearing you say is that you want us to do everything possible to prolong your father's life." "It sounds like you are concerned about this patient's suffering being made worse."
Self-disclosure: Reveal to listener some aspect of how you are feeling without blaming the other party for your emotions	"I am worried that even the best medical care will not be able to achieve your hopes." "I need a few minutes to cool off because I'm irritated; but later we need to talk about the next steps."
Explaining: Provide the listener with information about aspects of the situation you are most concerned about	"My view of this situation is that providing intravenous fluid would give her, at best, a 50-50 chance of improving."
Empathising: Provide the listener with evidence that you understand his emotional state	"I can see that you care a great deal about what happens to your mother." "This is a sad situation." "I think anyone would feel as worried as you given the circumstances."
Reframing: Describe situation as a mutual problem to be solved collaboratively	"Now I think we should look at the issue of intravenous fluid as not just 'Do we do it?' but as part of the bigger picture of her care."
Brainstorming: Propose potential solutions without critiquing them as a first step in problem solving	"Let's try to come up with a few ideas about how to prepare for her death and then pick a few to work on."

Note: the above table adopted from Back AL, Arnold RM. Dealing with conflict in caring for the seriously ill: "It was just out of the question". JAMA 2005;293(11):1374-1381

TABLE 4
LITERATURE STANDARDS FOR BREAKING BAD NEWS AND GRADES BY SORT TAXONOMY

RECOMMENDATION	GRADE
In general, patients desire information about their diagnosis, treatment and prognosis.	B
Clinicians should ask patients how much they want to know before giving information.	B
Clinicians should explore cultural issues in an open-ended dialogue with patients and families to ensure they are appropriately addressed.	B
If patients desire, family members should be present during discussions regarding their medical care.	B
During discussions of bad news, clinicians should explore patients' emotional cues through empathic statements.	B
Bad news should be given in an area free from distractions and with appropriate time allotted.	B
A clinician who is an expert about the patient's condition should provide the information.	B
Physicians should use appropriate body language during discussions, including removing obstructing objects.	C
Clinicians should limit the amount of information provided, giving no more than three pieces of information without a break.	C
Clinicians should meet frequently with patients and families	B
During discussions about care at the EOL, clinicians should elicit patient goals, values and desires for care.	B
Only professional medical interpreters should be used unless it is unavoidable.	B

Note: the above table adopted from Barclay et al. "Communication strategies and cultural issues in the delivery of bad news".   Journal of Palliative Medicine. 2007;10: 958-977.

TABLE 5
LITERATURE STANDARDS FOR BREAKING BAD NEWS AND GRADES BY SORT TAXONOMY

TECHNIQUE	EXAMPLE	GRADE
Acknowledgement	Naming of an emotion or communication barrier. "It sounds like you're angry."	C
Exploration	A probe for more information. "Tell me more."	C
Empathy	Expressing understanding of another's experience. "I can't imagine how difficult this is for you."	C
Legitimation	A statement which normalises or validates an opinion or emotion. "Most people would feel the same way."	C
Summarise	Rephrasing and confirming what has been said. "Let me make sure that I've heard you correctly…"	C
"Firing a warning shot"	Alerting the patient or family to impending bad news. "Mr. Smith, I've looked at your father's lab results, and I'm afraid I have some bad news."	C
"I wish" statements	A statement that allows alignment with a patient's desires but implicitly acknowledges that it is not likely to occur. "I wish we had a way to make him better."	C
Delivery of no more than three pieces of information before pausing for a break	"Your father is very weak, and has not been eating or drinking in the past several days. Unfortunately, I don't think that he is going to recover and be able to eat on his own. He will likely continue to decline and become less responsive over the next few days." "I've just shared a lot, are you still with me?"	C

Note: the above table adopted from Barclay et al. "Communication strategies and cultural issues in the delivery of bad news". Journal of Palliative Medicine. 2007;10: 958-977.

TABLE 6
WORKING WITH INTERPRETERS AND GRADES BY SORT TAXONOMY

RECOMMENDATION	GRADE
Only professional medical interpreters should be used unless it is absolutely unavoidable.	A
Clinicians should meet with interpreters prior to family conferences in order to plan the meeting.	C
Physicians and interpreters should agree on cues to signal stopping points or discuss how much can be said before pausing for interpretation.	C
Before starting, all participants should be introduced.	C
Interpreters should sit near the patient, but avoid obstructing the interaction between the patient and clinician.	C
Physicians should speak in the second person ("Do you have pain?") and interpreters should speak in the first person ("I will give you medicine for your pain").	C
Physicians should speak directly to the patient and should look at the patient while they listen to the interpreter, as if it is a normal conversation between the clinician and the patient.	C
Clinicians should use nonverbal communication, and respond to nonverbal cues by the patient to establish empathy.	C
To ensure understanding, it is important to check frequently for comprehension.	C
If a physical examination is needed, clinicians should ask the patient if it is okay for the interpreter to stay.	C
Following the interview, the clinician should meet with the interpreter to discuss the meeting and clarify misunderstandings. In addition, if further interpretation is needed for the same patient, the same interpreter should be used.	C

Note: the above table adopted from Barclay et al. "Communication strategies and cultural issues in the delivery of bad news". Journal of Palliative Medicine. 2007;10: 958-977[132]