
Using mediation in situations of withholding or withdrawing life-sustaining treatment: A New South Wales perspective

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Whether to withhold or withdraw life-sustaining treatment from a person lacking competency is an extremely difficult decision for both the person's family and for a medical practitioner. Family members face being part of a decision which may lead to the death of a loved one. Practitioners face considerable pressure to make the right care recommendation and to protect their patient's best interests. This creates a charged emotional environment, where clear and unambiguous communication between all involved is essential. Mediation may be under-utilised in these situations, offering, as it does, the prospect of improved decision-making processes and outcomes. However, certain aspects of the American "bioethics mediation" model would not work well in New South Wales or elsewhere in Australia. Instead, a more "classical" mediation model, utilising the New South Wales Health Conciliation Registry in a new way, is preferable.

DECISION-MAKING DYNAMICS AND FRAMEWORK

The position at law

At law, where a patient lacks sufficient capacity to make decisions about their own health care, decision-making is essentially based upon a determination of the patient's "best interests". This involves determining what is necessary to preserve, safeguard, secure and promote their physical and/or mental health.¹ A patient's expressed wishes are relevant, but not determinative.² A patient's "best interests" can include both continuing life-sustaining treatment,³ or withdrawing life-sustaining treatment and continuing palliative care only.⁴ Where there is unanimous agreement between practitioners as to there being no real prospect of significant recovery, it would be unusual for a court to order institution or continuance of life-sustaining treatment.⁵

Some problems

What makes situations involving the withholding or withdrawal of life-sustaining treatment particularly difficult are the different decision-making criteria of members of the treating team and the family. A treating team's views on initiating or continuing life-sustaining treatment will mostly hinge upon clinical factors, particularly whether the patient has a significant prospect of a meaningful recovery. By contrast, a family's decision-making is more likely to hinge upon emotional issues, such as a desire to preserve their loved one's life for as long as possible.

Acute emotion, the complexity of the various clinical, ethical and legal issues and the various interests involved can all significantly impede communication and inhibit decision-making. There are the preconditions for a decision-making process which risks being riddled with conflict. There is the

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¹ *MAW v Western Sydney Area Health Service* (1999) 49 NSWLR 231 at [41].

² *Minister for Health v AS* (2004) 29 WAR 517; [2004] WASC 286.

³ *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549.

⁴ *Messiha v South East Health* [2004] NSWSC 1061.

⁵ *Messiha v South East Health* [2004] NSWSC 1061 at [25].



potential for relationship breakdown between the treating team and the patient's family, creating impasse, disempowerment and/or the family seeking recourse through other avenues, such as court applications, to ensure that the decision which they want is made. This raises the question of whether there is scope for mediation to improve the decision-making process and outcomes.

Australian cases involving disputes between a treating team and a patient's family over whether to withhold or withdraw life-sustaining treatment illustrate some of the problems which can arise in these situations, namely:

- differences between treating team and family perceptions about a patient's capacities (eg, the family observing their loved one to be responsive, suggesting a prospect for improvement and recovery, whereas the treating team has either not found the same signs or disagrees that they offer an improved prognosis);⁶
- the family's perception that the treating team has not waited long enough to decide that treatment is futile;⁷
- the family has particular values impacting upon their decision-making (eg, a culture which requires continuing care);⁸
- poor communication by the treating team (such as referring to irrelevant resource requirements,⁹ displaying annoyance at family requests and lack of communication prior to making decisions);¹⁰
- the treating team fails to follow protocols for decision-making;¹¹ and
- the family feels under considerable psychological pressure.¹²

The complexity of determining whether treatment is futile and differing views of death create further opportunities for conflict. As Faunce and Stewart observe, the notion of futile treatment is a notoriously controversial concept in clinical medicine, bioethics and health law. Practitioners and family members may disagree about both what level of probability and what type of evidence should be used to evaluate the chances of treatment offering a meaningful quality of life.¹³ Similarly, Ashby, Kellehear and Stoffell observe that, despite apparent widespread public pragmatism about death and dying, when a treating team suggests withholding or withdrawing life-sustaining treatment with families, they can often meet with disbelief and even hostility. The idea that cure is improbable or impossible, and that continued treatment is inappropriate or unkind, is unacceptable to many families.¹⁴

Situational context also plays a part in creating the risk of conflict. According to Liebman, at least in the United States context, the hospital system is a "perfect incubator for miscommunication and conflict", created by

- the treating team working under impossible time pressures;
- the delivery of complex information and bad news to emotionally vulnerable families;
- the fragmentation of treating teams across shifts and specialities; and

⁶ *Messiha v South East Health* [2004] NSWSC 1061 at [13]-[14]; *Melo v Superintendent, Royal Darwin Hospital* (2007) 21 NTLR 197; [2007] NTSC 71 at [22]; *Re Herrington* [2007] VSC 151 at [17]-[18].

⁷ *Messiha v South East Health* [2004] NSWSC 1061 at [26]; *Re Herrington* [2007] VSC 151 at [18].

⁸ *Re Herrington* [2007] VSC 151 at [18].

⁹ *Messiha v South East Health* [2004] NSWSC 1061 at [9].

¹⁰ *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549 at [27]-[29], [38], [41].

¹¹ *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549 at [43]-[44], [103].

¹² *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549 at [40].

¹³ Faunce TA and Stewart C, "The Messiha and Schiavo Cases: Third-party Ethical Interventions in Futile Case Disputes" (2005) 183(5) MJA 261 at 262, citing Kerridge I, Mitchell K and McPhee J, "Defining Medical Futility in Ethics, Law and Clinical Practice: An Exercise in Futility?" (1997) 4 JLM 235.

¹⁴ Ashby MA, Kellehear A and Stoffell BF, "Resolving Conflict in End-of-life Care" (2005) 183(5) MJA 230 at 230-231.



- the involvement of multiple family members, each hearing only some of the clinical facts from different members of the health care team.¹⁵

NEW SOUTH WALES PROCEDURE

New South Wales hospitals and nursing homes are all subject to Department of Health Guidelines on the withdrawal of life-sustaining treatment from incompetent patients.¹⁶

The Guidelines seek to promote communication, compassionate and appropriate treatment decisions, fairness and the safeguarding of both patients and practitioners. They seek to do this by utilising a consensus-building approach, involving the treating team and family together planning care which is in the patient's best interests, namely reflecting the patient's own wishes and values as much as possible and avoiding both inappropriate over- and under-treatment.¹⁷

Practically speaking, the treating team makes care recommendations based upon their understanding of the patient's condition and prognosis, allows time for discussion and reflection and continues to work with, and support, their patient's family and to seek a consensus decision.¹⁸ Early, honest and regular communication is required to create the necessary trust for shared decision-making, to defuse tension and to avoid unrealistic treatment expectations.¹⁹

If the treating team and the patient's family disagree upon whether to withhold or withdraw life-sustaining treatment, the New South Wales Guidelines contemplate that disagreement can generally be prevented by early, sensitive and proactive communication clarifying treatment goals, possible outcomes and a patient's values and wishes. They outline a number of options, starting with further time and repeat discussion, and thereafter progressively to a second medical opinion, a time-limited treatment trial and third party facilitation. The facilitation, conducted by a senior hospital administration member, a senior health professional or another person with sufficient seniority mutually agreed upon, aims to clarify and address family concerns and/or to secure agreement. Failing resolution, the possibility of transfer to alternative care can be investigated, or a tribunal or court application can be made, seeking an order for authorising withdrawal or continuance of treatment.²⁰

If there is an inappropriate request for continuing treatment, the treating team is to consider the request, review diagnostic and prognostic certainty and explain why continuing is inappropriate. The need to support family members and assist them in accepting the reality of their loved one's situation is emphasised. It is preferable to continue treatment until conflict is resolved.

WHY MEDIATION CAN HELP

The New South Wales Guidelines contemplate a procedure which is very similar to that which a classical mediation seeks to achieve, namely communication of parties' interests and values, with a view to finding areas of agreement and working towards a consensus decision.

However, where there is no independent control over what is already a high-stakes process, there is a risk of procedural breakdown, leading to impasse, communication breakdown, stress and more drastic action. The parties will not always be able to recognise what they both should, and need to, do. They may also be unable or unwilling to understand other parties' positions and interests. They may be unable to explain their position and interests cogently. Disagreement may be inevitable, particularly where the parties adopt entrenched positions, have very different underlying reasons for their position or disagree over clinical issues, such as prognosis. In those circumstances, mediation may be the only forum for properly exploring a consensus-building approach.

¹⁵ Liebman CB, "Introduction to the Symposium Issue on Alternative Dispute Resolution Strategies in End-of-life Decisions" (2007) 23 *Ohio State Journal of Dispute Resolution* 1 at 8-9.

¹⁶ New South Wales Department of Health, *End-of-Life Care & Decision-Making – Guidelines* (March 2005), http://www.health.nsw.gov.au/policies/gl/2005/GL2005_057.html viewed 16 June 2009.

¹⁷ New South Wales Department of Health, n 16, p 1.

¹⁸ New South Wales Department of Health, n 16, pp 5-6

¹⁹ New South Wales Department of Health, n 16, p 8.

²⁰ New South Wales Department of Health, n 16, pp 9-10.



Mediation also offers other benefits to parties in dispute about whether treatment is futile. In the context of resolving health care disputes between treating teams and families generally, Antommara believes that mediation offers a number of benefits over litigation, including lower costs, quicker resolution and privacy.²¹ Liebman identifies that bioethics mediation (a form of mediation in a health care context – see below) reduces the risk of focusing merely upon the values and assumptions of the treating team and family, instead focusing upon the patient’s true interests and desires.²² Mediation can also allow parties to work out whether they are actually in disagreement about withholding or withdrawing treatment. Cohen suggests that many so-called disputes are really misunderstandings, not being differences as to appropriate treatment, but rather communication failures, or different perceptions of medical facts, prognosis, patient behaviour and personal values.²³

Studies showing an increasing potential for agreement over time suggest that mediation can assist in resolving disputes over whether to withhold or withdraw life-sustaining treatment. According to one study, 57% of families/surrogate decision-makers agreed immediately with the treating team care plan, with 90% reaching agreement with the treating team within five days.²⁴ In another study, consensus was reached in 51% of cases after the first meeting, 69% after a second meeting and 97% after a third meeting.²⁵ Clearly, the number of cases in which mediation would be required would be limited. This sliding scale of agreement suggests that, with an appropriately conducted mediation, there is significant scope for further reducing the number of outstanding disputes between treating teams and families.

THE AMERICAN EXPERIENCE

In the United States of America, Dubler and Liebman have advanced “bioethics mediation” as a way of dealing with complex treatment decisions, including withdrawal of life-sustaining treatment. In theory, their model:

- identifies the relevant parties (acknowledging that there are often more than two sides to a conflict);
- allows understanding of both the stated and latent interests of parties;
- minimises disparities of power, knowledge, skill and experience as far as possible;
- allows parties to define their interests;
- maximises resolution options;
- searches for common ground or areas of consensus; and
- ensures that any consensus is compatible with both bioethics and the law.

The fundamental goal is to maximise the likelihood of a principled resolution with which all parties are comfortable.²⁶

Dubler and Liebman propose the use of a bioethics mediator, who is not a treating team member, but is likely to be a hospital employee who must be impartial. The bioethics mediator provides information, enforces norms and ensures that any resolutions fall within medical “best practice”

²¹ Antommara AHN, “How Can I Give Her Antibiotics At Home When I Have Three Other Children to Care For? Using Dispute System Designed to Address Patient Provided Conflicts in Health Care” (2008) 29 *Hamline J Pub L & Pol’y* 273 at 281-282

²² Liebman, n 15 at 3.

²³ Cohen G, “Negotiating Death: ADR and End-of-life Decision-making” (2004) 9 *Harvard Negotiation Law Review* 253 at 275, citing Povar GJ, “Evaluating Ethics Committees: What Do We Mean By Success?” (1991) 50 *Maryland Law Review* 904; Dubler NN, “Heroic Care Cases: When Difficult Decisions About Care Are Near, Mediation Can Help Bridge the Communication Gap” (Spring 1999) *Disp Resol Mag* 7.

²⁴ Prendergast TJ et al, “A National Survey of End-of-life Care for Critically Ill Patients” (1998) 158 *American Journal of Respiratory Critical Care Medicine* 1163.

²⁵ Garros D et al, “Circumstances Surrounding End-of-life in a Paediatric Intensive Care Unit” (2003) 112 *Pediatrics* E371 at E372.

²⁶ Dubler NN and Liebman CB, “Bioethics: Mediate in Conflict in the Hospital Environment” (2004) 59(2) *Dispute Resolution Journal* 32 at 35-36.



guidelines.²⁷ The mediator ensures that options are based upon respect, interests, rights and differences.²⁸ The mediator may limit solutions, including treatment options, to those which the hospital is willing to offer. While Dubler and Liebman acknowledge that this could represent the imposition of a treating team's will upon a family, they argue that this allows the family to control the elements of care which they can control, to acknowledge elements beyond their control and to improve relationships between the treating team and family.²⁹ They acknowledge the possibility that entrenched positions by any one or more parties, preventing a consensus decision, are most likely signs that an alternative process is necessary to resolve the dispute.³⁰

Bioethics mediation involves the bioethics mediator first meeting with the treating team to discuss the clinical situation, treating team recommendations and to learn about both the relationship between the treating team and the family, and family dynamics impacting upon any disagreements. The mediator will subsequently meet with the family. During the "formal" bioethics mediation, a member of the treating team commences by setting out the clinical situation, to ensure that all participants are working from the same clinical data, even if there are differing views about their relevance. Dubler and Liebman believe that this prevents familial embarrassment at committing to erroneous positions which they feel unable to move from in order to save face. They identify that the mediator should exclude any recommendations and clinical predictions from the explanation. The mediator then determines whether another treating team member or family member should speak next. They also ensure that family members introduce the patient, describing what he or she was like before illness. The mediator ensures that families' values, interests and perspectives are both heard and honoured, by using frequent summaries and open-ended questions, trying to discern underlying interests, separating conflict into manageable and "discussable pieces" and helping the treating team and family generate and evaluate options. The mediator ensures that any consensus agreement is justified as a principled resolution, compatible with both bioethical norms and legal rights.³¹

Although initially querying whether hospital employees could act as bioethics mediators, Liebman thought that "insider knowledge" and time constraints made hospital employees preferable. However, this does not address the fact that there are persons, independent of any hospital involved, with sufficient expertise and understanding to conduct such mediation. This problem could be removed through the use of the New South Wales Health Conciliation Registry (see below).

Liebman contemplates that bioethics mediators may need to educate both the treating team and the family about ethical norms. While acknowledging that educating and enforcing norms calls into questions mediator neutrality and impartiality, she observes that mediators in other contexts have norm-enforcing roles, such as ensuring that "best interests" are protected.³² The role of educating and enforcing norms calls into question whether bioethics mediation represents more of an open bioethics committee discussion forum than a true mediation. Where there are most likely to be differing views as to the identity of, and weight to be given to, relevant ethical norms between various mediators, there is a risk that inconsistent positions will be presented to different families. As families come from a variety of backgrounds, they may not share these norms, thus impeding any mediation and prospect of reaching consensus. A mediator adopting both an educative role and limiting options creates a significant risk that families will feel that a solution is being imposed upon them and adopt entrenched positions, again impeding the prospect of consensus. While it is clear that any discussion of various options must take place within the legal framework, namely what the patient's best interests are, to attempt to impose ethical norms beyond that is fraught with danger, particularly in light of the variety of cultural and religious backgrounds of various families, the complexity of the issues involved and the high levels of emotion present.

²⁷ Dubler and Liebman, n 26 at 36.

²⁸ Dubler and Liebman, n 26 at 37.

²⁹ Dubler and Liebman, n 26 at 38-39.

³⁰ Dubler and Liebman, n 26 at 37.

³¹ Liebman, n 15 at 12-13.

³² Liebman, n 15 at 14-15.



DOWNSIDERS TO MEDIATION: THE AMERICAN EXPERIENCE

The utility of mediation in situations of withholding or withdrawing life-sustaining treatment has been questioned, arising out of issues of lack of focus upon the patient in question, limited scope for decisions and power imbalances.

Bierlein considers that classical mediation's emphasis upon autonomy and finding both expansive and creative options limits the utility of mediation in the end-of-life care context.³³ He proposes "person-centred" mediation, based upon "seeing the face of the other", focusing upon the patient's life and needs through an intimate understanding who they are as a person.³⁴ This produces a mediation which aims to build a conception of the patient and the patient's situation which allows both the treating team and family to reach a decision which is aligned with what the patient would want.³⁵

While "person-centred" mediation has considerable attraction, it has inherent practical limitations. The nature of the patient's "personhood", namely their values and beliefs, may be disputed between the treating team and the family, or even between various members of the family. Although the most reliable source of a patient's "personhood" is likely to be their family, discerning "personhood" is likely to be compromised by the emotion and high stakes surrounding the dispute. While focusing upon the patient may be helpful during the process of reaching consensus, where the parties adopt entrenched positions, a focus upon the patient's "personhood" is unlikely to be the optimal way of determining their best interests, particularly where there may be little indication as to what the patient would want in a situation of clinical futility. In any event, "person-centred" mediation risks failing to adequately deal with the clinical issues involved, the various parties' emotions and any communication breakdown which may be at the root of the dispute. Ultimately, it may be that the mediator not merely assists the parties in determining the patient's "personhood", but also addresses other important issues impeding the potential for any agreement.

Bierlein suggests that end-of-life care disputes differ from other mediation disputes as they essentially involve a binary decision, namely whether to treat or not.³⁶ This view fails to acknowledge the variety of intermediate options which mediation could generate, such as a time-limited treatment trial or the opportunity to transfer the patient to another care facility. In Cohen's view, many "intermediate" options in the context of end-of-life decision-making are never explored.³⁷

The utility of mediation in determining whether to withhold or withdraw treatment has also been questioned upon the grounds of power imbalance. According to Pope and Waldman, as United States law gives families disproportionate power, mediation cannot allow parties to work together to find a creative solution somewhere between their initial starting points, as treating teams usually back down and allowing the family to obtain the treatment that they want.³⁸ In New South Wales the emphasis upon clinical factors in determining best interests suggests that greater power is in the hands of the treating teams as opposed to the family.³⁹ Indeed, Pope and Waldman acknowledge that a clear "safe harbour" for a treating team to refuse to provide inappropriate medical treatment can foster the necessary conditions for mediation.⁴⁰ The current test provides that "safe harbour". If a court is likely to decide in favour of the treating team's desire to withhold or withdraw treatment, mediation may provide an opportunity for it to clearly and comprehensively communicate the reasons for their views,

³³ Bierlein M, "Seeing the Face of the Patient: Considerations in Applying Bioethics Mediation to Non-competent End-of-Life Decision-making" (2007-2008) 23 *Ohio State Journal on Dispute Resolution* 61 at 62, 71.

³⁴ Bierlein, n 33 at 74-77.

³⁵ Bierlein, n 33 at 77-78.

³⁶ Bierlein, n 33 at 81.

³⁷ Cohen, n 23 at 274.

³⁸ Pope TM and Waldman EA, "Mediation at the End of Life: Getting Beyond the Limits of the Talking Cure" (2007-2008) 23 *Ohio State Journal on Dispute Resolution* 143 at 149.

³⁹ *Messiha v South East Health* [2004] NSWSC 1061 at [25].

⁴⁰ Pope and Waldman, n 38 at 192.



provide a chance for the team to hear the family's views, for the family to deal with the emotion involved and, particularly with the assistance of a mediator, to provide them with an opportunity to see the reality of their loved one's situation.

DEVELOPING A MEDIATION MODEL FOR THE NEW SOUTH WALES CONTEXT

Clearly, mediation offers many potential benefits where a treating team and a patient's family are in disagreement over whether to withdraw or withhold life-sustaining treatment. The question then is, how should mediation operate?

The bioethics model, while offering considerable benefits, also has certain limitations, particularly its more "interventionist" mediator. It also seems inconsistent with the consensus-building approach of the New South Wales Guidelines. Instead, a "classical" mediation model – involving a neutral mediator working as a conduit for communication between parties to explore underlying assumptions, values, interests and positions, with a view to clarifying what is in dispute and whether any consensus can be reached – offers the prospect of greater therapeutic advantage to the parties involved, as there is less risk of a perception that any solution is being imposed. The mediator should be independent of the treating team and its originating hospital or nursing home.

The New South Wales Health Conciliation Registry may provide a viable source of mediators, as it has a number of independent and trained conciliators, with sufficient expertise and understanding of the various issues and interests involved to help the parties explore these interests and attempt to either reach a consensus decision or narrow down the areas of disagreement. It presently conducts conciliation of more minor complaints about health care. A conciliator aims to allow the parties to the complaint to get together to discuss, negotiate and settle a complaint and, if possible, assist them to reach agreement.⁴¹ Accordingly, conciliation is very similar to classical mediation, based upon models used in resolving family law disputes. The conciliator has no advisory or determinative role beyond the process itself, being limited to identifying issues, developing options and considering alternatives.⁴² As at late 2008, there was a panel of 32 conciliators, with a further recruitment process under way.⁴³ Any necessary legislative amendment could be achieved with little difficulty. Achieving funding for additional activities may be more problematic, but perhaps not impossible.

Mediation should be mandatory where a treating team and a patient's family cannot agree upon withholding or withdrawing life-sustaining treatment and the options of further time and repeat discussion, second medical opinion and a time-limited treatment trial (as contemplated under the New South Wales Guidelines) have been exhausted. After this point, unless one party is willing to give way, the next option is a tribunal or court application. It is preferable to avoid the expense, publicity and stress associated with such a step. The benefits of mediation over such a step are clear. Unless there is good cause why mediation should not take place, parties should be required to participate in good faith.

CONCLUDING REMARKS

Mediation seems underutilised in the context of disputes relating to withholding or withdrawal of life-sustaining treatment from an incompetent patient. These highly charged situations can involve impeded communication, high emotion and complex issues. In most cases, mediation will provide an appropriate forum for allowing the parties to the dispute to explain their positions, express emotions, explore options for common ground and determine whether there is any scope for final agreement upon a treatment plan. Even if a final agreement cannot be reached, the time taken to see if this is possible is worthwhile, with the parties having both explored the possibility of consensus and minimising the chance that the dispute does not arise out of a fundamental disagreement as to the

⁴¹ *Health Care Complaints Act 1993* (NSW), ss 48, 49.

⁴² Committee on the Health Care Complaints Commission, *Discussion Paper of the Health Conciliation Registry* (Report No 4, June 2004) pp 4-5.

⁴³ Lines J, "Something's Happening Here: Resolving Complaints in the NSW Health Conciliation Registry", paper presented to the National Mediation Conference, Perth, September 2008, p 2.



nature of treatment to be provided. It also avoids the cost, stress and publicity associated with tribunal or court hearings. It offers the prospect of improving parties' comfort and satisfaction, of reference to a wider range of interests in reaching a decision and of improving community confidence in the decision-making process. Clearly, more widespread use of mediation in these situations is worth exploring.

