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# Bioethics Outlook

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### Truth, justice, understanding: a reflection

Susan Crennan

*Then shall the just stand with great constancy against those that have afflicted them and taken away their labours. These seeing it shall be troubled with terrible fear, and shall be amazed at the suddenness of their unexpected salvation. Saying with themselves, repenting, and groaning for anguish of spirit: These are they whom we had some time in derision and for a parable of reproach. We fools esteemed their life madness and their end without honour. Behold how they are numbered among the children of good, and their lot is among the saints. Therefore we have erred from the way of truth, and the light of justice has not shined unto us, and the sun of understanding hath not risen upon us. The Book of Wisdom 5:1-6*

*And, behold, a certain lawyer stood up, and tempted him, saying Master, what shall I do to inherit eternal life? He said unto him, What is written in the law? How readest thou? And he answering said, Thou shalt love the Lord thy God with all thy heart, and with all thy soul, and with all thy strength, and with all thy mind; and thy neighbour as thyself. And he said unto him, Thou hast answered right: this do, and thou shalt live. But he, willing to justify himself, said unto Jesus, And who is my neighbour? And Jesus answering said, A certain man went down from Jerusalem to Jericho, and fell among thieves, which stripped him of his raiment, and wounded him, and departed, leaving him half dead.*

#### In this Issue

We begin with Justice Susan Crennan's remarkable reflection on the 'practical human endeavour' which the truth, as established in a court room, is. It is a fine response to Pilate's question. And we might add: The restoration of health as brought about by the relationship between a trustworthy doctor and his or her patient is another such 'practical human endeavour'.

Next, Bernadette Tobin comments on some recent developments in the debates about public policy concerning the practices which are described by that most slippery of terms: 'euthanasia'.

Finally, the paediatrician Jonathan Gillis, an Honorary Fellow of Australian Catholic University at the Plunkett Centre and currently National Medical Director of the Organ and Tissue Authority, together with his colleague Janet Rennick, argue that the literature on the role of the family with respect to the care of children in intensive care has failed properly to understand the phenomenon of parental love.

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*And by chance there came down a certain priest that way: and when he saw him, he passed by on the other side. And likewise a Levite, when he was at the place, came and looked on him, and passed by on the other side. But a certain Samaritan, as he journeyed, came where he was: and when he saw him, he had compassion on him. And went to him, and bound up his wounds, pouring in oil and wine, and set him on his own beast, and brought him to an inn, and took care of him. And on the morrow when he departed, he took out two pence, and gave them to the host, and said unto him, Take care of him; and whatsoever thou spendest more, when I come again, I will repay thee. Which now of these three, thinkest thou, was neighbour unto him that fell among the thieves? And he said, He that shewed mercy on him. Then said Jesus unto him, Go, and do thou likewise. Luke 10:25-37*

The lessons today from the Book of Wisdom and the Gospel of Saint Luke remind us of three things essential to a just world. In the words of the Book of Wisdom, they are 'the way of truth', 'the light of justice' and 'the sun of understanding'.

None of these is tied to a specific branch of Judaism or Christianity or any other system of religious belief. However, as Durkheim demonstrated, it is human to seek and revere the sacred, so it is possible to speak of faith and justice in the one breath. Shared values captured in the simple metaphors of illumination, 'the way of truth', 'the light of justice' and 'the sun of understanding', underpin many ways of understanding the world.

Different ways of understanding the world can intersect surprisingly. There was a celebrated case in my home State of Victoria years ago in which the plaintiffs challenged the constitutionality of a law which provided financial aid for the educational activities of church schools. Appearing for the plaintiffs, opposed to funding church schools, was Neil McPhee QC. He was a celebrated advocate, widely considered to be a most formidable and cunning cross-examiner who regularly got the better of witnesses. In any event, one

morning McPhee was to cross-examine a nun who was, as I recall it, the principal of a Roman Catholic school and a Mother Superior in respect of a group of teaching nuns. She was a most dignified witness and he approached her with kid gloves. Somehow, in the course of some questions, they got onto the topic of prayer. She volunteered the information that she and her fellow nuns prayed 'every day'. He then enquired mildly 'Sister, what sort of things do you pray for?' 'Well,' she said 'this morning we prayed for you Mr McPhee.' McPhee subsequently admitted this was a good example of 'asking one question too many'.

The expression in the first lesson today, 'the way of truth', suggests both that truth is something exterior to the self to be valued as we make our way through life, and that truth is part of our interior selves, a way of being which helps us calibrate right and wrong, commands moral choices and esteems the pursuit of virtue. In either sense 'the way of truth' points to shared values and the role of community in human affairs. This is not to deny that for the saintly amongst us introspection and meditation may be 'the way of truth'.

The rule of law is predicated upon shared norms, the transgression of which may involve physical punishment or other sanctions or the enforcement of one person's right against another's impingement on those rights. Hence the importance of 'evidence' which, in its most metaphysical verbal sense, means the quality of making something clear. Lawyers are all familiar with evidence, as testimony, through witnesses and documents building up a clear picture of something which happened in the past leading to a jury verdict or a judgment.

Many lawyers have experienced what is called in today's reading 'the sun of understanding', that moment when the accretion of evidence allows one or other standard of proof in the common law system to be satisfied. Each of those standards operates to give as much of a guarantee as is humanly possible, that an accused or defendant is treated fairly before adverse consequences are visited upon them as part of the legal process. This is partly the

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source of the responsibility on all advocates to understand and apply the forensic techniques in which they are trained. There is accumulated wisdom in much of the court-craft in which advocates are acculturated.

This leads me back to 'the way of truth'. There is a maxim about courts of law: *res iudicata pro veritate accipitur*. It can be translated as: a thing adjudged is accepted for the truth. The maxim is profoundly uncompromising especially in our times when Continental philosophers have given fresh currency to the idea that truth is relative. The maxim would appear just as capable of applying to civil law systems as it does to common law systems.

In another famous Australian case known colloquially as 'the Banking case', one of our most famous judges, later the Chief Justice, Sir Owen Dixon, referred to that maxim. He said:

*'There are few, if any, questions of fact that courts cannot undertake to inquire into. In fact it may be said that under the maxim res iudicata pro veritate accipitur courts have an advantage over other seekers after truth. For by their judgment they can reduce to legal certainty questions to which no other conclusive answer can be given' (at 76 CLR 1 at 340).*

The truth to which the maxim refers is not a poet's 'Truth' - it does not double with 'Beauty' as in Keat's Ode, nor is it connected with 'purely untellable things': 'the hardness of life, the long experience of love' of Rilke's Ninth Elegy.

Equally it is not the truth of a mystic philosopher like Simone Weil who said 'The need for truth is more sacred than any other need'. This was a deeply personal, even introspective, truth expressed aphoristically. Nor is the 'truth' of the maxim equivalent to an historian's sense of truth.

When comparing historians and lawyers, F W Maitland said:

*'The lawyer must be orthodox otherwise he is no lawyer; an orthodox history seems to me to be a contradiction in terms.'*

Clearly there are many answers to Pilate's famous question.

Truth for the purposes of the rule of law is not to be found in the mob or at the other end of the spectrum in divine revelation or inspiration. Truth established in a court room is the product of a practical human endeavour circumscribed by the particular question or controversy before the court and severely restricted by the issues framed for a trial by reference to the law, including the laws of evidence. A judge's authority to decide a justiciable issue is limited by that framework. Establishment of truth in a court room calls upon human capacities for perspicacity, constancy, empathy and fairness applied to a particular set of facts and the inferences to be drawn from those facts. The truth established thus is not necessarily perfect truth or complete truth, if such a thing were ever possible in relation to a past deed or event. It is, however, severe truth to be applied for the purposes of exoneration on the one hand, or punishment, sanction or redress on the other.

Advocates are crucial in the court room because they mediate the process, the outcome of which is legal certainty in respect of some specific human transgression or conflict presented for resolution according to the law. For the law to be authoritative in society, legal certainty must correspond with justice. The maxim expresses a singular reality which binds us to past and future generations of lawyers because law depends for its continuing authority on a constructive dialectic between continuity and change. Truth in the law tests to the utmost the capacities of all those for whom it is a calling.

Let me conclude by saying that what the maxim expresses is reason enough to turn back to the words from The Book of Wisdom and to renew our own individual and collective efforts to keep 'the light of justice' shining.

***Susan Crennan is a Justice of the High Court of Australia. This is the text of an address she gave in the Temple Church, London, on 1<sup>st</sup> July 2012***

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## ***'If nobody wants you at the party, why should you stay?'***

### **Recent developments in the debate about euthanasia and public policy**

**Bernadette Tobin**

'Euthanasia': it's a term with no settled meaning. It comes from two Greek words: 'eu' meaning 'well' and 'thanatos' meaning 'death'. So 'dying well' is a rough translation. Who, then, is *against* 'dying well'? Who *could be* against 'dying well'? Who does *not* want to 'die well'? Who does *not* hope that family, friends, those who are least able to care for themselves, the frail elderly, the cognitively impaired, die well? 'Dying well' is like motherhood and apple pie: it is something that we all want, for our relatives, for our friends, for ourselves.

But, as John Finnis points out, the term 'euthanasia' has no generally-accepted and philosophically-warranted core of meaning. Rather it is a rhetorical term *designed to persuade*.<sup>1</sup> It is used by people who want to persuade the community that, if people are to die well, then the law must be changed to permit either the intentional killing of patients by doctors, or the intentional assisting-of-patients-to-commit-suicide by doctors (or both). The implication seems to be that it is not possible to 'die well' unless one has the option of having one's life deliberately terminated... by a doctor or with a doctor's help.

Now, it is true that most of us know someone whose dying could not be described as 'dying well'. And it is true that there is much to be done in Australia before we can say that everyone has the opportunity to die well.

General practitioners as well as doctors in hospitals need to master the modern skills of palliative medicine and to care for their dying patients as palliative specialists. Health departments need to prioritize access to first class palliative and end-of-life care: home-based, in hospices, in nursing homes, in hospitals. And we all need to be more sensitive to the burden that will be carried by those who will likely have to make decisions for us later in life – likely, our relatives. But all that said, it is clear that, in order to die well, one does not need to have one's life deliberately terminated. Some people die 'of old age' in their sleep. Some people die having had futile or overly-burdensome treatment appropriately withdrawn or withheld. Some die having symptoms effectively relieved. And those are just some of the ways in which modern medical practice can help to ensure that people 'die well'. In addition there are all the non-medical circumstances which contribute to a good death: the re-establishment of harmonious relations with family and friends, their presence at the time of death, etc.

These thoughts about the word 'euthanasia' are prompted by the frequent re-emergence, in Australia as elsewhere, of proposals to legalize 'euthanasia' and 'assisted suicide' – purportedly on the grounds that there is small group of people for whom the legalisation of these procedures would ensure the chance to die well. The most recent was a proposal,

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rejected by the voters in Massachusetts, that doctors should be allowed to *'prescribe medication, at the request of a terminally ill patient meeting certain conditions, to end that person's life'*.

Two opinion pieces in the *New York Times* about the Massachusetts proposal were striking. In one, Ezekiel Emanuel, a Professor of Public Health at the University of Pennsylvania who previously worked in the Obama White House, identified four major falsehoods in the debate about 'physician-assisted suicide'.<sup>2</sup> In the other, Ben Mattlin, a freelance journalist who suffers from spinal muscular atrophy, explained why – as a disabled person - he could not support the proposal.<sup>3</sup>

#### **Four misconceptions**

The first falsehood identified by Emanuel concerns pain. *'The fundamental claim behind arguments for physician-assisted suicide is that most patients who desire it are experiencing excruciating physical pain.'* But this view, notably expressed in 1996 by the United States Court of Appeals for the Ninth Circuit, is false. Studies based on interviews with patients with such conditions as cancer, AIDS and Lou Gehrig's disease have shown that patients who want the doctor to administer a lethal drug to them or to prescribe one for them that they can take themselves tend not to be motivated by pain. And, as Emanuel says, among the seven patients who received 'euthanasia' in the Northern Territory in the 1990s, three reported no pain and the pain of the other four was adequately controlled by medications. In general patients say that their primary motive is not to escape pain by to avoid psychological distress: depression, hopelessness and fear of loss of autonomy and control. Our normal response to people

who suffer with depression and hopelessness is to offer them counselling and care.

The second falsehood concerns advanced technology. It's the misconception that euthanasia and assisted suicide are the inevitable results of a high-tech medical culture that can sustain life even when people have become debilitated, incontinent, incoherent and bound to a machine, the *'inevitable consequence of changes in the causes of death, advances in medical science, and the development of new technologies'* as the court put it. But as Emanuel points out, the ancient Greeks and Roman advocated euthanasia, and proposals have been revived for at least the last one hundred years.

The third falsehood concerns so-called 'mass appeal'. It's said that a change in the law will improve things for everyone. Death afflicts everyone, so surely legalizing assisted suicide will allow any individual to avoid a painful death. But in jurisdictions where it has been legalized, few have taken advantage of it. For the vast majority of dying patients, a change in legislation will have no impact on the end of their lives. Legalizing assisted suicide would, in Emanuel's view, *'benefit well-off, well-educated people, typically suffering from cancer, who are used to controlling everything in their lives'*. The people most likely to be abused by the legalization of assisted suicide are *'the poor, poorly educated, dying patients who pose a burden to their relatives'*.

The fourth misconception about assisted suicide is that it is quick, painless and guaranteed as a way to die. But, as Emanuel points out, nothing in medicine is without complications and many things (he mentions several) can go wrong with assisted suicide.

Emanuel concludes that, instead of attempting to legalize assisted suicide, we should focus our efforts on 'what really

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matters': improving care for the dying, 'ensuring that all patients can openly talk with the physicians and families about their wishes and [having] access to high-quality palliative or hospice care before they suffer needless medical procedures. The appeal of physician assisted suicide is based on a fantasy. The real goal should be a good death for all dying patients'.

## The fantasy of patients deciding for themselves

A few days later the piece by Ben Mattlin appeared in the same newspaper. On Mattlin's view there are strong arguments in favour of the adoption of an assisted-suicide law. As a pro-choice liberal he thinks he ought to support such a law. As a lifelong disabled person he cannot.

Why so? Mattlin puts it this way: *'I've lived so close to death for so long that I know how thin and porous the border between coercion and free choice is, how easy it is for someone to inadvertently influence you to feel devalued and hopeless – to pressure you ever so slightly but decidedly into being 'reasonable', to unburdening others, to "letting go".'*

Mattlin, who was born with spinal muscular atrophy, who has never walked or stood or been able to use his hands, is a 50-year-old husband, father, journalist and author. He says that he has had periods in hospital when doctors have seriously questioned whether it was worth trying to save his life. (Fortunately for him, they consulted his wife!) He has learned how easy it is for doctors to perceive a disabled person as a failure of their profession. That is what he calls an 'invisible force of coercion', one which can occasion a cloud of depression in even the most cheery of optimists. Such depression in a disabled

person can seem rational to doctors. And, adds Mattlin, given the dearth of alternatives, it may be rational: *'If nobody wants you at the party, why should you stay?... Who chooses suicide in a vacuum? We are inexorably affected by our immediate environment. The deck is stacked.'*

The philosopher Elizabeth Anscombe once said that, with respect to 'euthanasia', she thought the emphasis on the 'voluntary' was spurious. Emanuel's catalogue of the misconceptions which bedevil the debate, and Mattlin's experience of the attitude of some doctors, certainly seem to support this impression. He asks: Why are we in such a hurry to ensure a right to die before we've done all we can to ensure that those of us with severe, untreatable, life-threatening conditions are given the same open-hearted welcome, the same open-minded respect and the same open-ended opportunities due everyone else?

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<sup>1</sup> John Finnis. 'Euthanasia and Justice' in *Collected Essays, Vol 3 (Human Rights and Common Good)*, Oxford University Press, 2011, p 211

<sup>2</sup> Ezekiel J. Emanuel. Four myths about doctor-assisted suicide, *New York Times*, 27 October, 2012: <http://opinionator.blogs.nytimes.com/2012/10/27/four-myths-about-doctor-assisted-suicide.html>

<sup>3</sup> Ben Mattlin. Suicide by choice? Not so fast. *New York Times*, 31 October 2012: <http://www.nytimes.com/2012/11/01/opinion/suicide-by-choice-not-so-fast.html>

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## Affirming parental love in the pediatric intensive care unit

Jonathan Gillis & Janet Rennick

Among all the writings on pediatric intensive care, and especially on the role and responses of parents to the admission of their critically ill child to such a unit, there is a startling absence of any discussion on the central defining role of the love of a parent for his or her child (1–4). What accounts for this silence? Is it because it seems too sentimental or too obvious to be mentioned? Or is it because the nonrational, nonquantifiable power of parental love simply doesn't "fit" in the immensely technical scientific world of critical care medicine? In pediatric critical care, clinicians bear witness to untold amounts of parental pain and suffering on a daily basis. Perhaps the silence on the subject of parental love—be it conscious or unconscious—allows practitioners to protect themselves against the daily tragedies with which it would be all too easy to relate. It is our contention that the silence has been to the detriment of the practice of pediatric intensive care and constitutes one of the sources of conflict between physicians and parents over demands for so-called "futile" therapy. We suggest that the recognition and acknowledgement of parental love will benefit not only children and parents but also the nursing and medical staff who care for them and, as a result, will improve the overall process of care delivery.

### The Silence on Parental Love

The admission of an acutely ill child to an intensive care unit is *prima facie* a stressful experience for that child's parents. Although there has been much research and many publications on the nature of parental stress, the majority of that work has been reported in nursing journals with limited exposure across disciplines. Most authors have placed great emphasis on the loss of control that

parents experience as a result of the sudden change and threat to their parental role. Until the moment of admission, parents are the primary caregivers, decision makers, and protectors of their children. Suddenly, at a time when the life of their child may be in jeopardy, they must abdicate their role and place their child into the hands of anonymous professionals (1–3). In these reports, there is an emphasis on the understandably negative parental behaviors and emotions that often surface, including fear, guilt, frustration, anger, and even hostility, which, in turn, can lead to conflict with health care professionals when futile treatment discussions are held. In general, nursing authors have turned to the theoretical literature on stress and coping and have developed interventions aimed at promoting the parental role in the critical care setting in an attempt to diminish parental stress and instill a sense of control in an otherwise uncontrollable situation (1–7). What is most striking in that body of work is the silence on the subject of parental love. Authors have pointed to various components of the parental role (protector, educator, caretaker, advocate), and intervention research has been structured accordingly. Although parental love is assumed by most to be part of the very essence of parenthood, there is no overt acknowledgement of its presence in the literature. The focus on parental roles—that is, what parents "do" or, in the case of pediatric intensive care, are unable to do for their child—has the potential for directing clinicians away from the most fundamental and important issue that confronts parents of a critically ill child, that is, the threat that critical illness imposes on one's child, which in turn threatens one of the deepest forms of human relationship: that of parenthood.

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## Understanding Parental Love

Parental love appears intuitively understandable, but in fact it is quite difficult to elucidate. From a theological viewpoint, the parent-child relationship has been endowed as the very basis of human existence (8). From a psychological perspective, Sternberg (9) proposed a theory of love in which distinct components including intimacy, passion, the decision to love someone else, and commitment to that relationship interrelate and give rise to different kinds of love.

The love between parents and children is described as consummate or complete love in which all these components are present and balanced. Love for one's children often carries the deep emotional involvement of intimacy, the satisfaction of motivational needs (e.g., nurturance and self-actualization), the firm decision to love one's child, and the commitment to maintain that love. At a very fundamental level love is emotional: "pleasure in (the thought of) the existence and well-being of the loved individual, whether the pleasure take the intense form of joy or delight or the quieter form of gladness, and pain in (the thought of) his nonexistence or ill-being, is central to the emotion of love" (10). For a parent, love is in essence passionate, visceral, and instinctual. Philosophically, the centrality of the parent-child relationship to one's sense of personhood is striking. The philosopher Levinas (11) discussed parenthood as a state in which one sees the child's possibilities as his or her own. The relationship is so profound that the parent steps out of the confinements of his or her own identity and the child becomes a living part of that parent's life. The parent-child relationship constitutes a core element of the parent's, and the child's, existence. Thus, in the face of a child's critical illness, the parent, credibly and emotionally, can conceive that illness to be a part of him- or herself. The child's illness would therefore have to be addressed as an integral part of that parent's own identity. The implications are profound for

understanding how a parent may view clinicians' attempts to discuss the notion of "futile" therapies.

## Clinicians' Interpretations of Parental Responses to Critical Illness

Critical care clinicians interpret parents' responses depending often on unstated theoretical assumptions. So, for example, various models of grief and mourning (12–14) in which acceptance is considered central to healthy adjustment may form the basis of one's understanding of a parental response and, in turn, influence clinical practice. Similarly, classic psychoanalytic theory influences clinicians' understanding of parental responses as defense mechanisms of denial, projection, or repression (15). It is not unusual to hear clinicians speak about a parent "not accepting" a child's poor prognosis or being "in denial". Such responses are typically viewed as dysfunctional rather than as appropriate responses from a loving parent who cannot bear the anguish of his or her child's poor prognosis. In studying parents of children with developmental disabilities, Kearney and Griffin (15) observed that parents demonstrated a clear and informed understanding of their children's impairments yet maintained a sense of optimism and hope. They concluded, "not having a map, [parents] have learned to live without expectations, but said they could not function without hopes and dreams". Similarly, in questioning whether people with life threatening illnesses were, in fact, denying reality, Cousins (16) found that "they did not deny the diagnosis; they denied and defied the verdict that was supposed to go with it". These parents expressed anger that their expressions of optimism were interpreted as maladaptive. They felt that sensitive, honest communication with clinicians that allowed them to maintain hope was a necessary source of strength. The key to understanding and responding to parents' concerns may be to realize and acknowledge the centrality of the caring relationship and the associated emotion of love (17). Remaining silent on the

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presence and influence of parental love does an injustice to the intensity, passion, and commitment of the parent-child relationship and, in turn, may exclude the development of powerful positive emotions that can result from healthy parent-child-clinician interactions.

## Altering the Critical Care Encounter

Within the context of life-threatening illness, some will continue to argue that a discussion of parental love is superfluous. The focus must remain on treating the child, and although parents should be kept informed and their presence at the bedside acknowledged and accepted, there is room for little more. We would counter that the positive presence of parental love stands out as a stable and strong constructive element in an otherwise awful situation, and it cannot be ignored. Parental love remains stable in situations when parental roles are threatened or changed. The pediatric intensive care milieu is often threatening, and staff assume many aspects of the parental role. However, the relationship between the parent and the child remains sacred, and by concentrating on, validating, and recognizing parental love, clinicians allow parents to assert themselves within the context of that relationship and to retain some control—thereby possessing nobility and gravitas in all interactions with the nursing and medical staff. This acknowledgment recognizes the unique and fundamental position of parents in the care of their sick child and facilitates their recognition as automatic and authentic partners in the process.

The affirmation of the presence of parental love brings with it an acceptance of its visceral nature and allows us to better understand how parents can wildly swing between denial and acceptance, particularly in situations in which a child has a severe disability or where treatment is deemed to be futile. In this world there is no such thing as futility. The cry for “everything to be done” must be understood as an expression of parental love, and clinicians need to respond to and engage

parents at that level. Similarly, love does not follow the rules of “rational choice”, and so meetings with the health care team to discuss treatment options, held under the pretense that decisions regarding the child’s treatment can be based on logic and medical reason, may only serve to obscure what is truly at issue for the child’s parents and result in anger and alienation.

Levinas (18) defined loneliness as being with others but not *of the others*. Relationships, he suggested, are maintained through sight, touch, empathy, and particularly speech. The child who is critically ill is normally unable to communicate, and often his or her appearance is drastically altered. Although parents are able to touch their child gently, they cannot normally hold their child. They can speak to their child but often do not receive any response in return. One can only imagine the sense of loneliness and isolation that parents must feel, and for those whose child’s condition is deteriorating, that sense of isolation surely becomes overwhelming as the existence the parent has shared with that child disappears.

What appears to be a simple act of displaying family photographs in the pediatric intensive care unit may be an attempt to keep a mounting sense of loneliness and isolation at bay. One study suggested that parents derive comfort, positive reinforcement, and purpose from the visual reminder of their children’s healthy appearance (19). Such observations have typically been framed in terms of strategies to help parents cope with the intensive care environment. However, this act may be more fully understood as an affirmation of the parent’s love and a way of helping the parent to feel better connected to the critically ill child. It can also be seen as an attempt by parents to show the staff their loved individual child, as distinct from the intensive care patient.

Similarly, studies have shown that restricted visiting and separation from their child increase parental stress and may lead parents to “cope” by becoming more vigilant at the

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bedside (20 –22). Parental vigilance has not always assumed a positive connotation in the context of the intensive care unit, yet perhaps the use of stress and coping as a framework for understanding this kind of parental behavior is limiting. Levinas (18) noted that the depth of the parent-child relationship means that a parent can never let go of the sense of responsibility that he or she feels for the child, because no one can take his or her place in that relationship. Similarly, parenthood implies a duty to find a means of alleviating the suffering of the ill child. Connection through sight, touch, and talk will allow parents to experience a sense of closeness with their ill child. Lack of opportunity for connection may lead to feelings of isolation and abandonment. This is illustrated in a case report describing a mother's love for her anencephalic child. The mother understood that her child was dying but wished to care for and love her child during the child's death. She felt the medical team had abandoned her in this desire. Fortunately, she did experience a sense of support from a nurse who recognized her love for her child and encouraged her involvement (23).

“Narrative skills” have recently been advocated for clinical practice and research (24,25). This involves learning to encourage and hear patient's stories to gain insight and understanding into the experiences of those we care for. Charon (24) noted that “only in the telling of the patient's [or parent's] story is the suffering made evident. Without the telling, not only treatment but suffering too, might be fragmented”. The recognition and validation of parental love can restore the narrative for parents. It provides the connection between their previously well child and their critically ill child, who may now be disfigured and threatened by death; it can help restore the continuity that is often lacking in clinical care.

The act of listening and hearing parents' stories also reinforces the authority of their involvement in their child's care and their unique contribution to the clinical decision

making process (26). Parents can then meet health care providers from a position of strength and equality. Acknowledging parents' love and unique right to speak for their child's welfare will likely prove invaluable in team discussions and help achieve consensus in situations where physicians consider all curative therapies to have been exhausted.

## Conclusion

It is our contention that the silence around parental love has been to the detriment of the practice of pediatric intensive care. Recognizing and acknowledging parental love have the potential for benefiting parents and clinicians and improving the overall process of care delivery. Listening for and hearing parents' stories without judgment and within the context of their love for their child will allow clinicians to better understand parents' experiences and work with them in providing the best care for their child. Parents are likely to feel that they are being truly heard, that their unique position in the encounter is being recognized, and that they have something that cannot be taken away by the critical care experience, that is, parental love.

Is the silence in the critical care literature on the subject of parental love a reflection of a depersonalization of clinical practice? It has been observed that “somewhere along the way, modern medicine has forgotten that it is grounded and sustained by and through the very nature of our being [human]” (27). Recognizing parental love harnesses a profoundly positive emotion in the morass of anger, hostility, and despair that may constitute the parent's experience at any given time in an intensive care unit. It gives meaning to that experience by placing it in the long tradition of the parent, out of instinctual love, guarding and caring for his or her sick child (28,29).

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