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## Obstetric Fistula

*Obstetric fistula is the most devastating complication of parturition. The impact of this ailment extends beyond physical morbidity, with immense social repercussions for the women who suffer from it.*

### The Scenario

A young pregnant woman living in a remote village, in an impoverished part of the world, goes into labour. She endures intense labour pains, but the baby cannot be delivered. The village birth attendant uses herbal preparations, as well as a rusty blade to widen the birth canal, but to no avail. Days after the labour began, she finally gives birth and is told that the baby is dead. Exhausted and delirious from her excruciating ordeal, she falls asleep. When she wakes up, she is not only tormented by the loss of her child, but discovers that urine is leaking from her body. Her husband and family are shocked by her condition; they believe that this venereal disease is a curse from God. As she struggles to come to terms with her predicament, she lies very still in a fetal position, hoping the leakage might stop...

### The Disease

Over 2 million women worldwide suffer from obstetric fistula.<sup>1</sup> It is the most devastating, yet preventable and treatable complication of childbirth. This disease almost exclusively affects women from impoverished, resource-poor and remote regions of the world. Prolonged obstructed labour is the most common cause of obstetric fistula.<sup>2</sup>

A fistula is an abnormal connection between an organ and another structure, usually as a result of injury or surgery. In obstructed labour, the fetal head is impacted in the maternal pelvis, thereby compressing the soft tissues of the vagina, bladder, and rectum against the pelvic bones. Uterine contractions push the fetal head downward, increasing the compression of the soft tissues, and progressively reducing blood supply to these tissues. Eventually, the blood supply is completely cut off, which causes widespread ischemic injury, and extensive tissue damage throughout the maternal pelvis. As the ischemic tissue is no longer viable, it sloughs off, creating a connection between the vagina and the bladder or between the vagina and the rectum. The former is termed vesicovaginal fistula, while the latter is called rectovaginal fistula. Obstructed labour also results in fetal death from asphyxiation. Over time, the dead fetus becomes macerated, is able to conform to the birth canal, and is expelled.

### The Consequences

The fistula that forms between the vagina and the bladder or rectum, causes urinary or faecal incontinence, such that urine and often faeces dribble unabated from the vagina. Of the two types of obstetric fistula, vesicovaginal fistulae are more common.<sup>3</sup> The constant and unremitting dribbling of urine causes a range of physical, social and psychological consequences. The physical complications include: genital ulceration, infection, dehydration, renal disease, vaginal scarring and infertility.

The inability to maintain personal hygiene and the odour associated with the fistula result in social isolation and stigmatization. This can lead to depression, anxiety, and high risk of suicide. As most women with obstetric fistula are young first-time mothers, the psychological trauma of losing their child also profoundly impacts their health. The socio-economic implications can be devastating: these women are ostracized by their husbands, families and community; the husbands of more than fifty percent of these women divorce them.<sup>4</sup> They are shunned from communal life, forced to live in tiny isolated shelters outside the village, and rely on charity for sustenance. As a result, they are forced further into abject poverty and destitution.

Aside from the direct complications of obstetric fistula, these women may also often suffer from limb weakness, nerve damage resulting in foot drop and muscular contractures. Contractures are permanent shortenings of muscles that occur in fistula sufferers as a result of lying curled up in a fetal position for extended periods of time, to ebb the flow of urine. Most women with contractures

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need intensive physiotherapy to enable them to walk again.<sup>5</sup> These disabilities, along with the inability to maintain personal hygiene, render them unfit to work and many resort to begging for their livelihood.

## The Causes

The aetiology of obstetric fistula is comprised of a complex array of biological, cultural and socioeconomic factors. In terms of biological risk factors that play a major role, primigravid status, fetal malpresentation, and young age at pregnancy and/or malnutrition, often result in a narrow pelvic architecture and insufficient progress of labour. These factors in association with the lack of obstetric care considerably increase the risk of obstetric fistula. Studies have shown that on average, fistula patients are younger than 25 years of age while some are as young as 13 years old.<sup>6,7</sup> Cultural practices such as low social status of women, early marriage, social pressure to have children and a preference for home deliveries, also contribute to the risk of obstetric fistula. These women have little say in decisions regarding their health, which can affect their ability to access health care. Another reason is that pregnancy is not regarded as an illness; it is deemed a natural process that requires little or no intervention. Female genital cutting (FGC) is also a common cultural practice in some populations. The severest form of FGC has been associated with prolonged obstructed labour, increasing the risk of obstetric fistula.<sup>8</sup> Due to these cultural practices these women are highly predisposed to obstructed labour and fistula. For these young women, life is often effectively over before it has begun.

*... the maternal health crisis in the world's poorest nations is "the scandal of the century," ...*

Despite the contribution of biological and cultural factors, by far the most significant etiological factor for obstetric fistula is socioeconomic disadvantage. In this regard, both personal and national economic conditions have an impact on fistula prevalence. Parts of the world with high fistula prevalence lack health infrastructure, and services that do exist are often inaccessible to a large population living in remote communities. The cultural aspects such as lack of empowerment of women and home birthing practices compound the problem, where women often do not seek or receive obstetric care until it is too late. Lack of awareness and access to health care also limit the possibility of treatment and cure of obstetric fistula for these women. They are so ashamed and devastated by their condition that they do not know who to turn to and are often unaware that it is possible to cure their condition.

## Burden of Disease

It is believed that at least 7 million women annually undergo obstructed labour, 93% of whom live in the most under-developed parts of the world. In light of this high prevalence of obstructed labour, the popularly quoted figure of 2 million current cases and nearly 100,000 annual cases of obstetric fistula, seem to be gross underestimations.<sup>9,10</sup> Lack of resources not only

contributes to the disease, but is also the reason why the exact prevalence and burden of this disease cannot be ascertained.<sup>11</sup> Another factor possibly contributing to high disease burden is the chronicity of the disease due to lack of treatment capacity, which considerably affects quality of life among these women.

Maternal and child health parameters are often a litmus test for the state of the health system as well the socioeconomic condition of a country. This is evidenced by the sharp contrast of maternal health parameters between developed and developing countries. To put it into perspective, in 2005, 99% of all maternal mortalities world wide occurred in developing countries.<sup>12</sup> Furthermore, in developed countries there is a one in 30,000 chance that a woman will die from a pregnancy-related cause, whereas in developing countries there is a one in six chance.<sup>13</sup> In his article, Wall fittingly quotes that the maternal health crisis in the world's poorest nations is "the scandal of the century,"<sup>14</sup> with a 100-fold disparity in maternal mortality ratios between the developed and the developing world.<sup>15</sup>

When there is a dearth of resources, indicators of maternal and child health plummet. Despite the prioritization of maternal health in WHO's Millennium Development Goals (MDGs), indicators of maternal health in developing countries have shown little improvement.<sup>16</sup> One of these indicators is the presence of skilled attendants during birth. It is estimated that every year nearly 60 million women give birth without a skilled birth attendant, again mostly in developing countries.<sup>17</sup> This is highly relevant to the prevalence of obstetric fistula, as one of the common complications of unsupervised parturition is obstructed labour. This may directly contribute to the incidence of obstetric fistula. Availability of post-partum care is even lower than intra-partum support services, despite the significance of this period in maternal and child mortality. It is believed that almost half the maternal fatalities and a large proportion of neonatal deaths occur during the post-partum period.<sup>18,19</sup> This also has implications for the burden of disease due to obstetric fistula, as early intervention is crucial in the treatment of this disease.

## The Cure

The treatment for uncomplicated obstetric fistula is a simple surgical procedure with a success rate in excess of 90%, yet less than 20% women with this condition ever seek treatment.<sup>20</sup> A fistula repair typically costs between \$200 and \$400 AUD, with a small amount for the trip to the hospital. Most women cannot afford this amount and being unable to work due to their condition, start to beg in their village to raise money. For one woman, it took six years to raise the mere \$20 for the bus ticket to the fistula hospital.<sup>21</sup>

In the past, fistula treatment was limited to the efforts of a few dedicated individuals, primarily functioning on charitable contributions. The Hamlin Fistula Hospital in Addis Ababa was among the first of such initiatives, where patients are treated free of charge. It was set up in 1974 by Drs. Reginald and Catherine Hamlin, two

Australian doctors who on their visit to Ethiopia witnessed the suffering of local women. Nearly 2000 women are treated annually in this hospital, and with five new centres to open in the next few years, the treatment capacity will increase to nearly 5000 patients per year. Since the work commenced in the 1970s, over 25,000 women have been treated at the hospital.<sup>22</sup> Despite these efforts, it is foreseen that it will be a long time before treatment capacity becomes sufficient to cater to all current and new cases.

However, in recent times obstetric fistula has been recognised as an international public health issue, and health bodies like the WHO and UNFPA have set up various initiatives in high prevalence countries, to treat and prevent obstetric fistula.<sup>23</sup> In 2003, the UNFPA with a number of partners launched a global Campaign to End Fistula. In line with the WHO Millennium Development Goals to improve maternal health, the Campaign has set 2015 as its target to eliminate obstetric fistula from the developing world. The Campaign is active in more than 45 countries across Africa, Asia and the Middle East. It has three main focus areas: fistula prevention, treatment of affected women, and supporting them after surgery to return them to a socially integrated and productive life.<sup>24</sup>

## The Way Forward

The WHO estimates of fistula prevalence are based on women who seek medical care<sup>25</sup> and are likely to be the tip of the iceberg, as a vast majority of women continue to live with this debilitating condition, with treatment out of their reach, both physically and financially. The irony lies in the fact that measures to reduce the incidence of obstetric fistula as well as other common causes of maternal morbidity and mortality are incredibly simple. But even basic obstetric services that could potentially avert a large number of complications of childbirth such as IV fluids, antibiotics, oxytocic drugs and basic surgical facilities are often non-existent in resource-poor settings. Basic obstetric services do not require complex surgical training and are not resource-intensive, yet women continue to suffer and die during childbirth.

The most effective approach to fistula treatment is the creation of specialised centres catering specifically to fistula patients. This presents the opportunity to utilize limited resources in an efficient manner, as well as creating a supportive community environment for the patients, which is conducive to healing and rehabilitation. Former fistula patients often take on the role of ambassadors spreading awareness and hope to others. However, as with all health issues, the foremost challenge, is the recognition of this problem at a national and global level. Without political commitment and major policy reforms, obstetric fistula will continue to devastate thousands of women.

Obstetric fistula has been eradicated from the Western world due to the almost universal availability of obstetric care. The fact that this condition continues to persist in the developing world is testimony to the immense and increasing maternal health disparities between the developed and developing world. To successfully address

the fistula problem, effective and practical, treatment and preventive measures will be required. It is increasingly being recognised that the treatment of obstetric fistula goes beyond the provision of surgical facilities. Women suffering from fistula require psychological counselling, physiotherapy, rehabilitation services and social support to recover completely from this condition and re-integrate into society. Preventive measures such as delaying the age of first pregnancy, cessation of harmful cultural practices, empowerment of women and providing accessible maternal and obstetric care can reduce the burden of disease from obstetric fistula.<sup>26</sup> As the most important risk factors, poverty, social status of women and their education also need to be addressed in order to eradicate this condition from the developing world.

## How You Can Help

You can donate to UNFPA's Campaign to End Fistula ([www.endfistula.org](http://www.endfistula.org)), the Hamlin Fistula® Relief and Aid Fund ([www.fistulatrust.org](http://www.fistulatrust.org)) and the Worldwide Fistula Fund ([www.wfmic.org](http://www.wfmic.org)).

After fistula repair, one patient commented about her new life, "I have become a person again." We can help their voices be heard, we can help them be people again.

## ENDNOTES

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## Caring for Ageing Persons: Attending to All the Issues

*Person-centred care is the mantra of contemporary health and aged care. Delivering such care effectively is an enormous challenge. Much effort goes into the basics of care delivery. In an era of limited resources and financial constraints the temptation arises for aged care in particular to ignore some of the non-measurable dimensions of care. This paper puts forward a range of issues that merit greater attention as we reflect on the realities of human ageing in Australia today. If taken seriously, I suggest, they will contribute to the delivery and quality of person-centred care.*

The inalienable dignity of the human person in all the dimensions of the person – physical, psychological, emotional, spiritual – is central to the provision of Catholic health and aged care. "In the provision of health and aged care, patients, residents, practitioners, family and carers become a small community united in working for a person's good. The relationship which unites them is best understood as one of trusting collaboration in a common purpose."<sup>1</sup>

No one chronological age makes a person old. The difficulty is in describing what "aged" means. The adjective *aged* is defined as "having lived or existed long".<sup>2</sup> How we understand what living long means is context specific. In societies where elders are respected and honoured, old age is valued for the wisdom it brings. Modern industrial societies, on the other hand, see a long life as entailing loss (of productivity), and increasing deterioration (of vital functions). Notions such as senescence, obsolescence, dependency prevail where the understanding of old age is portrayed primarily in terms of chronology and dependence. In this view the main phases in the life-cycle are threefold: the dependence of

childhood and youth (education), the independence of the middle years (employment), and the dependence that increases after age sixty-five (retirement).

A child born in the period 2003-2006 can be expected to live for 83.3 years (for females) and 78.5 years (for males). A consequence of our increasing longevity is that "the elderly" in Australia do not constitute a homogeneous group. The capacities of the young-old (65-74 years) diminish through the years of middle-old age (75-84 years) and reach their nadir in the lives of the old-old (85 years +). According to the 2006 census, there are 2.7 million persons 65 years and older in an Australian population of 20.7 million people. They make up 13% of the total population. Within this older cohort, 6.8% are in the 65-74 age group, 4.6% are in the 75-84 years group, and 1.6% are 85 years and older. Women make up a greater proportion of older Australians (55%), and their predominance increases with age. This will change over time as male life expectancy is increasing faster than that for women.

Three other factors have implications for our ageing population. First, Indigenous Australians constitute 0.5%

of the total older Australian population. With a shorter life expectancy of 17 years as compared to other Australians, the 65+ age group make up a mere 2.8% of our entire Indigenous population. Second, our older Australian population is becoming increasingly diverse. The distribution of overseas-born older Australians is necessarily related to the waves of immigration from 1945 to the present. At the present time, 35% were born overseas. 39% of these came from English-speaking countries, and 61% from non-English-speaking countries. Third, the proportion of older Australian varies from state to state, from 14.7% in South Australia to 3.9% in the Northern Territory.<sup>3</sup> All of these factors have long-term implications.

## Enlarging Our Horizons

Jesus answered the question “Who is my neighbour?” by telling the story of the Good Samaritan. Acting in a neighbourly way towards elderly members of our community requires us to take into account four perspectives: the God dimension, ethical questions, how we care for them, and the challenges of meaning.

### The God Dimension

The commandment, “Honour your father and your mother” (Ex. 20:12; Deut. 5:16) is not limited solely to the respect and obedience children owe their parents. Rather, it entails life-long honour and support particularly when parents grow old and frail.<sup>4</sup> Our current nuclear family structure, a variety of family patterns, increasing female participation in the workforce, and social mobility have all placed pressures on the obligations linking the generations. This is especially the case when family care-givers are sandwiched between the demands of their own children and the needs of ageing parents.

It is imperative that Christians think seriously about the experience of growing old. There are rich resources at hand – the teaching of the bible, tradition, and the experience of believers. Let me suggest three lines of reflection. The first is to view ageing as both an inner and an outer journey. A significant challenge for elderly persons in particular is how they deal with their inner life. What does my life mean now that I am no longer as active or engaged in society as I once was? How an ageing person deals with this inner journey hinges on two skills – the capacity to reflect and the ability to remember. The inner journey often involves a re-weaving of the tapestry of one’s individual life journey, understanding it anew and re-interpreting the disparate (and at times discordant) elements of a long life. This enables the ageing person to re-member parts of their story. This process is greatly enhanced if they can also share these memories with friends and carers. Growing old also brings a heightened awareness that the time ahead is limited. There is a more intense sense of time – much has gone before, little remains! Frequently during the activity of our busy middle years, the pressures of living in the present obscure the events of the past and the possibilities for the future. Elderly people who reflect on the events of the past, actively live in the present, and

look to the future with hope and confidence alert younger generations to the reality that time is always three-dimensional.

Second, one of the hardest aspects of experiencing the limits of old age is the realisation that the future will most likely bring increasing dependence on others. As our powers diminish, the challenge is to grow to appreciate that independence is still possible even as dependence on others for daily activities grows. A care that facilitates and honours this independence allows the ageing person not only to glimpse the kindness of God but also the ways that we are all radically dependent on God. The vulnerability which accompanies the diminishment of ageing necessitates a letting go of much that we hold dear – what has contributed to our identity, our story, and our sense of self into the future. This self-emptying, hard as it very often is, mirrors in a small way the self-emptying that Christ endured as he fulfilled his Father’s will on the cross (Phil. 2:5-11).

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Third, Christian reflection on ageing should offer the possibility that human living can be transformed in a significant way. The ancient world viewed old age (at least for the wealthy) as a time of leisure. Our activist modern world, on the other hand, merchandises recreational activities and lifestyles for retirees. These may provide a focus during the active years immediately following retirement. Leisure in the Bible, however, is essentially a religious reality. The Sabbath and the Lord’s Day indicate the need for persons at all stages of their lives to bring balance and enriching human activities and commitments to the rhythm of life.

### A Matter of Ethics

The current pressures on intergenerational obligations and the moral and ethical conundrums that have to be faced were mentioned earlier in this paper. Much also could be said about the distribution of scarce resources, the demands of the common good and the care needs of each individual elderly person in Australian society. In addition, there are many other considerations that could be pursued regarding quality-of-life and end-of-life issues. Unfortunately, lack of space does not permit me to develop these in detail. One area little considered in contemporary literature on human ageing, however, merits a mention here. The Protestant theologian and bioethicist W.F. May calls attention to the virtues and vices of old age.<sup>5</sup> As current philosophical and theological ethics increasingly focus on the place of character and virtues in human living, the personal qualities of ageing persons and their contribution to community living must be re-appraised. Engaging in grandparenting and volunteering roles are without doubt examples of virtuous living. Often overlooked is the way elderly persons reach out and befriend others. This

frequently crosses barriers of age, race, and creed. The call to live virtuously challenges everyone to see that there are no stages in life where an individual should not be contributing to the common good or participating in their society.

## Quality Care

Earlier periods of human history provided care of the needy in an environment very different to that of our own day. Frequently, infectious or contagious diseases ended lives regardless of age. Today, chronic illness and long-term co-morbidity raise urgent questions about long-lived individuals. How long must we offer care to such people? What types of care ought to be offered where human and material resources are limited? Who is to offer this care when it exceeds the capacities of individuals, families, or local communities? To address adequately these questions exceeds the limited space of this article. However, three aspects of care can be briefly mentioned. First, Jesus frequently touched those he healed or brought to life. Professional care today can at times appear impersonal, just part of a service given to another. For some elderly people, the loss of a spouse or close friends, the absence of family members, lead to what has been called “skin hunger”. While recognising the importance of boundaries in all care delivery, the phenomenon of skin hunger calls us to re-evaluate the role of touch in our care of aged persons. The quality of such touch adds an important human and religious dimension to what occurs in the ordinary events of daily living. Second, care of the neighbour in Christian tradition gives priority to the intentions that shape our service. Love of neighbour as personal service and care is embedded in the two great commandments Jesus gave us. This focus on the motives and intentions of the carer is more-than-ever vital in an ethical environment that emphasises measurable outcomes and standards of care. Care of another is a concrete expression of the Christian call to neighbour love. Third, human ageing demands a continuity of care that goes beyond the brief interactions of much medical and hospital care. The need to accompany the ageing person, often for long periods, demands fidelity to care and a high level of commitment in the carer. These factors are little considered or valued

in current thinking about care for the elderly.

## Questions of Meaning and Purpose

In our multi-media environment, it is at times necessary to distinguish between facts, information, and wisdom. As mentioned already, the ability to reflect and remember, to tell personal stories, and to have them received enhances the experience of growing old as a journey into wisdom. These provide the mechanism that enables elderly persons to grasp the meaning of their lives. The attempt to answer such questions as “What have I achieved in my life?”, “What does my life mean especially now in my later years?”, “Is there anything beyond the grave?” all indicate the spiritual quest in every person. Everyone has to address them. Religious believers, however, have a richer landscape within which to locate their quest. Their personal story is immersed in the saving story of God’s people and in the reality of Jesus’ life, death, and resurrection.<sup>6</sup>

In conclusion, this paper has proposed four dimensions that should be part of the landscape of person-centred care – the theological, the ethical, the pastoral and the spiritual.

### ENDNOTES

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## Ethical Decision Making

*In my years working with healthcare professionals trying to figure out how we can make ethical decisions reliably, I have often been confronted by the reality that those I have come to think of as wise and just, analyse matters differently from others. It seems to me that what sets such people apart is a capacity to reflect on experience and interpolate that into their decision making. What follows is my attempt to identify those processes, and to suggest ways that we can all access this sort of wisdom. It is not to suggest that one approach is superior, but rather to supplement the standard approaches with another sort of information that is frequently overlooked by adhering strictly to one method.*

The capacity to reflect on experience in a way that is useful for ethical thought is something which is personal and, in a sense, difficult to identify or operationalise. However, our ethical decisions should reflect our deep

convictions, and so the attempt to speak meaningfully about how that proceeds seems to me to be a valid objective in ethical inquiry. If we held that ethical content could be free of experience, belief and/or personal values,

then we would simply set about working out a formula and putting it into a computer programme. Essentially, I am suggesting that the process of ethical decision making is a peculiarly human function, and that engaging in ethics in a sense defines us as human beings. The social environment which we inhabit requires us to make choices about the things which make our lives together meaningful, and so we cannot avoid the moral 'quest' as Taylor puts it so eloquently:

'... our being selves is essentially linked to our sense of the good, and... we achieve selfhood amongst other selves...The issue of how we are placed in relation to this good is of crucial and inescapable concern for us...One could put it this way: because we cannot but orient ourselves to the good and thus determine our place relative to it and hence determine the direction of our lives, we must inescapably understand our lives in narrative form, as a 'quest'.<sup>1</sup>

It is the nature of what constitutes this richness and how it is to be encouraged in ethical education, that is the focus of this paper. Far from seeking to simplify or streamline the process of ethical analysis, I am seeking to fill it out and enrich it. This will not yield a one-size-fits-all answer nor will it give rise to ethical agreement but it will require a further stretching of our powers of judgment, and this is what, for me, constitutes the human person, for the making of ethical judgments is a privileged human activity.

## Standard Approaches to Ethical Problem Solving

The standard approaches to solving ethical dilemmas are to evaluate some aspect of the moral act by an agreed criterion or criteria. It may be that we consider the outcome(s) of any action, and decide what is the most acceptable in terms of delivering the most beneficial end. The main issue with this focus is that it does not take into account the nature of the act or its meaning to those concerned. If, on the other hand, we agree that some actions are wrong in and of themselves, there may be some circumstances which would yield terrible outcomes and we would be left feeling that our judgment was wanting.<sup>2</sup> In the third instance, there are some actions which are not universally understood in the same way, and so what we may choose may be unacceptable to another who understands the act differently. Many ethical discussions are dominated by issues of rights of individuals without mentioning what or who the human person might be and what the community might owe such a being.

In writing about developing a broader and deeper approach to bioethical questions, Ron Hamel<sup>3</sup> advocates a theological anthropology as providing a more satisfactory basis for analysis. He also suggests that we need more than honed skills of logical thought, and he would like to see the imagination given a more prominent position in the scheme of things. In this, he echoes Martha Nussbaum<sup>4</sup> who has been advocating the development of ethical skill through the study of literature for years. She

holds that the ethical imagination is every bit as important as the intellectual powers of rational analysis. She thinks that ethical excellence demands the skill of empathy and seeing the relationships served as central to the meaning of the decisions made.

The central matter now becomes defining the skills necessary for wise ethical judgment, and Nussbaum<sup>5</sup> has identified ten such functional capabilities which she sets out as basic political principles which ought to inform the constitutional law of states. This is an argument for the value of universal agreement about notions of what is good for humans. It is also clearly something which cannot be settled by appeal only to the rational self: it is in fact an appeal to the relational self which is fundamental to the enterprise.

These capabilities are:

- i. Life, being able to live and not die prematurely;
- ii. Bodily health, having access to shelter, food to live a normal life;
- iii. Bodily integrity, being free of those things which impede freedom of choice;
- iv. Sense, imagination and thought, development of those mental skills through basic education;
- v. Emotions, being able to express one's feelings and sense of connectedness with others;
- vi. Practical reason, being able to construct a notion of the good;
- vii. Affiliation, being able to both form and maintain relationships of social meaning;
- viii. Earthed-ness, feeling part of the universe;
- ix. Play, enjoying recreational activities; and
- x. Exercising some control over one's environment both political and material.

The sensitivity needed to form this capacity for judgment is not something easily arrived at, and this is clearly seen in the sort of considerations of which persons may be best suited to judicial appointments. We require some one learned in the law, but over and above that we want somebody known to have good judgment of human situations. In other words we desire to have a judge who is both learned and wise. Moreover, we can have some agreement about candidates for such an office. The same characteristics are essential to someone we would describe as wise with respect to moral judgments.

The fact that we can reach broad agreement upon who is a person of wise judgment presupposes agreement about what constitutes the good for human persons. This is reflected in various attempts to arrive at a common statement of bioethical norms, such as that undertaken by UNESCO in 2005.<sup>6</sup> There appear to be a set of norms or principles which are 'universally and self-evidently true.'<sup>7</sup>

## The Experience of Negotiating Difference

Martha Nussbaum<sup>8</sup> is of the opinion, and I agree with her, that for today's reality, we face too difficult a task if we begin by thinking what is right or wrong. She recommends the Socratic method of facing up to the fact

that we are really pretty ignorant, combined with a realistic cross-cultural education which shows that many of the things that we hold dear are in fact culturally conditioned. I remember as a first year university student, I participated in a work scheme in what was then known as the Territory of Papua and New Guinea, and came home after two months very shaken up by the experience because so many of the things that I had certainty about seemed questionable.

My time in New Guinea was not a formal introduction to anthropology or cultural studies but more of an immersion experience, which I think is what Nussbaum has in mind. This sort of experience certainly alerts one to the reality that there are in fact many perspectives to be engaged when trying to see where the truth and the good sit in relation to each other. Moreover, for Nussbaum and for me, this does not amount to saying that the good is relative, only that a person's perspective is limited to the range of experience available to them. Thus the experience of living in or at least parallel to a different value system is instructive in the ordering of one's own way of seeing the world.

The experience of placing people in these social laboratories is enlightening for everyone, and Nussbaum's observation of group processes in India suggested to her that the result is convergence, not submission to a dominant approach to values. Often, in debates in the United Nations, there are complaints from countries that the West is dominant and forcing their values on the rest as a sort of intellectual colonialism; for instance, the debate on whaling or frequently the Western nations seem to be on a collision course with south-east Asian nations. Maybe negotiations need to begin at a stage earlier than when the question is to be put to the vote. It seems to me that the establishment of the undergirding values and priorities is really the most important element about which to gain agreement. Then the decision about how to honour those agreed values will be easier.

The negotiators may reject this idea on the grounds that starting from first principles is unnecessarily time-wasting. On the other hand, many times we see decisions stalled at the time of voting and attended by all the angst of stalemate and disagreement. What I am advocating is a system by which the basic agreement is around fundamental principles which I claim we, simply by virtue of our humanity, agree on. Further, I would assert that the experience of discussing what we have in common rather than beginning with disagreement will engender those sentiments which are enshrined in the Charter of the United Nations.

The framing of the United Nations Charter was negotiated immediately following a war which had devastated the world, left a great gap in our self-understanding and shame all round. The sort of moral wasteland which we faced dictated that 'we', collectively, could never allow such a calamity to arise again. Whilst it is true that the remainder of the twentieth century was hardly an improvement, and there is little evidence to suggest that the twenty-first will be much better, what we

should have learned from the experience was precisely the wisdom of starting a discussion from the basic commitments that each of us holds.

## Developing Moral Judgment

The notion of developing sensitivity by the practice of critical reflection on daily experience is not new: it was advised among others by Plato, Aristotle, Thomas Aquinas, and Ignatius of Loyola. All four believed that by carefully tracking one's own reactions to events and experiences, a clear idea of what each interaction told one about oneself and one's relations to truth or rightness could be established. The disciplined interrogation of experience through the use of imagery, poetry and spiritual insight conducted on a regular basis was what they thought to be the way to wisdom. These ways are still available to us, but there have been other writers who have subsequently suggested further means.

Both Aristotle and Thomas Aquinas believed that human beings were oriented towards the good and would not knowingly act against that tendency. For Aquinas, it was a mark of the created order being in keeping with the mind of God: in fact, he held that even if the individual was ignorant of God, this tendency to the good was a sign of presence of God nevertheless. For Ignatius of Loyola, the presence of peace about a decision was a sign of the decision being in keeping with the mind of God; the reverse, feeling troubled or divided about a decision, was a signal to reflect on the choice again. In thinking about moral judgment this way, we are invited to consider that the best guide to moral choice is not a matter for judgment so much as being alert to the movements of our own spirits.<sup>9</sup>

*... disciplined interrogation of experience through the use of imagery, poetry and spiritual insight conducted on a regular basis was thought to be the way to wisdom. ...*

The development of moral judgment comes through experience and reflection on that experience. As we become sensitive to the ways of God's movement in our lives, we become more reliable moral arbiters. This was the theme that Margaret Somerville developed in her 2006 Massey Lectures, which were broadcast by the Canadian Broadcasting Commission.<sup>10</sup> She speaks of the secular sacred as a means of finding common ethical ground, and sees this as necessary for global policy development. She suggests that the use of poetic language rather than the language of logic or law will free up our moral imagination in ways that will be powerful and overcome differences. Further, she holds that the discoveries associated with science are challenging old categories, and endorses incorporating ideas of neuroscience and ecological insights which show us to be ultimately linked with every other living being in a complex and fundamental way. This sort of thinking challenges the imagination to go beyond the merely factual, and allows us to think of reality as always in a state of flux and movement forwards. In short, she argues for the possibility of acknowledging the sacred, apart from a particular religious connotation.

## Conclusion

I have tried to identify those elements which seem to make wise ethical judges, and then suggested some ways in which to educate for these traits. I have said that the study of literature and in particular poetry can assist in developing an ethical imagination. Another means to aiding this development is to spend time in another culture, for this can touch our sensibilities in a more direct way than reading. In the end, it is perhaps the readiness to engage in the process which sets apart those whom we see as sound ethical judges.

### ENDNOTES

<sup>1</sup> Charles Taylor, *Sources of the Self: The Making of the Modern Identity* (Cambridge, MA: Harvard University Press, 1989), 51-2.

<sup>2</sup> These two approaches have been called Ends-Means ethics and Duty ethics. See, for example, Benedict M. Ashley, Jean K. deBlois, and Kevin D. O'Rourke, *Health Care Ethics: A Catholic Theological Analysis*, 5<sup>th</sup> ed. (Washington, DC: Georgetown University Press, 2005), 9-18.

<sup>3</sup> Ron Hamel, "Health Policy and a Theological Anthropology," in *Health and Human Flourishing: Religion, Medicine, and*

*Moral Anthropology*, ed. Roberto Dell'Oro and Carol R. Taylor (Washington DC: Georgetown University Press, 2006), 231-240.

<sup>4</sup> Martha C. Nussbaum, *Cultivating Humanity: A Classical Defense of Reform in Liberal Education* (Cambridge, MA: Harvard University Press, 2000).

<sup>5</sup> Martha C. Nussbaum, *Women and Human Development* (Cambridge, UK: Cambridge University Press, 2001), 77f.

<sup>6</sup> UNESCO, "Universal Declaration on Bioethics and Human Rights," UNESCO, [http://portal.unesco.org/en/ev.php-URL\\_ID=31058&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html) (accessed 24 March 2009).

<sup>7</sup> Edmund D. Pellegrino, "Toward a Richer Bioethics: A Conclusion," in *Health and Human Flourishing*, 247-270 at 266.

<sup>8</sup> Nussbaum, *Cultivating Humanity*.

<sup>9</sup> Margaret Silf, *Landmarks: An Ignatian journey* (London: Darton, Longman & Todd, 1998).

<sup>10</sup> Margaret Somerville, *The Ethical Imagination: Journeys of the Human Spirit* (Toronto, ON: House of Anansi Press, 2006).

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# Brain Death and the US President's Council on Bioethics

*In December 2008, the US President's Council on Bioethics issued a White Paper titled 'Controversies in the Determination of Death.'<sup>1</sup> Responding to contemporary critiques of the concept of brain death, the Council upholds the validity of this neurological standard for determining death. Significantly, it also proposes replacing the existing explanation of this standard with a new, very different rationale. As well, it argues that 'total brain failure' is a better name for this condition than 'brain death.' This article summarises and then comments on this important statement.*

The US President's Council on Bioethics was established on 28 November 2001. By June 2009, it had issued ten reports on such topics as human cloning, stem cell research, caring for an ageing society, human dignity, and the genetic screening of newborns. It began to deliberate on organ transplantation at its meeting of 20-21 April 2006, and soon decided that it needed to address brain death as a separate issue. The Council discussed a draft statement about brain death on 6 September 2007. It was written by a member of the Council staff, but its chief architect seems to have been the founding Chairman of the Council, medical ethicist Leon Kass.<sup>2</sup> On 9 November 2007, the Council heard from a leading critic of brain death, neurologist Alan Shewmon. Dated December 2008, their White Paper is 168 pages in length – or approximately 43,000 words. It contains seven chapters, personal statements from three members of the Council, and twenty pages of bibliography. This document is summarised below:

## Summary

**Chapter One** of the White Paper begins with a record of the history of brain death. Shortly after the invention and widespread use of mechanical ventilation, a condition eventually described as brain death was observed. In 1968, an ad hoc committee of Harvard Medical School

described and defined brain death, and concluded (without offering a philosophical rationale) that patients in this condition may be pronounced dead. In 1981, the US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research offered a rationale for this conclusion. To be alive, the Commission noted, an organism must be whole. The Commission asserted that the brain is the central integrator of the body, and argued from this that after brain death a body has ceased to be a unified whole and is therefore dead. The Commission also claimed that even with the best of care, respiration and circulation cannot be maintained for long in brain-dead bodies. This fairly imminent collapse, they argued, reflects the loss of integration in these bodies.

Recently, however, critics of brain death have published evidence of ongoing integrated activity in bodies diagnosed as brain dead, and also reported many cases of ongoing survival after brain death.<sup>3</sup>

Chapter One continues by noting what the White Paper aims to do, and how it is organised. The central question which the report addresses is: "Does a diagnosis of 'whole brain death' mean that a human being is dead?" (p. 89)

**Chapter Two** notes problems with the term '(whole/total) brain death.' Perhaps the most significant

is that the term “implies that there is more than one kind of death.” (p. 17) For example, I once heard someone ask, “Is *brain* dead the same as *dead* dead?” Further, especially given the question which this report addresses, this term “begs the question of whether this condition does or does not warrant a determination that the patient has died.” (p. 18) Possible alternatives include ‘total brain failure,’ ‘*coma dépassé*,’ ‘irreversible coma,’ ‘(total) brain infarction,’ ‘irreversible apneic coma,’ and ‘brain arrest.’ While admitting that “there is no perfect term,” the report opts for ‘total brain failure.’ Use of this term maintains the “distinction between naming the medical diagnosis of a condition and declaring an individual dead on the basis of that medical diagnosis.” (p. 19)

**Chapter Three** details the physiology of both normal functioning and total brain failure. It has five parts. Part I explores the ‘vital functions’ of respiration and circulation, and the distinctive features of the functioning of the heart, the lungs, and the centres in the central nervous system involved in breathing. Part II sets out how a diagnosis of total brain failure is made. Part III details the pathophysiology of total brain failure. In most cases, there is a “self-perpetuating cascade of events.” (p. 35) Brain injury leads to brain swelling. Brain swelling elevates intracranial pressure (ICP). Ultimately, elevated ICP prevents blood flow to the brain. This causes even more brain swelling until the brain herniates through the tentorium and foramen magnum. Significantly, the Council notes that the destruction of the brain is not always complete. Indeed, “in some cases, the preserved tissue... actually does support certain isolated functions of the brain.” (p. 37) For this reason, the fact that brain failure is ‘total’ does not necessarily mean that the brain is totally without function, but rather that “the brain injury has reached the *endpoint* of a process of self-perpetuating destruction of neural tissue.” (p. 38)

*... To be alive, the Council argues, an organism must be engaged in “the fundamental vital work of a living organism – the work of self-preservation.” ...*

Part IV of Chapter Three explores the physiological findings behind the contemporary critique of brain death. Firstly, even after total brain failure, “some degree of somatically integrative activity... persists.” (p. 39) These integrative functions include “some degree of hemodynamic stability and body temperature, the elimination of wastes, the immune response to infection,” and even the “successful gestation of a fetus... sexual maturation of a [brain dead] child (and) proportionate growth of a [brain dead] child.” (pp 40, 56) Secondly, even after total brain failure, total collapse of the body need not be imminent. Reports include “more than a hundred documented cases that demonstrate survival past one week’s time, with one case of survival for more than fourteen years.” (p. 54)<sup>4</sup> Finally, Part V of this chapter distinguishes total brain failure from post-coma unresponsiveness (vegetative state).

In **Chapter Four**, the Council enters into the philosophical debate about brain death. They present two

opposing positions. This is Position One:

We do not know with certainty the borderline between life and death... Moreover, we have sufficient grounds for suspecting that the artificially supported condition of the comatose patient may still be one of life, however reduced... In this state of marginal ignorance and doubt the only course is to lean over backward towards the side of possible life.<sup>5</sup>

In other words, this view holds that “there are ‘sufficient grounds’ for doubt as to whether the patient with this condition has died.” Further, “in the face of such persistent uncertainty, the only ethically valid course is to consider and treat such a patient as a still living human being.” (p. 57-58)

Position Two accepts that the neurological standard of whole brain death or total brain failure does indeed reveal death. It also accepts that the new evidence from the critics of brain death has indeed disproved the 1981 rationale for this standard. Thus, this position offers a new rationale for the neurological standard for death. As it does so, the Council asks us to reflect on both how we define life, and how we define death. There is a difficulty here: many such attempts “end in some form of circular reasoning – defining death in terms of life and life in terms of death without a true ‘definition’ of one or the other.”<sup>6</sup> Why do we not say that a rock is alive? Two chemicals might react to form a new chemical, but why do we not say that this chemical reaction is alive? On the other hand, why do we say that things as different as a plant, an animal and a human being are all alive? The answer is not as obvious as it may at first seem.

To be alive, the Council argues, an organism must be engaged in “the fundamental vital *work* of a living organism – the work of self-preservation.” While the organism remains engaged in this vital work, it is still alive. But when it ceases to be so engaged, it has died. The Council adds that this vital work is “achieved through the organism’s need-driven commerce with the surrounding world.” (p. 60) For this reason, the work of an organism depends on three fundamental capacities:

1. Openness to the world, that is, receptivity to stimuli and signals from the surrounding environment.
2. The ability to act upon the world to obtain selectively what it needs.
3. The basic felt need that drives the organism... to obtain what it needs.<sup>7</sup>

From this conceptual framework, the Council is now ready to make its argument. One such felt need is expressed in the impulse to breathe. Other such felt needs (including the need for food and drink) are mediated through consciousness. So:

If there are no signs of consciousness *and* if spontaneous breathing is absent *and* if the best clinical judgement is that these neurophysiological facts cannot be reversed,

Position Two would lead us to conclude that a once-living patient has now died.<sup>8</sup>

Position Two's rationale for the neurological standard for death is quite complex and at first not easy to grasp. It merits careful study and consideration. It is arguably "the most significant contribution of the white paper."<sup>9</sup>

The Council has already insisted that the question of whether a human being in the state of total brain failure is alive or dead "should be answered on its own terms, not with an eye to the practical effects that a new standard for determining death might have" on organ transplantation. (p. 9) Even so, these implications must also be noted. This is done in **Chapter Five**. From Position One, two paths could be followed. The first would be to weaken or abandon the dead donor rule, and thus to procure organs from individuals recognised as dying but not yet dead. The Council rejects this path, arguing that it "would entail dismantling the moral foundations of the practice of organ donation." (p. 71) The second path from Position One would be to abandon Donation after Brain Death (DBD), and to continue only Donation after Cardiac Death (DCD). Meanwhile, from Position Two, "there would be no need to change the current standard of practice." (p. 75)

**Chapter Six** is a brief discussion of non-heart beating organ donation or Donation after Cardiac Death (DCD). The Council notes that in DCD, to exclude the possibility of auto-resuscitation, there is a delay between the declaration of death and the procurement of organs. Usually, it is assumed that two to five minute's delay is sufficient. The Council argues, however, that "there is insufficient scientific evidence to decide whether this assumption is always justified." (p. 84) It therefore calls for "more research... to investigate the question of auto-resuscitation." (p. 86)

**Chapter Seven** provides a four-page summary of the Council's findings.

The three **Personal Statements** are from Council members Alfonso Gómez-Lobo and Gilbert C. Meilander, and from the current Chairman of the Council, Edmund D. Pellegrino. The Council concluded that brain death or total brain failure truly is death. This finding was not unanimous. Fifteen of the Council's eighteen members agreed; three dissented.<sup>10</sup> Meilander writes in support of this conclusion. On the other hand, Gómez-Lobo writes that he is "provisionally inclined to side with... Position One." (p. 99) Pellegrino also endorses Position One. He recommends that we abandon DBD, and continue only with DCD. Finally, another Council member Floyd Bloom dissented "in the opposite direction." He thought that the standard of whole brain death was too rigorous, and instead endorsed the lesser standard of higher-brain death.<sup>11</sup>

## Comment

I offer three comments on the Council's White Paper:

- (i) **'Total brain failure'**: The Council's suggestion to replace the term 'brain death' with the term 'total brain failure' has been described as the "first

important change" of the paper.<sup>12</sup> Given that some function may remain in the brain, it is less than ideal to describe this brain failure as 'total.' For this reason, Zamperetti and Bellomo describe the term as "inaccurate," "imprecise," and "open to criticism." They prefer their own term, 'irreversible apnoeic coma.'<sup>13</sup> However, people who are not medically trained may struggle to understand that term. On the other hand, Alan Shewmon describes the chapter on terminology as "superb," and enthusiastically endorses the replacement of the "question-begging and ambiguous term 'brain death' with the philosophically neutral and physiologically clearer term 'total brain failure.'"<sup>14</sup>

Is the authority of the President's Council sufficient to facilitate a change from the familiar term 'brain death' to the new term 'total brain failure'? It is too soon to tell. As we have noted, one of the significant difficulties with the term 'brain death' is that it implies that there might be more than one kind of death. Use of the new term 'total brain failure' would eliminate this ambiguity. For example, using the new terminology, a clinician might tell a family, "Your loved one has died of total brain failure." This statement is clear and unambiguous.

- (ii) **The new rationale**: As the Council has noted, the question of the validity of the neurological standard should be considered on its own terms, not in the light of its possible impact on organ donation. One way to facilitate this separation of issues is to note that, for a while at least, the existing practice of organ donation can continue without a fully articulated rationale for the neurological standard. At one point in its report, the President's Council on Bioethics helpfully observes that there is an "intuition" that "after total brain failure the body is... no longer alive." (p. 60) Elsewhere in the report, Edmund Pellegrino quotes Aristotle to note that definitions and rationales are "the easiest of all things to demolish, while to establish one is the hardest." (p. 108) In this context, for a while at least, the existing practice of organ donation is sufficiently justified by the intuition of reasonableness, even as efforts continue to express this intuition in a fully articulated rationale. There are many other things that we do in life without completely understanding the reasons why.

There are two questions. Firstly, should the 1981 rationale be abandoned? The early consensus seems to be that it should. Alan Shewmon endorses the Council's "studied rejection of the mainstream rationale of organismic integrative unity," and indeed calls it "remarkable." Similarly, moral theologian Christian Brugger holds that, given the evidence against it, the Council was "forced to abandon" the older rationale.<sup>15</sup>

The second question is whether the new rationale is convincing. Because of the complexity of the argument, some commentators experienced an initial hesitation. For example, Brandon Keim warns that at

first the account “might sound like so much philosophical mumbo-jumbo.” Beyond that, Alan Shewmon is not convinced. On the other hand, Christian Brugger finds the argument “elegant and persuasive.” Bioethicist Art Caplan comments, “They reaffirm brain death as an acceptable standard – and I think they succeed.” Zamperetti and Bellomo conclude that the argument “effectively gives a new foundation to the justification for the neurological standard of death.”<sup>16</sup>

Some clarification and refinement of the rationale will surely occur as the argument is debated. For example, Christian Brugger asks:

Cannot some of the expressions of apparently living somatic activity in brain dead bodies be categorized as expressions of this threefold commerce with the world?

Are not homeostasis, oxygen assimilation, wound healing, the fighting of infections and the process of nutrition activities in which a body receives complex signals, and then responds by securing needed resources?

- (iii) **Read and Debate:** Finally, I encourage readers to read the Council’s White Paper, to consider its arguments, and to discuss their merits. For those who are unfamiliar with this issue, the report is a clear and very readable introduction. I also echo Zamperetti and Bellomo’s comment that in particular “intensivists” and the “intensive-care community” should read and discuss this important report.

**ENDNOTES**

<sup>1</sup> (US) President’s Council on Bioethics, *Controversies in the Determination of Death*, President’s Council on Bioethics, [http://www.bioethics.gov/reports/death/determination\\_of\\_death\\_report.pdf](http://www.bioethics.gov/reports/death/determination_of_death_report.pdf)

<sup>2</sup> See the transcript of this discussion at <http://www.bioethics.gov/transcripts/sept07/session1.html>, and William E. May, *Catholic Bioethics and the Gift of Human Life*, 2<sup>nd</sup> ed. Huntington, Indiana: Our Sunday Visitor, 2008), 336.

<sup>3</sup> “A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the

Definition of Brain Death,” *Journal of the American Medical Association* 205, no. 6 (1968): 337-340; (US) President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,” *Defining Death: A Report on the Medical, Legal and Ethical Issue in the Determination of Death* (Washington, DC: US Government Printing Office, 1981). Perhaps the most significant critique is D. Alan Shewmon, “The Brain and Somatic Integration: Insights into the Standard Biological Rationale for Equating ‘Brain Death’ with Death,” *Journal of Medicine and Philosophy* 26, no. 5 (2001): 457-478.

<sup>4</sup> See D. Alan Shewmon, “Chronic ‘Brain Death’: Meta-Analysis and Conceptual Consequences,” *Neurology* 51, no. 6 (1998): 1538-1545.

<sup>5</sup> *Controversies*, 53. The Council is quoting Hans Jonas, “Against the Stream,” in *Philosophical Essays: From Ancient Creed to Technological Man* (Englewood Cliffs, NJ: Prentice-Hall, 1974), 138.

<sup>6</sup> Edmund D. Pellegrino, “Personal Statement,” in *Controversies*, 107-121 at 110.

<sup>7</sup> *Controversies*, 61. <sup>8</sup> *Ibid.*, 64.

<sup>9</sup> Gilbert C. Meilander, “Personal Statement,” in *Controversies*, 103-105 at 103.

<sup>10</sup> Nancy Frazier O’Brien, “Brain death raises questions from U.S. to Vatican,” *AmericanCatholic.org*, <http://www.americancatholic.org/news/newsreport.aspx?id=662>

<sup>11</sup> D. Alan Shewmon, “Brain Death: Can It Be Resuscitated?” *Hastings Center Report* 39, no. 2 (March-April 2009): 18-24 at 20.

<sup>12</sup> Nereo Zamperetti and Rinaldo Bellomo, “Total brain failure: A new contribution by the President’s Council on Bioethics to the definition of death according to the neurological standard,” *Intensive Care Medicine* Epub 17 April 2009. <sup>13</sup> *Ibid.*

<sup>14</sup> Shewmon, “Brain Death,” 19.

<sup>15</sup> *Ibid.*; E. Christian Brugger, “Are Brain-Dead Patients Dead?” Westchester Institute for Ethics and the Human Person, [http://www.westchesterinstitute.net/index.php?option=com\\_content&view=article&id=425](http://www.westchesterinstitute.net/index.php?option=com_content&view=article&id=425)

<sup>16</sup> Brandon Keim, “Bioethicists Save Organ Donation by Tweaking the Definition of Death,” *Wired Science*, <http://www.wired.com/wiredscience/2009/01/braindeath>; Shewmon, “Brain Death,” 20-22; Brugger; Keim; Zamperetti and Bellomo.

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