

# *Chisholm Health Ethics Bulletin*

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## **The Pope on the Moral Obligation to Continue Tube Feeding for Patients in Post-Coma Unresponsiveness**

*This article begins with large extracts from Pope John Paul II's address to the International Congress on 'Life-Sustaining treatments and Vegetative State: Scientific Advances and Ethical Dilemmas', Vatican City, 20 March 2004. Clearly, the Pope's speech should be accepted as authoritative teaching. Some explanatory comments are made on it and the article concludes with some practical implications for Catholic healthcare facilities.*

'Scientists and researchers realize that one must, first of all, arrive at a correct diagnosis, which usually requires prolonged and careful observation in specialized centres, given also the high number of diagnostic errors reported in the literature. Moreover, not a few of these persons, with appropriate treatment and with specific rehabilitation programmes, have been able to emerge from a vegetative state. On the contrary, many others unfortunately remain prisoners of their condition even for long stretches of time and without needing technological support.

'In particular, the term permanent vegetative state has been coined to indicate the condition of those patients whose "vegetative state" continues for over a year. Actually, there is no different diagnosis that corresponds to such a definition, but only a conventional prognostic judgment, relative to the fact that the recovery of patients, statistically speaking, is ever more difficult as the condition of vegetative state is prolonged in time. However, we must neither forget nor underestimate that there are well-documented cases of at least partial recovery even after many years ....

'I feel the duty to reaffirm strongly that the intrinsic value and personal dignity of every human being do not change, no matter what the concrete circumstances of his or her life. A man, even if seriously ill or disabled in the exercise of his highest functions, is and always will be a man, and he will never become a "vegetable" or an "animal". Even our brothers and sisters who find themselves in the clinical condition of a "vegetative state" retain their human dignity in all its fullness. The loving gaze of God the Father continues to fall upon them, acknowledging them as his sons and daughters, especially in need of help.

'Medical doctors and health-care personnel, society and



*Pope John Paul II who addressed the International Congress, Vatican City 20 March 2004*

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the Church have moral duties toward these persons from which they cannot exempt themselves without lessening the demands both of professional ethics and human and Christian solidarity. The sick person in a vegetative state, awaiting recovery or a natural end, still has the right to basic health care (nutrition, hydration, cleanliness, warmth, etc.), and to the prevention of complications related to his confinement to bed. He also has the right to appropriate rehabilitative care and to be monitored for clinical signs of eventual recovery.

I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering. ...

The evaluation of probabilities, founded on waning hopes for recovery when the vegetative state is prolonged beyond a year, cannot ethically justify the cessation or interruption of minimal care for the patient, including nutrition and hydration. Death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission.

In this regard, I recall what I wrote in the Encyclical *Evangelium Vitae*, making it clear that "by euthanasia in the true and proper sense must be understood an action or omission which by its very nature and intention brings about death, with the purpose of eliminating all pain"; such an act is always "a serious violation of the law of God, since it is the deliberate and morally unacceptable killing of a human person" (n. 65). ...

'Considerations about the "quality of life", often actually dictated by psychological, social and economic pressures, cannot take precedence over general principles.

First of all, no evaluation of costs can outweigh the value of the fundamental good which we are trying to protect, that of human life. Moreover, to admit that decisions regarding man's life can be based on the external acknowledgment of its quality, is the same as acknowledging that increasing and decreasing levels of quality of life, and therefore of human dignity, can be attributed from an external perspective to any subject, thus introducing into social relations a discriminatory and eugenic principle.

Moreover, it is not possible to rule out a priori that the withdrawal of nutrition and hydration, as reported by authoritative studies, is the source of considerable suffering for the sick person, even if we can see only the reactions at the level of the autonomic nervous system or of gestures. Modern clinical neurophysiology and neuroimaging techniques, in fact, seem to point to the lasting

quality in these patients of elementary forms of communication and analysis of stimuli.

'However, it is not enough to reaffirm the general principle according to which the value of a man's life cannot be made subordinate to any judgment of its quality expressed by other men; it is necessary to promote the taking of positive actions as a stand against pressures to withdraw hydration and nutrition as a way to put an end to the lives of these patients. ... It is necessary, above all, to support those families who have had one of their loved ones struck down by this terrible clinical condition.'<sup>1</sup>

## Practical Implications

In 1998 the Pope spoke on this issue to a group of U.S. Bishops and he limited himself to saying that the presumption should favour providing medically assisted nutrition and hydration (MANH) 'to all patients who need them'.<sup>2</sup> In his address on 20 March 2004, the Pope has taken Catholic teaching a step further on the needs of MANH for patients in post-coma unresponsiveness (PCU), formerly called the 'vegetative state' - a term which scarcely honoured these patients, as Pope John Paul II mentioned in his talk. His speech contains an important statement of moral principle, but, as Father Maurizio Faggioni, a Franciscan bioethics expert and consultant to the Vatican's doctrinal congregation, said it is 'authoritative without being definitive'.<sup>3</sup>

Patients in PCU are usually stable and not dying. In itself, PCU is not a fatal pathology for patients provided they are given MANH. They are living human beings and persons with their own inherent dignity. They breathe spontaneously and ordinary means of treatment and normal nursing care should be given to them, including MANH. This is because it is the only means of sustaining their lives and it may prevent suffering from hunger and thirst. It is universally agreed that it is unethical to give patients in PCU a lethal injection. The Pope's teaching morally equates the deliberate withdrawal of MAHN from patients in PCU with terminating their lives, ie., euthanasia by omission because their death is the only result of its withdrawal.

The rationale of the Pope's teaching is that human life is a gift from God and a basic good of the person that should be preserved by the use of ordinary and proportionate means, ie., what is reasonably due in the circumstances, and without unjust discrimination against patients in PCU. It is important to note the exact translation of the Pope's teaching on the precise extent of the moral obligation to provide MANH to patients in a state of PCU. He said its provision is morally obligatory 'to the extent in which and as long as it is seen to achieve its proper purpose, [nella misura in cui e fino a quando esso dimostra di raggiungere la sua finalita' propria] which in the present case consists in providing nourishment to the patient and alleviation of his suffering.' It is a different

matter if a patient is unable to assimilate the nutrition provided by MANH: it would no longer be morally necessary to provide it since it would be futile. Further, if MANH were to cause pain or suffering there would be no obligation to continue to provide it in much the same way as life sustaining treatment may be withdrawn if it is burdensome for the patient.

Bishop Elio Sgreccia, vice president of the Pontifical Academy for Life, said during an interview: 'If the patient no longer assimilates food and if the patient no longer has thirst quenched by fluids but is only tormented, there's no longer an obligation to administer it. ... As long as nutrition and hydration are a support, as long as it is food and thirst-quenching drink that helps avoid suffering, it is obligatory.<sup>4</sup> Clearly there is scope for the responsible exercise of professional judgement by doctors and health carers to determine if patients are truly being nourished and their suffering alleviated. The Pope's teaching applies in principle and does not rule out the ethical use of professional judgement by doctors should other medical contraindications arise. In poor countries where food is scarce even for young babies and facilities are lacking to provide MANH, health professionals cannot be blamed for this tragic situation.

The Pope's speech is directed specifically to the care of patients in PCU. It does not apply to fatal degenerative conditions if MANH would only prolong a painful dying process. Nor was his speech meant to modify the normal ethical practices of palliative care professionals for their patients as they approach imminent death. Dying patients are known to lose appetite and they should not be force-fed against their wishes. In these cases it suffices to keep dying patients comfortable, by using an intravenous drip as required and caring for their mouth hygiene, eg, by the use of ice cubes.

Life is a basic good in its own right for human flourishing along with knowledge, play, aesthetic experience, sociability (friendship), practical reasonableness and religion.<sup>5</sup> Pope John Paul II had written in his Encyclical Letter *Veritatis Splendor*:

'It is precisely these goods which are the contents of the natural law and hence that ordered complex of 'personal goods' which serve the 'good of the person': the good which is the person himself and his perfection. These are the goods safeguarded by the commandments.'<sup>6</sup>

Hence, in principle, it is morally obligatory to provide MANH to sustain and nourish patients in PCU if this does not cause pain or there are serious medical complications.

The Pope mentioned in his speech the need to take positive action to prevent the lives of patients in PCU being terminated by the withdrawal of MANH. Catholic healthcare facilities need to heed this teaching and to implement it. The public should be made aware that the

policy to continue MANH for patients in PCU as long as they are alive. Certainly advocates of euthanasia would not see any moral difference between giving a lethal injection to patients in PCU and deliberately withdrawing MANH from them.

Careful attention, however, may need to be given to the situation of their staff and any agents with an Enduring Power of Attorney (Medical) who find they are in conscience unable to accept the Pope's teaching.

## An Unresolved Issue

It has been assumed for some time that patients in PCU were unaware of themselves and their environment. Hence it was taken for granted that they lack the instinct to eat and drink and so would not suffer starvation in the usual sense of the word nor experience pain -- a psychophysiological state. Evidence is now emerging for the existence of minimal consciousness in PCU patients. The assumption that they could not experience pain is now beginning to be questioned. Dr Steven Laureys, a Belgian neurologist, wrote: 'In the absence of a generally accepted neural correlate of human consciousness, it remains very difficult to interpret functional neuroimaging data from severely brain injured patients as a proof or disproof of their "unconsciousness".<sup>7</sup> Australia's health advisory authority, referring to patients in PCU, has recently stated 'that awareness cannot be reliably excluded' by any tests.<sup>8</sup> Furthermore we know from experience that inability to remember former conscious states does not negate their existence: this could also apply to patients who emerge from PCU.

If it is confirmed that there are reasonable grounds to believe a patient in PCU is rationally self-conscious and aware of the environment, but unable to show this, then continuing MANH indefinitely could risk inflicting on the patient psychological distress. Any new relevant evidence would need to be carefully evaluated, granted its serious implications for patients in PCU.

### ENDNOTES

<sup>1</sup> *L'Osservatore Romano*, Weekly Edition in English, 31 March 2004.

<sup>2</sup> *L'Osservatore Romano*, 7 October 1998.

<sup>3</sup> John Thavis, *Catholic News Service*, 7 April 2004. [www.catholicnews.com/data/stories/cns20040407.htm](http://www.catholicnews.com/data/stories/cns20040407.htm)

<sup>4</sup> John Thavis, *Catholic News Service*, 7 April 2004. [www.catholicnews.com/data/stories/cns20040407.htm](http://www.catholicnews.com/data/stories/cns20040407.htm)

<sup>5</sup> John Finnis, *Natural Law and Natural Rights*, Oxford: Clarendon Press, 1980, 85-97; *Fundamentals of Ethics*, Oxford: Clarendon Press, 1983, 50-53.

<sup>6</sup> *Veritatis Splendor*, Vatican City, 1993, n. 79

<sup>7</sup> Dr Stephen Laureys et al., 'Residual cerebral functioning in the vegetative state', *Life-Sustaining Treatments and Vegetative State: scientific advances and ethical dilemmas*, Supplement to *L'Arco di Giano* n. 4, 2004, p. 90.

<sup>8</sup> *Post-coma unresponsiveness (vegetative state)*, Australian Government. National Health and Medical Research Council, Commonwealth of Australia, 2004

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# The Moral Distress of Nurses

*This article discusses the factors that generate pressure in the professional life of conscientious nurses and why they may experience moral distress in their work..*

Nurses are the backbone of the health care industry. They continue to work in an increasingly market-driven health care industry that is known to be under pressure from many directions. Well, the backbone is under strain, and the public image of the nurse is a myth. Many nurses don't want to nurse any more. There is a plethora of other career options now available to potential nurses. Recruitment and retention schemes are ineffectual in resolving the nursing shortage crisis. This article looks at the phenomenon that is nursing and the emerging theme that moral distress is a contributing factor in the exodus of nurses out of the profession. This is not to deny that there are many individuals who are not only dedicated nurses but are satisfied with their particular working situation.

## Market Driven Health Care

There is some agreement that nursing provides a unique service to society, such as caring, comforting, supporting, promoting dignity, preventing harm, advocating, and maximising autonomy, and as such nursing is a relational, inherently moral activity.<sup>1</sup> Yet poor working conditions are impacting on the capacity of nurses to provide the type of nursing care they feel ethically obligated to give.<sup>2</sup> Constraints faced in moral distress have been described as external, such as administration and policy, physicians, and the law, and internal, such as self-doubt, socialisation to follow orders, fear of job loss, and the futility of past actions. As a phenomenon, moral distress has affective, cognitive, and behavioural dimensions.<sup>3</sup>

Patients traditionally accepted that there were limits in terms of what medicine could cure but there was an understanding that care would not be stinted. Now there are clients, or customers, who demand health care services. Carers are forced to meet some demands that may be unwarranted (perhaps debatable), unrealistic or futile, despite reduced resources. Some employers may value the productivity of nurses, not necessarily the nurses themselves, nor acknowledge that each nurse is a person. In this respect, some health organisations treat nursing care as a generic skill, that can be provided by non-nurses. Yet, very recent research suggests that it is the goodwill of nurses which is holding the public hospital system together.<sup>4</sup> This may not last.

In today's health care environment, it's suggested that task completion and capital expenditures take precedence

over caring. Whilst there is an abundance of care in health care, it is often invisible. Caring is touted to have the potential to improve the economic position of health care facilities if the concept of caring is elevated to a position of prominence within the organisation's mission, vision, values, culture, leadership, and clinical practice.<sup>5</sup> There is an expectation that care will be provided despite the evidence that many nurses are leaving the profession due to the very changes managed care has engendered.<sup>6</sup> But when economy is valued more than skilled nursing care it may be fair to point out that one need not care to be productive, and vice versa.

## What is nursing?

It is suggested that nursing is founded on 'an obligation to care for another and is an interactive process in which the patient's privacy has been invaded in egregious and profoundly physical ways, but the patient is compliant, blindly trusting that their best interests will be served'.<sup>7</sup> Nurses are said to go into nursing from a sense of commitment to help others.<sup>8</sup> In prehistory the first nurse was probably the mother. The origin of the word nurse is linked to the word nourish in regards the infant, and was only applied to a person who cares for the infirm from the early 18th century. Interestingly the word care originally referred to a 'burdened state of mind' and only much later came to mean, 'to feel concern or interest'.<sup>9</sup> The nurse as healer through the ages is another representation.<sup>10</sup> It is suggested that 'the nurse is the mirror in which is reflected the position of woman through the ages'.<sup>11</sup>

Despite claims that nursing is both an art and a science, it is caring behaviour that distinguishes nursing from the other professions, with the capacity to 'care too much' seen as an essential ingredient of professional nursing.<sup>12</sup> Caring has emotive as well as behavioural dimensions. This 'emotional labour' is suggested to be hard and productive work that should be valued in the same way as physical or technical labour, though it is generally conceptualised as being an altruistically motivated, but marginalised skill, that a female nursing force would naturally possess.<sup>13</sup> Yet, nursing as emotional work is professed 'as a special gift to people' and 'service and duty above self, tending to others regardless of personal need and deprivation' and 'if the nurse cannot summon up caring, then he or she has failed as a nurse and that nurses must care to do the job properly'.<sup>14</sup>

## How Can Nurses Always Care?

A team of researchers asked this exact question. Their findings suggest that nurses instinctively bring to the profession the moral code of eudaemonism, which is described as a 'system of ethics basing moral obligation on the tendency to produce happiness' and that this is an under-appreciated commodity in the acute health care world. Unfortunately this was found to be a factor causing nurses to leave.<sup>15</sup> If nurses are so good at gifting happiness on others, why are nurses finding it difficult to apply that gift to themselves? Nursing has a chequered history and the profession has struggled, perhaps because of the perpetuation of inaccurate images of nurses by the public. As one commentator suggests, 'in any text concerning the genesis of nursing, there is considerable content that refers to the history of nursing as an episode in the history of woman.'<sup>16</sup>

Nurses are accountable for the care they provide yet have rarely been involved in health care policy making that influences their practice, though this may be remedied with appointments of Nursing Policy Advisers in State Government.<sup>17</sup> Health care policy is oriented towards the maximum benefit while nursing care is about individual good. Stress researchers have found that persons who have no control over their work situation and at the same time experience high demands may be prone to illness.<sup>18</sup> Findings in a study attempting to identify the preconditions for moral stress in nursing indicate that nurses are morally sensitive to the patient's vulnerability, but external factors over which they have no control, prevent them from doing what is best for the patient.<sup>19</sup>

But what does that mean? It may be as simple as an individual's own moral code about what is right or wrong, yet be powerless to promote the former and prevent the latter, and become distressed due to the stress inherent in trying to find a way to resolve the problem. For example, research shows that nurses who work in high stress environments, such as Neonatal Intensive Care Units, experience high levels of moral distress regarding aggressive courses of treatment for some infants, resulting from feeling powerless regarding treatment decisions. These researchers also question how can those responsible for the day-to-day care of extremely premature infants and their families, continue to minister to their patients while experiencing such intense conflict?<sup>20</sup> In aged care, stress was related to conflicts experienced in balancing caring and efficiency demands and the difficulties in managing emotions. Emotions such as frustration, anger and grief find little support and nurses labour to shield such emotions from management, peers and residents.<sup>21</sup>

## The Ethical Dilemma of Moral Distress

Some argue that characteristics of nursing may pose some unique ethical issues. Unlike an ethical dilemma

where one does not know the right thing to do, in contrast, moral distress occurs when one knows the right thing to do but is constrained by the institution or one's co-workers in doing it. Nurses are accountable to both patients and large bureaucratic systems, yet nurses often lack power in the hierarchy of health care professionals. Moral distress may occur when obligations to employers and patients are at odds.<sup>22</sup> The Code of Ethics for Nurses in Australia recognises that such conflicts of interest are not always within a nurse's control and acknowledge that such factors may 'affect the degree to which nurses are able to fulfil their moral obligations'.<sup>23</sup>

My belief is that the essence of nursing has changed so much that nursing may need to be viewed differently. Moral distress may arise due to the ongoing challenge nursing faces in striving to be acknowledged as a profession. Perhaps the spirit of the change is inherently difficult for some nurses to accept especially when the way nurses were educationally prepared changed. Some may believe that such fundamental change was unnecessary, but there are pressing economic and social reasons for sustaining this evolution. Gone are the days of a rigid hierarchy and unquestioning devotion and loyalty to an organisation. Nurses are morally and legally accountable for the care they give. Whilst many in society cling to the notion that nursing is 'a calling', most modern nurses are secular individuals who appreciate that making a living demands that nursing be recognised as a career, not a lifestyle. Perhaps this achievement has irreversibly changed the 'heart' of nursing and thus is, in itself, a subconscious source of moral distress.

Nurses have united to become an influential force. Threats to take industrial action have been a means for nurses to seek fair conditions and recompense. Nurses have been reviled for 'walking off the job' when their reasonable demands are rejected. Outrage erupts, fuelled by political and media propaganda, which calls into question a nurse's altruistic attitude and integrity in taking such action and supposedly causing public risk. Yet nurses plan and stage these actions in ways, which minimise public risk.<sup>24</sup> The funding of health care is both a contentious and expensive enterprise. Morally distressed staff cannot be expected to be indomitable forever. Some nurses may aspire to be altruistic, but our society does not accept altruism in exchange for food and shelter.

## Is Nursing a Tired Anachronism

So many natural events in the human life cycle have been medicalised. The rites of passage between birth and death that were once celebrated have been reduced to medical events that need treatment, cure or palliation. And thus care. These ritualistically emotional and cathartic events have been secreted away, with the belief that they are best dealt with by those, such as nurses, who seem to be both caring but immured to emotional in-

volvement. But nurses are skilled at masking their emotions. But at what cost? Maladaptive coping skills are implicated in leading to ill health, anger and burnout, low staff morale, poor customer service, high staff turnover and a global shortage of nurses. Nurses are not immune to emotionally intense situations.<sup>25</sup>

Moral distress is possibly descriptive of the experience of many nurses today. Nursing may not be a unique activity but it is valued by society for a variety of reasons. A society seeking succour perpetuates the myth that nursing is not only a vocation but also takes for granted that there will always be a never-ending supply of nurses. Potential nurses have a number of other attractive and better-paid options for work which may make nursing seem an undesirable career. Nurses are part of this society and subject to its demands. And that may mean that in today's world, nursing needs acceptance as a skilled profession which demands commensurate conditions. Cutting funding and linking nursing with productivity will not retain nurses. Adequate resources, recompense and respect may!

#### ENDNOTES

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<sup>2</sup> M Johnstone, 'Poor working conditions and the capacity of nurses to provide moral care', *Contemporary Nurse*, 2001, 12(1):7-15.

<sup>3</sup> J M Wilkinson, 1988, cited by L Tidje, 'Moral distress in perinatal nursing', *The Journal of Perinatal & Neonatal Nursing*, 2000, 14(2):36-43.

<sup>4</sup> J Buchanan, T Bretherton, S Bearfield, S Jackson, (March 2004), *Stable, but Critical*. The working conditions of Victorian Public Sector Nurses in 2003, Australian Centre for Industrial Relations Research and Training (ACIRRT), p. 35

<sup>5</sup> J Felgen, 'Caring: core value, currency, and commodity...is it time to get tough about "soft"?', *Nursing Administration Quarterly*, 2003, 27(3):208-214.

<sup>6</sup> J Buchanan, G Considine, (May 2002), *Stop telling us to cope! NSW nurses explain why they are leaving the profession*, Australian Centre of Industrial Relations Research and Training, (ACIRRT).

<sup>7</sup> J Summer, J Townsend-Rocchiccioli, 'Why are Nurses leaving nursing?' *Nursing Administration Quarterly*, 2003, 27(2):164-171, p. 164

<sup>8</sup> *ibid.* p. 164

<sup>9</sup> <http://www.etymonline.com> accessed 2/4/04; and [www.dictionary.com](http://www.dictionary.com) accessed 2/4/04.

<sup>10</sup> C Jackson, 'Healing ourselves; Healing others: First in a series', *Holistic Nursing Practice*, 2004, 18(2):67-81.

<sup>11</sup> V Robinson, 1946, cited in M Donahue, *Nursing The Finest Art*, 2<sup>nd</sup> Ed., St Louis Mo, Mosby-Year Book, Inc., 1996, p. 2

<sup>12</sup> S Bolton, 'Who cares? Offering emotion work as a 'gift' in the nursing labour process', *Journal of Advanced Nursing*, 2000, 32(3):580-586.

<sup>13</sup> *ibid.*

<sup>14</sup> Summer, Townsend-Rocchiccioli, 'Why are Nurses leaving ... p. 164

<sup>15</sup> *ibid.* p. 164

<sup>16</sup> M P Donahue, *Nursing ...* p. 2

<sup>17</sup> Office of the Principal Nurse, Department of Human Service, State Government of Victoria, <http://www.nursing.vic.gov.au/ir/index.htm> accessed 8/4/04.

<sup>18</sup> K Lutzen, A Cronqvist, A Magnussonand, L Andersson, 'Moral Stress: Synthesis of a Concept', *Nursing Ethics*, 2003, 10(3):312-322.

<sup>19</sup> *ibid.*

<sup>20</sup> P Hefferman, S Heilig, 'Giving "Moral Distress" a voice: Ethical concerns among neonatal intensive care unit personnel', *Cambridge Quarterly of Healthcare Ethics*, 1999, 8:173-178.

<sup>21</sup> S Gattuso, C Bevan, 'Mother, daughter, patient, nurse: women's emotion work in aged care', *Journal of Advanced Nursing*, 2000, 31(4):892-899.

<sup>22</sup> L Tidje, 'Moral distress in perinatal nursing', *The Journal of Perinatal & Neonatal Nursing*, 2000, 14(2):36-43.

<sup>23</sup> *Code of Ethics for Nurses in Australia*, 2002, Australian Nursing Council, Australian Nursing Federation, and Royal College of Nursing Australia.

<sup>24</sup> J Illiffe, 'A Government out of touch', *Australian Nursing Journal*, November 2003, 11(5):1

<sup>25</sup> J Medland, J Howard-Ruben, E Whitaker, 'Fostering psychosocial wellness in Oncology nurses: Addressing burnout and social support in the workplace', *Oncology Nursing Forum*, 2004, 31(1):47-54; T Brosche, 'Death, dying, and the ICU nurse', *Dimensions of Critical Care Nursing*, 2003, 22(4):173-179; Z Gellis, 'Coping with Occupational Stress in Healthcare: A comparison of Social Workers and Nurses', *Administration in Social Work*, 2002, 26(3):37-52; T Kalliath, R Morris, 'Job satisfaction among nurses: A predictor of burnout levels', *The Journal of Nursing Administration*, 2002, 32(12):648-654.

Anne Moates



## STEM CELLS

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The Commonwealth Act, Research Involving Embryos Act 2002 is coming up for review in the near future. Become better informed about the issues involved. Read *Stem Cells Science, Medicine, Law & Ethics* by Norman Ford SDB and Michael Herbert, published by the Caroline Chisholm Centre for Health Ethics in conjunction with St Pauls Publications earlier this year. Chapters include the science of adult and embryonic stem cells, international and Australian legislation, benefits and future prospects of the technology. An entire chapter is devoted to the ethical issues; the book also includes internet resources and a glossary. The cost is \$20.00 (including GST, and postage).

**To order your copy** contact Alice Steinar during office hours at the Centre. See last page for contact information.

*This article does not condone the use of donated gametes, anonymous or not, nor the practice of IVF. Nevertheless, given the fact that couples have legal recourse to the use of donated gametes in Australia, and the practice gives rise to offspring, an ethical evaluation is both necessary and timely. Moral concerns regarding IVF in general have been dealt with in a previous article.<sup>1</sup>*

Artificial insemination by donor was first introduced into the clinic during the 1930s. Whether donor-conceived (DC) children had a right to know information about their antecedents, however, was not considered an issue. Since its earliest days, confidentiality of donors was assured and recipients were strongly advised not to tell children about their origins. An excerpt from an article by Bloom in 1957 vividly encapsulates this attitude:

‘For the child’s sake particularly I prefer that absolutely nobody but the parents themselves should know of the insemination therapy. My last advice to the parents is that under no circumstances should they, or need they, ever tell the child the method of conception – in fact they should forget about it themselves.<sup>2</sup>

This is primarily because the focus of infertility treatments has undoubtedly been infertile adults.<sup>3</sup> To that end, clinicians in assisted reproductive technology (ART) have tended to favour donor anonymity (DA) and the privacy (perhaps secrecy is more apt) of the donor and recipients alike. Although such views are still espoused, there has been a gradual change amongst clinicians towards greater openness. Some now even advise it.<sup>4</sup> Despite these changes, it is not routinely seen as part of the clinicians’ responsibility to act as adviser: they see their role as solving the infertility problem.<sup>5</sup>

Is it ethical to continue the practice of DA when it can cause harm to those conceived in this way for a lifetime? Two particularly serious, but related consequences which arise from the practice of DA will be scrutinised. On the one hand, deliberate secrecy about the circumstances of conception can cause serious ethical issues for the family involved. And on the other, a lack of vital information about the DC child’s biological origins has obvious downstream psychological and health implications, especially in the era of genomic medicine.

## Secrecy and Deception

Studies have shown what is intuitive to us all: that good, stable relationships function best when based on openness and honesty.<sup>6</sup> This engenders the trust that is essential to all good human relations. As a society we are committed to this principle:

‘This goes beyond medical science into the heart of a human being’s story. Ancestry is part of a human being’s story and we should not be afraid to acknowledge it.’<sup>7</sup>

It follows that failing to tell the truth, particularly about one’s origins, can and does damage relationships and individuals. It is perhaps surprising that so few recipients (the legal parents) of donated gametes tell children of their origins. In Australia alone, a recent survey showed only 5% of recipients actually told their children this fact.<sup>8</sup> Although this may be changing slowly, there are currently no accurate, comprehensive figures showing how many parents tell children about their origins. Of further concern, once parents have shown the DC child, to all intents and purposes, as a child of the partnership, they maintain the *status quo*. It has proven hard to turn back after the deception has been established.<sup>9</sup>

Although it is debatable whether secrecy has a negative effect on DC-children at an early age, this certainly changes as they grow up.<sup>10</sup> While it is legitimate to argue that individuals (in this instance the parents) have a right to privacy about personal matters, such as infertility, in the long-term it is the offspring who have to bear the burden of their parents’ infertility and their secrecy about the use of anonymous donor gametes. ‘It is one thing to adopt a child whose natural parents are unable to discharge their responsibilities-but quite another to engineer anonymity of a child’s genetic origins by the use of donor gametes. Parenthood is important, but it should not be achieved to the detriment of children’<sup>11</sup> conceived in this fashion.

Even if the deception is confessed later in the individual’s life, there is a risk of a profound identity crisis for the child, who discovers that he is not who he thought he was. Moreover, ‘if the deception is exposed during a family crisis, or accidentally by a third party, serious damage can occur to the relationship which exists between the parents and the child.’<sup>12</sup>

Some parents find it harder to expose their child to the uncertainties of knowing that she was conceived by the use of donor gametes, than to pretend she was conceived naturally. Nevertheless, parents who have disclosed a child’s origins remain adamant that it was the right decision. Repeatedly one hears: ‘I couldn’t have lied to

them." Nevertheless, it is "not an easy option", nor is the issue addressed by the single disclosure. Even if they return to the IVF clinic, little information is available to them, and not specific at that.<sup>13</sup>

The ethical imperative to tell the truth, however, should not apply to parents alone. The state, through its legislation and regulation of ART, would do well to accept ethical responsibility for the welfare of the child in this respect. The state's complicity in the deception of donor offspring may take the form of regulations, which condones secrecy, or at the very least, makes it harder for parents to tell the truth than to maintain the deception. Victoria is still the only state in Australia that has passed legislation mandating DC-individuals the right to gain identifying information about the donor. But only those conceived in Victoria after January 1998 [commencement of this part of the Infertility Treatment Act (ITA)] will be able to know the identity of the donor when they reach the age of 18. Unfortunately, every other person now being conceived or already born in Australia through donor conception still has no right to identifying information about the donor.<sup>14</sup>

## Crisis of Self-identity and Loss of Connectedness

Far and away the major problem arising from DA is that half of the genetic and familial history of the child remains unknown. This can have serious consequences throughout the development of the child, affecting both their physiological and psychological health, and impacts well into adulthood.

It has not been possible to perform any comprehensive study of the effects of DA because of the secrecy surrounding the practice since its inception. However, from the small studies that have been published, the emerging trend is clear.<sup>15</sup> 'All DC individuals reported feeling a loss of self identity, compounded with resentment and anger at the deliberate deception.'<sup>16</sup> Without exception all wished they had been told sooner. A major theme emerging from DC individuals' responses was that no one had thought them important enough to keep detailed records about their donor and worse, 'the system was intentionally set up to deceive them and to make it impossible for them to ever know. Even their birth certificate is a lie.'<sup>17</sup> Whatever their individual circumstances, all clearly stated that they had fallen victim to a major injustice and wanted the matter rectified. A 42 yr old woman commented: "we have the right to know our identity and to grow up in truth."<sup>18</sup>

Being gregarious by nature, the network of familial relationships is central to our personal identity. In other words, our father, mother, siblings and relatives are all part of who we are, and these relationships are not chosen at will but determined by our ancestry---'we are aware of

this and appreciate the importance of family relationships and bonding.'<sup>19</sup> That half of this heritage is denied to DC individuals, through no fault of their own, seems grossly unfair. They are also discriminated against in the increasingly important field of genetic medicine and genomic health, such as in the diagnosis of preventable genetic diseases. DC individuals will only ever know half of their genetic origins, and half of their respective familial relationships are denied access to them.

Besides being unethical, such a practice may well breach international conventions and state laws. In 1995, Victoria passed the ITA, and Clause 5 states that the welfare of the child is 'paramount'. The meaning of this statement has proven to be highly controversial. Does it simply mean ART clinicians should do all in their power to ensure the process of fertilisation and the resulting embryo is protected from harm prior to uterine transfer? Or should the import be more comprehensive, mirroring Adoption legislation, covering the long-term welfare of the developing individual throughout their formative years?

Contemporary society values transparency and fair access to relevant records. The Australian Government has accepted the United Nations Declaration of Human Rights and is a signatory to the UN Convention on the Rights of the Child.<sup>20</sup> In respect to DA, the two most pertinent articles are:

### Article 7

1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents.

### Article 8

1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.

2. States where a child is illegally deprived of some or all of the elements of his or her identity, Parties shall provide appropriate assistance and protection, with a view to speedily re-establishing his or her identity.<sup>21</sup>

Donor offspring do not consider that their voice has been heard, their perspective given any consideration or that they have been treated fairly. It is questionable whether the governments of Australia have provided adequate assistance or protection for DC-individuals. Anonymous donation of gametes might well be seen as flying in the face of those conventions to which the Commonwealth is a signatory.

## Conclusion

Individuals conceived by ART have rights and needs

which have to be recognised---not denied or ignored. Reproductive services should take on board the perspective of those conceived through such programs, both as a developing child and as an autonomous adult. This requires a shift in both thinking and priorities for donors, potential parents and clinicians. Although the availability of sperm donors would be affected by changes, it is evident that significant numbers of volunteers are aware of, and understand, issues that arise from donated gametes.<sup>22</sup>

Furthermore, practice from other countries, such as Sweden, New Zealand and elsewhere, shows change is possible. In Sweden, DC individuals have the right to access donor information from the age of 14 years. In the Netherlands, DC individuals, after reaching 16 years of age, may request identifying information about the donor and it will be provided if the donor agrees. If the donor does not agree, the DC individual may still be given the information if it is thought that withholding it may cause psychological damage.<sup>23</sup>

Improvements, however, require that the obligations of donation be fully explored with potential donors---that the children conceived receive information about their biological parents and that it is not just about helping infertile partnerships achieve parenthood. Donors have been the silent partners in the process of creating donor families and as a result many assumptions have been made. The over-riding ethical premise is that priority should always be given to the lifelong well-being of children.<sup>24</sup>

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## Mental Health: Burdens and Challenges

*This article gives a brief account of the prevalence, costs, shortcomings and burdens of caring for persons with a mental illness as well as the challenges facing the community.*

It's reported that approximately half as many Australians have a mental disorder as have a chronic physical disorder with peak prevalence occurring in the 18 to 24 year old age group. About 62% of persons with a mental disorder do not seek any professional help for mental health problems. Whilst mental disorders account for about 20% of the burden of disease in Australia, only 5% of the health budget is spent on services to the mentally ill.<sup>1</sup>

### Mental Health is a Global Concern

Mental health has been found to contribute significantly to the global burden of disease. In 2001 mental disorders accounted for 13% of the world's burden of disease and is expected to increase with time. 450 million people worldwide are affected by mental, neurological or behavioural problems at any given time. Mental problems are common to all countries, cause immense human suffering, social exclusion, disability and poor quality of life as well

as increasing mortality and causing staggering economic and social costs.<sup>2</sup> Mental health is one of the five National Health Priority Areas identified by the Commonwealth and State Governments of Australia.<sup>3</sup>

What is mental health? The World Health Organisation (WHO) has this definition: 'A state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community'.<sup>4</sup> The WHO describes the undefined and hidden burden of mental health problems, with the former referring to the economic and social burden for families, communities and countries, and the latter referring to the burden associated with stigma and violations of human rights and freedoms. Both are difficult to measure and evaluate.<sup>5</sup>

## Rising Cost and Burden of Mental Illness

Researchers in the USA set out to put a price on how costly certain conditions were in terms of productivity costs. They analysed evidence about the total cost of health, absence from employment, short-term disability, and productivity losses for 10 health conditions. They looked at prevalence and associated absenteeisms and presenteeism (on-the-job-productivity). Presenteeism costs for mental health conditions were suggested to be higher than medical costs in most cases. This refers to productivity loss 'on the job' due to effects of the condition.<sup>6</sup>

Depression is the largest cause of disability burden in Australia. Depression affects 1 in 20 employees but only half ever seek treatment. This translates to 3 to 4 days of absenteeism each month and those lost due to presenteeism is 5 times as much again. Depression costs each employer up to \$483 per employee per year.<sup>7</sup> The Australian Institute of Health and Welfare (AIHW) estimated the burden of depression and its consequences using the DALY (disability-adjusted life year) as 122,332 years for a 12 month period in 1996 and 338,000 years for mental illness. (One DALY is one lost year of healthy life and is calculated as a combination of years of life lost due to premature mortality and equivalent healthy years of life lost to disability).<sup>8</sup> Prolonged untreated depression creates degenerative changes to the brain which may make sufferers more susceptible to dementia later in life.<sup>9</sup> Dementia is the second largest cause of disability in Australia though it is predicted to become the largest by 2016. Dementia cost \$6.6 billion dollars in 2002, including direct care costs and indirect such as lost earnings of patients and carers.<sup>10</sup>

## From custodial to community to informal care

Managing mental health illness has shifted from custodial inpatient models to supported community care. The effects of deinstitutionalisation has been widely discussed and the consensus seems to favour the continued support for managing even severe mental health conditions in the community. Whatever the reasons for this shift, it is less costly in monetary terms, especially since mental health does not top the list in health care spending.<sup>11</sup> The shift to community care has left gaps in service. Many, but not all, may have family and friends willing to take on care responsibilities. Unfortunately these relationships may become too burdensome and some people with mental illness are abandoned or left to fend for themselves.

A review about the subjective well-being of people caring for a family member with a severe disability at home suggests that the powers that encourage family care are minimally concerned with family welfare. Data shows that primary caregivers are at considerable risk of high stress, clinical depression, and abnormally low subjective quality of life and wellbeing related to time constraints, sleep deprivation, worry, depression and lack of support.<sup>12</sup>

About 2.3 million Australians, including children as young as ten years, are providing care for family members or friends with a disability, mental illness, chronic condition or who are frail aged --- and this is thought to be an underestimate. Nearly 20% of these are providing unpaid informal support. Most carers are female and provide care because the alternative is too costly, or there is no alternative. Carers save the community and government over \$18.3 billion dollars per year by helping the people they care for stay at home. Unfortunately, many carers are among the poorest, most disadvantaged people in the community.<sup>13</sup>

The Australian Bureau of Statistics reports that nearly half of primary carers' financial situation is adversely affected due to extra expenses. The competing demands of the care-giving role and the requirements of paid employment push carers out of the work force, with many carers reliant on government pensions or allowances as their principal source of income.<sup>14</sup> Cummins suggests that 'the care recipient is probably, on balance, better off being cared for in their family, while their family, on balance, is worse off through the provision of such care'<sup>15</sup>.

## Mental Health Services in Crisis

A nationwide review of the experiences of those who use and provide mental health services has documented that there are ongoing problems with mental health policy and services with current community-based systems failing to

provide adequate care. Specifically, these services are characterised by restricted access, variable quality, poor continuity, lack of support for recovery from illness, and inadequate protection against human rights abuses.<sup>16</sup> There are more demands and emerging issues such as the effects of threats of terrorism. Evidence of links between brain injury and psychiatric disorders<sup>17</sup> and post traumatic stress disorder and psychosis<sup>18</sup> are mounting. While the move to non-institutionalised care is lauded, the responsibility has been passed onto community services that are struggling to cope. The failure to meet the service and care demands of mental illness in the community is said to have contributed to rising suicide statistics and resulted, sadly, in a new form of institutionalism: homelessness and imprisonment.<sup>19</sup>

The stigma attached to mental illnesses isn't helped by evidence that there is disagreement amongst service providers about the provision of care, especially in rural areas, where out of hours services are inadequate and police are forced to attend rather than mental health workers.<sup>20</sup> This trend of criminalising people with mental illness is acknowledged as an area that needs urgent re-dressing.<sup>21</sup> The National Mental Health Report 2002, provides evidence that accessing services remains problematic, especially during psychiatric emergencies.<sup>22</sup> This is clearly unsatisfactory.

## Living with Deinstitutionalisation

Acceptance of care in the community is not universal. There is the perception that people with mental illness pose a danger, though evidence suggests that people with mental illness are not more violent than other people.<sup>23</sup> Deinstitutionalised clients may not always conform to accepted social expectations and norms within their community. Lack of information and witnessing frightening behaviour was identified as causing local neighbourhood concern by neighbours of people with mental illness who live in group-homes. This contributed to the experience of exclusion and segregation and social isolation of those with long-term mental illness, rather than the goal of normalised integration.<sup>24</sup> The 'theory of difference' may contribute to this phenomena. People receiving mental health services may experience being cast out of their original group but are not a full member of the next - a transitional space that may not lead anywhere.<sup>25</sup>

Empowering individuals by helping them make the most of available sources of social support, providing assistance with coping strategies and enhancing feelings of mastery or self-efficacy has been identified as worthwhile for care-givers, though these are not usually part of mainstream services.<sup>26</sup> Promoting the concept of social capital, in which mutually supportive social relationships confers public good, is advocated.<sup>27</sup> This puts the onus on the community to accept, take responsibility for, and

manage mental health issues as another facet of life. More effort needs to be put into prevention and promotion from an early age, especially since research shows that childhood behavioural problems may be predictive of developing depression, social phobia and violence in adulthood.<sup>28</sup> How does a society know if they are doing a good job by their mentally ill community? The Victorian Government is attempting to measure this very thing though it seems an impossible undertaking as the determinants of what constitutes a mental illness seems to grow each year.<sup>29</sup>

Mental illness is now so pervasive that it should be considered just another commonplace fact of life, not necessarily a burden. Despite the drive to eliminate the stigma it persists and this is reflected in the *ad hoc* way that the mental health needs of the community are serviced. The carers of Australia should be applauded for the considerable contribution they make. They should also be adequately funded, extensively supported, and have their own well-being needs catered for. To reiterate, mental health illness accounts for 20% of the burden of disease in Australia but only receives 5% of the health budget. It warrants much more.

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