

# *Chisholm Health Ethics Bulletin*

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## **Highlights from 'Challenges in End of Life Care' Conference - 31 October 2002**

**Bishop Mark Coleridge**, Auxiliary Bishop of Melbourne made a brief inspirational opening speech about the *Dignity of the Human Person and Healthcare*. Health has always been of interest and concern to the broader Christian community. He affirmed that all have the right to adequate health care, and to respect for the dignity of the human person. Suffering and death are not native to humans. Depth of life should not be equated with length of life!

*... all have the right to adequate health care, and to respect for the dignity of the human person*

**Dr Peter Hunter**, Clinical Director of Aged and Continuing care, St Vincent's Health spoke about the *Relationships of Health Professionals and Patients: an aged care perspective*. Ethics in this area, he suggested, is about a kaleidoscope of issues and lots of questions without answers. Health care has changed due to technology, demand, resources and quality of care. The heart of the matter, as quoted, is that... 'moral dilemmas in a medical context commonly involve conflict either between justifiable principles or between principles and consequences'. The principle of self-determination is foremost in attempts to resolve medical ethical problems in this area today.

Ethical issues include decision

making and ageism, the distribution of resources, informed consent, quality of life and lifestyle decisions, resuscitation, withholding or withdrawing treatment, ordinary or extraordinary treatment, competence and advanced care directives.

Questions about how quality of life, suffering, and burdens and benefits are determined are a challenge for the aged care practitioner.

*validated tools to assess competence are lacking*

The principle of beneficence and competence in the elderly becomes an important ethical consideration. Validated tools to assess competence are lacking and questions about *what does* constitute a person's best interest

must be determined.

As an ethical example, Dr Hunter discussed the case of enteral feeding in terminal dementia care, citing that, to date, no studies prove

*Conference Speakers: Angelina Schweitzer and Mary Pearson*

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that enteral feeding in these cases is effective. The prevailing view is that tube feeding is a medical therapy rather than basic humane care and may only be indicated if the benefit outweighs the burden, and if consistent with the patient's preference. Rabeneck's Approach,<sup>1</sup> which describes ethical and clinical guidelines for percutaneous endoscopic gastrostomy tube placement (PEG), was advocated as a method to resolve this issue in practice. Dr Hunter concluded by stating that ethical thinking in aged care is not easy, with more questions than answers, but thinking about principles helps.

*a person's choice of where they die is important*

**Mary Pearson and Angelina Schweitzer**, Quality Manager, Aged and Continuing Care St George's Health Service, and Manager Prague House, respectively, spoke about *Care of the dying in various settings*, reflecting on their experiences of providing end of life care in various roles spanning a range of settings. A person's choice of where they die is important. There are reasons why these choices are not always available, eg, unresolved family and grief issues. Health professionals and carers help people in their journey to peaceful death. Vignettes were used to highlight issues such as, when are extreme or experimental solutions appropriate, how do we recognise when our care and compassion lead us to avoidance behaviours, and when does choice change to hope and collusion with denial begin? People get on the *treatment carousel* and sometimes never get home. The speakers expressed the view that there is a need to involve family in choice about all aspects of end of life care. Level of care varies and is inconsistent in the area of pain relief and symptom management due to lack of standard approaches. Carers were urged to focus on the needs of the person.

Challenges in residential settings may include staff feeling and expressing anger about residents who choose to let go their grip on life. Listening concerns more than just hearing what a resident says. Staff become *family* to long term residents. If a person has some choice about the environment or setting as their life is ending, it can enable them to have some control in their movement towards a destiny that is finally unknown. End of life care is about enhancing quality of life by the provision of appropriate and responsive care as health declines.

**Pauline Arnold**, Chaplain of Baptist Community Care, spoke about *Pastoral Care and Spirituality*. Her theme centred on the *Hospitality of Pastoral Care*. When moving from home to residential care there is loss and grief at leaving many things behind. New residents enter a situation where they may need to share meals and activities with people from different backgrounds.

*the good manners of hospitality is sometimes neglected*

Hospitality in aged care settings is an appropriate consideration, however, the good manners of hospitality is sometimes neglected. Residents are *not* invited guests. It is their home. The good manners of hospitality are 'the outward manifestations of one's innate character and attitude to life'.

The basis of hospitality is that there is both guest and host with the sacred rule of hospitality being to treat the guest with respect going back to biblical times when guests were 'given water to wash feet, feasted, and protected from enemies'. Pauline presented a *Model of Hospitality* as discussed under the headings of good manners, relational, and giving and receiving. Spirituality is seen as the core values that becomes the essence of one's own *personhood* and includes belief systems and patterns

of thought. Giving and receiving is that free space that allows the unexpected to happen. The basic meaning of *palliative* is to provide comfort. The concept of a *Cloak of Hospitality* as an idealistic metaphor to provide comfort concluded the presentation.

**Dr Jane Fisher**, Clinical Director Palliative Care Bethlehem Health Care, discussed *Symptom Control and Management of the Terminal Phase*. This practical session covered aspects of the medical management of symptoms at the terminal phase. Dr Fisher suggested that it was important, in terms of management, to redefine the goals of care when a patient is identified as approaching the terminal phase. The duration of this phase is variable. Recognition of the terminal phase is related to a patient becoming weaker, being bed-bound, drowsy, disorientated, disinterested in food and drink, having swallowing difficulties, or having peripheral shutdown. Physical symptoms such as pain, breathing difficulties, urine retention, nausea and vomiting, restlessness and agitation, delirium, jerking and twitching, and haemorrhage can all be managed either by the use of medications or alternatives. Choice is of paramount importance.

*palliative care seeks to allow a peaceful and dignified death in the setting of the dying person's choice*

The time before death can be distressful to the family, especially if they are unprepared for physical manifestations exhibited by the dying person. Preparing family for the possibility of terminal events such as delirium, respiratory changes, eg Cheyne-Stoke breathing and death rattle, or massive haemorrhage goes far to prevent distress should these occur. Palliative care seeks to manage these symptoms and allow a peaceful and dignified death in the setting of the

dying person's choice, with family involvement, and observing cultural traditions when appropriate.

A paper by **Professor David Kissane**, Director Centre for Palliative Care, University of Melbourne on *Impact of Demoralisation on Informed*

*Consent*, and one from **Barbara Carter**, Senior Guardian, Office of the Public Advocate on *Legal Issues at the End of Life* will be published in a future bulletin. The conference paper presented by **Dr N Ford** is published in this edition.

## ENDNOTES

<sup>1</sup> See Rabeneck *et al.*: *Lancet*, Volume 349(9050). February 15, 1997. 496-498.

Anne Moates



# Treatment at the End of Life and Ethics

## Duty of Reasonable Care and Treatment of Patients

In health care, the basic moral principle is that we are bound to undergo the medical treatment that is reasonably required in the circumstances to restore health or to save life. It is the responsibility of healthcare professionals, in dialogue with their patients, to interpret the duty of reasonable care in individual cases. This ethically excludes deliberately choosing to cause the death of patients by deeds or undue omissions. This is not part of medicine. Pope John Paul II recently confirmed this constant Christian tradition when he rejected euthanasia, defined as 'an action or omission which of itself and by intention causes death, with the purpose of eliminating all suffering.'<sup>1</sup>

*we are bound to undergo the medical treatment that is reasonably required in the circumstances to restore health*

Doctors may not treat competent patients without their informed consent. They have the right to refuse unwanted medical treatment. This requires that patients be given the relevant information before they make decisions: there is a difference between an 80% or a 20% likelihood of a cure. Clinicians should respect their patients' eminently human decisions. Medical treatment is to serve patients who should not be subordinated to the duress of technological imperatives against their reasonable wishes.

It has traditionally been axiomatic that

all reasonable means should be used to cure or save life. This was often equated with 'everything possible', but with modern high-tech medicine this slogan is not a useful guide. Treatment should be given until a confident prognosis indicates the patient's condition is incurable and that further treatment is disproportionate to the benefits expected. Treatment, then, is futile when, given due time, it cannot restore health or function, cannot cure illness, disease or relieve distress. Healthcare professionals and the State are not morally obliged to go beyond the bounds of reason to provide every possible medical treatment. The availability of medical resources, personnel, family and state finances, and the prospects for the patient's recovery all enter into the complex judgement of *the duty of reasonable treatment in the circumstances*.

At times it is justified to let nature take its course, even if death occurs, rather than to intervene and prolong a life of suffering. It is psychologically more difficult to withdraw futile treatment once it has commenced than to withhold it at the start. Carers may feel they cause death by withdrawing treatment whereas patients really die from their underlying fatal pathology. When the withholding of treatment is morally justified, its withdrawal is also justified bearing in mind the reasonable wishes of the competent patient.

Multi-disciplinary communication is important for the right advice to be given to patients when a change from acute to palliative care is considered. Attention should be paid to the knowledge and advice of nurses and carers in hospitals and nursing homes

because they know their patients well, including their limits of endurance for pain after treatment. A time comes when medical treatment may cease in favour of initiating palliative care in patients' best interests. The withdrawal of burdensome or futile treatment in terminal cases is good medicine. This is not morally the same as euthanasia when it is withdrawn in order to cause death.

*Patients have a right to prepare emotionally and spiritually to die naturally, in peace and with dignity*

Competent patients who have been informed of what is involved in *cardiopulmonary resuscitation* (CPR) and its success rates for others in a similar condition, may morally refuse to have it if they have a cardiac arrest. This does not imply that life itself has no value but that CPR, in the circumstances, would be disproportionate to its benefits.<sup>2</sup>

## Approach of Death for the Terminally Ill

Dying patients need to be informed in good time of their condition by their doctors. Patients have a right to prepare emotionally and spiritually to die naturally, in peace and with dignity, without being deprived of an opportunity to attend to their outstanding personal, family and religious duties. Patients' decisions about treatments at the end of life could also be influenced by their religious faith or personal beliefs. They

ought to know there is no need to resist the approach of death and that they may in good faith let go and die. Chaplains or pastoral carers should help the dying be sustained by their own religious faith or personal beliefs and to realise that they are under no moral obligation to accept burdensome life prolonging treatment.

## Use of Drugs to Alleviate Pain

John Paul II's teaching on the use of pain-killing drugs is instructive:

... it is licit to relieve pain by narcotics, even when the result is decreased consciousness and a shortening of life, "if no other means exist, and if, in the given circumstances, this does not prevent the carrying out of other religious and moral duties". In such a case, death is not willed or sought, even though for reasonable motives one runs the risk of it: there is simply a desire to ease pain effectively by using the analgesics which medicine provides.<sup>3</sup>

***when taken as medically prescribed, morphine is safe and patients soon develop tolerance***

When taken as medically prescribed, morphine is safe and patients soon develop tolerance to it. When a high dose of a drug is required to alleviate extreme pain it may be given, with the competent patient's informed consent, if consciousness may be diminished or life shortened.

Provided one's aim is the alleviation of pain, decisions of the sort should not be confused with *deliberately* choosing to cause death. If the terminally ill are very debilitated or in great pain, they may be asked if they want to be sleepy. They may then be appropriately sedated, allowing for conscious periods for meals and for renewed awareness that they are still loved until death comes naturally.

## Treatment at the End of Life

The duty of care of health and life requires sharper focussing at the end of life. Over 40 years ago Pope Pius XII said extraordinary treatment is not obligatory:

A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, health, and all temporal activities are in fact subordinated to spiritual ends.<sup>4</sup>

UK theologian Kevin Kelly agrees:

To fight against the normal dying process when the quality of life has become virtually sub-human is to mistake the place of physical life as a dimension of the good of the person... Christian morality is pro-person more than it is pro-life.<sup>5</sup>

John Paul II also agrees that goods for the person serve the good of the person -- the good which is the person as such and his or her perfection.<sup>6</sup> Consistent with this he teaches:

when death is clearly imminent and inevitable, one can in conscience "refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted". Certainly there is a moral obligation to care for oneself and to allow oneself to be cared for, but this duty must take account of concrete circumstances. It needs to be determined whether the means of treatment available are objectively proportionate to the prospects for improvement. To forgo extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death.<sup>7</sup>

These traditional moral principles apply also to incompetent patients,

including those in a permanent vegetative state (PVS). Life support should not be withdrawn without the agreement of their legally recognised representatives, who, as trustees, provide a social guarantee that their interests are duly protected. Discerning clinical judgement is required to see if it is justified to withhold or withdraw life saving treatment, including CPR, from incompetent patients.

## Provide Artificial Nutrition and Hydration to all Patients

Ethicists agree that ANH should be given to patients who cannot eat and drink until it is established whether the condition is curable or not. If curable, artificial feeding should continue as it would be necessary. Though artificial feeding does not cure a pathology, it sustains life for patients who can assimilate it and can prevent suffering from dehydration, hunger and thirst. Patients vary in their capacity to cope with artificial feeding. Some may find it too physically distressing or psychologically repugnant. But it would be inhuman to refuse ANH to competent or conscious mentally impaired patients who want it.

***it would be inhuman to refuse ANH to competent or conscious mentally impaired patients who want it***

In palliative care the provision of patient comfort is *the priority*. This excludes forced feeding against the wishes of a competent patient. Loss of appetite is part of the dying process. Failure to respect this process shows a lack of respect for the dying person who accepts the inevitability of death without any *intention* of suicide.

Is it necessary to provide ANH for Patients in a PVS?

There is no agreement on whether there is a duty to continue ANH for patients who have been confidently diagnosed as permanently unconscious due to their irreversible *vegetative state*

(PVS). Patients in a PVS lack the instinct to eat or drink. They cannot suffer starvation in the normal sense nor experience pain. If any doubts exist about pain, PVS patients should be given analgesics. The U.S. Bishops' Pro-Life Committee admits that Church teaching

has not resolved the question whether medically assisted nutrition and hydration should always be seen as a form of normal care.<sup>8</sup>

Yet, referring to PVS patients they say:

It is our considered judgement that while legitimate Catholic moral debate continues, decisions about these patients should be guided by a presumption in favor of medically assisted nutrition and hydration. A decision to discontinue such measures should be made in the light of a careful assessment of the burdens and benefits of nutrition and hydration for the individual patient and his or her family and community. Such measures should not be withdrawn in order to cause death, but they may be withdrawn if they offer no reasonable of sustaining life or pose excessive risks or burdens.<sup>9</sup>

***the omission of nutrition and hydration intended to cause a patient's death must be rejected***

Though both are forms of treatment, there is a reluctance to apply the logic of withdrawing a ventilator from a patient in PVS to withdrawing ANH from a patient in PVS. In both cases death is the natural effect of PVS unless artificial ventilation or feeding is continued. Indeed, there does not seem to be an ethical difference between withdrawing life sustaining artificially administered oxygen and nutrition from a person in PVS.

The Texan Bishops agree:

The morally appropriate foregoing or withholding of artificial nutrition and hydration from a permanently unconscious person is not abandoning that person. Rather, it is accepting the fact that

the person has come to the end of his or her pilgrimage and should not be impeded from taking the final step.<sup>10</sup>

Bishop Bullock sums up the position well:

The benefit to patients of a particular procedure should be judged in view of what it will contribute to human functioning so that they may complete their life tasks and achieve their spiritual destiny.<sup>11</sup>

Bryan Jennett says the argument on artificial feeding should depend on

how those involved regard the prolongation of life in a permanent vegetative state. Lack of benefit will always be a stronger argument than the burden of continuing treatment.<sup>12</sup>

Catholic teaching is still not resolved on this difficult question. In 1998 Pope John II endorsed part of the U.S. Pro-Life Bishops' Statement but significantly omitted its reference to a duty to provide artificial feeding to patients in a PVS. He said their Statement

rightly emphasises that the omission of nutrition and hydration intended to cause a patient's death must be rejected and that, while giving careful consideration to all the factors involved, the presumption should be in favour of providing medically assisted nutrition and hydration to all patients who need them.<sup>13</sup>

A presumption is not definitive nor does it rule out the exercise of judgement by clinicians to withdraw artificial feeding after a proper assessment of the needs of unconscious patients whose PVS has been diagnosed as irreversible. Life, being a basic good, may never be deliberately terminated in a patient in PVS. But this does not imply that there is an unending duty to provide ANH for patients in PVS. It is hard to prove there is a duty to sustain the life of a patients in PVS for years by ANH if it cannot be shown that this is *good for*

*the person in PVS*, serves the good of the person or their *spiritual ends*.

## Conclusion

The law should allow doctors, after an ethical assessment of the needs of dying patients, to follow their clinical judgement for treatment options, provided social guarantees are in place to prevent abuses.

Fear of being sued encourages the practice of defensive medicine, hinders making correct clinical decisions and is not in the best interests of patients nor of the community.

***the community and doctors should not regard the existence of incurable disease or the inevitability of death as indicators of failure***

The community and doctors should not regard the existence of incurable disease or the inevitability of death as indicators of failure. Education is the right way to deal with the community's culturally entrenched death *angst*. People need help to form a correct understanding of the right to refuse medical treatment in common law and state jurisdictions as well as the right to appoint an agent with an enduring power of attorney (medical). This would avoid dilemmas for family members, legal representatives and healthcare professionals alike.

## ENDNOTES

<sup>1</sup> John Paul II, Encyclical Letter *Evangelium Vitae*, (Vatican City: Libreria Editrice Vaticana, 1995) n. 65.

<sup>2</sup> For more on a similar line of thinking see James J Walter "The Meaning and Validity of Quality of Life Judgement in Contemporary Roman Catholic Medical Ethics", in J.J. Walter and T.A. Shannon, eds., *Quality of Life - The New Medical Dilemma*, (New York: Paulist Press, 1990) 78-88.

<sup>3</sup> John Paul II, *Evangelium Vitae*, n. 65.

<sup>4</sup> 'The Prolongation of Life', *The Pope Speaks* (1957-58) 395-97.

<sup>5</sup> Kevin Kelly, *New Directions in Moral Theology: The Challenge of Being Human*, London; Geoffrey Chapman, 1992, 25-26, 42

<sup>6</sup> See John Paul II, Encyclical Letter *Veritatis Splendor*, (Vatican City: Liberia Editrice Vaticana, 1993) N 79.

<sup>7</sup> *Evangelium Vitae* n. 65.

<sup>8</sup> 'Nutrition and hydration: Moral and Pastoral Reflections', *Origins* April 1992, 707.

<sup>9</sup> *Ibid.* 710.

<sup>10</sup> Texas Catholic Bishops and Texas Conference of Catholic Health Facilities, "On

Withdrawing Artificial Nutrition and Hydration" *Origins*, 20 (4) June 7, 1990, 53-55.

<sup>11</sup> Bishop Bullock, "Assessing Burdens and Benefits of Medical Care" *Origins*, January 30, 1992, 555.

<sup>12</sup> Bryan Jennett, *The Vegetative State*.

*Medical Facts, Ethical and Legal Dilemmas*, Cambridge: University Press,

2002, 112.

<sup>13</sup> *L'Osservatore Romano*, 7 October 1998, 5.

Norman Ford SDB



## Preimplantation Genetic Diagnosis &

### Introduction

Amniocentesis and chorionic villus sampling (CVS) are currently the mainstays of prenatal genetic testing, having been developed primarily to detect a wide range of genetic abnormalities during the first 10–16 weeks of gestation. Both procedures involve the sampling of fetal cells, either from the amniotic fluid surrounding the fetus in the case of amniocentesis or from placental projections for CVS. DNA can be extracted from the cells and tested for mutations in specific genes or gross chromosomal disorders.

### What is Preimplantation Genetic Diagnosis?

An alternative to CVS and amniocentesis, which is routinely used for couples known to be at high risk of transmitting a genetic disorder, is Preimplantation Genetic Diagnosis (PGD).

*PGD only gives a diagnosis for the particular abnormality under scrutiny*

PGD is the result of combining our increasingly specific knowledge of the human genome with assisted reproductive techniques, such as IVF. This involves the diagnosis of genetic disease, usually after the time of fertilisation, but before implantation. Patients requesting PGD undergo IVF treatment because in this way multiple embryos, which are readily accessible for tests, can

be generated giving an increased probability that an 'affected' embryo will be identified. PGD only gives a diagnosis for the particular abnormality under scrutiny; it is by no means a definitive all-clear for every genetic disorder.

*56% of embryos undergoing PGD are deemed 'affected' and discarded*

In most cases, the embryos formed are cultured for three days, by which time they are usually composed of 6–10 cells. One or two cells (blastomeres) are then removed from each embryo and subjected to genetic analysis. While the cells are tested, the embryos remain in culture. If the blastomere examined is shown to be clear of a genetic disorder, then it can be inferred that the remaining cells in the embryo are also free of that particular disease. Those embryos testing negatively are transferred to the uterus while 'affected' embryos are discarded. The main technical limitation of PGD is the low efficiency of IVF. Around 20% of couples achieve a pregnancy per IVF cycle and the success rate for couples undergoing PGD is similar.

### Who gets PGD?

PGD is usually offered for three major categories of inherited disease. Firstly, it can be used to identify single gene defects residing on a particular chromosome, such as haemophilia.<sup>1</sup> In such conditions the

molecular abnormality is testable with highly specific probes after applying a technique known as polymerase chain reaction, or PCR. Basically, this enables massive amplification of the DNA segment of interest after it is extracted from single cells. Single mutations can then be easily and accurately detected. Secondly, it can be used to determine the sex of the embryo for sex linked disorders where the specific genetic defect at a molecular level is unknown, highly variable, or unsuitable for testing on single cells; eg. Duchenne muscular dystrophy.<sup>2</sup> Thirdly, it can be used in analysing chromosomal disorders. Offspring typically inherit one copy of each chromosome from each parent, so that each cell of the new individual contains 23 chromosome pairs. Fluorescence *in situ* hybridisation (FISH) has been developed to detect a variety of chromosomal abnormalities, including chromosome deletions (monosomies), trisomies (three copies instead of the pair), rearrangements and inversions.<sup>3</sup>

### PGD of single gene disorders

The first autosomal (non-sex linked) single gene disorder to receive diagnosis at the preimplantation stage was cystic fibrosis, in 1992.<sup>4</sup> Since then, the strategies for PGD have increased in sophistication and the number of diseases to which PGD has been applied has grown steadily.<sup>5</sup> Diagnostic protocols now exist for more than 30 single-gene

disorders, including recessive disorders such as spinal muscular atrophy and  $\beta$ -thalassaemia and dominant disorders such as Huntington's disease.

## PGD of Chromosomal Abnormalities

The detection of chromosomes in a single biopsied blastomere is usually achieved using FISH, which uses the hybridisation of fluorescent DNA probes to complementary regions within chromosomal DNA. Although FISH continues to be used for sexing, its principal application now lies in the detection of unbalanced chromosome complements that cause conditions such as Down's syndrome (trisomy 21).<sup>6</sup>

*of all embryos undergoing PGD, only 2.8% actually result in an established pregnancy*

Diagnosis of chromosomal abnormalities in the preimplantation embryo has been developed for two distinct groups of patients. The first group consists of women over 35 years old undergoing routine IVF treatment. Women in this age group have a high probability of producing eggs with a chromosome imbalance and so a significant proportion of their embryos may well be abnormal. The second group consists of couples in which one partner carries chromosomal rearrangements. Such occurrences are relatively common throughout the population (around 1 in 500) and can lead to repeated spontaneous miscarriages.<sup>8</sup>

## Results of PGD So Far

To date, there have been tens of thousands of PGD cycles for inherited diseases conducted worldwide and these have resulted in the birth of more than 1000 healthy children.<sup>9</sup> The genetic conditions to which PGD has been applied are varied. About two-fifths of all diagnoses have been for carriers of

autosomal single-gene disorders, one-third have been for chromosome imbalance and the remaining one-quarter have been aimed at

*apart from the substantial costs there is an unacceptable loss of early human life arising from the overall procedure of PGD*

determining embryo sex to avoid X-linked diseases.

The principal reasons given by patients for seeking diagnosis at the preimplantation stage are: objection to termination of pregnancy on moral or religious grounds (~40%); genetic risk coupled with low fertility (ie. the patient carries an inherited disorder and is infertile, requiring IVF to become pregnant) (~32%); and patients who have undergone previous terminations of pregnancy and do not wish to have another (~28%) (data from the European PGD consortium).<sup>10</sup>

*the human being is to be respected and treated as a person from the moment of conception*

During the past decade, the efficacy of PGD has been demonstrated and the number of diseases for which PGD is available has grown. Despite this, several misdiagnoses are known to have occurred following PGD; the misdiagnosis rate is estimated to be around 2% for PCR-diagnosed recessive gene PGD, and up to 11% for dominant gene PGD.<sup>11</sup> PGD is now considered to be an important alternative to standard prenatal diagnosis using CVS or amniocentesis, although the relatively low efficiency of IVF means that PGD is unlikely to supersede the more conventional methods of prenatal testing at present. Nevertheless, the success in decreasing the rates of miscarriage and increasing the ongoing pregnancy rate by screening embryos will most probably lead to this technique being applied to a broader section of the community.

There are now at least 40 PGD centres in approximately 20 countries worldwide.<sup>12</sup> A summary of PGD procedures over a two year period and their outcomes is shown below:

|                            |                   |
|----------------------------|-------------------|
| <b>Biopsy attempted</b>    | 2395 IVF embryos  |
| <b>Diagnosed</b>           | 2086 10% lost     |
| <b>Transferable</b>        | 919 56% discarded |
| <b>Embryos Transferred</b> | 659 28% lost      |
| <b>Positive heart beat</b> | 67                |

Thus, of all the embryos undergoing PGD, only 2.8% actually result in an established pregnancy.<sup>13</sup>

## Ethical Evaluation

### *Loss of human life*

A preimplantation diagnosis cycle is a major undertaking for any couple, and the psychological, emotional, and financial costs are considerable. Apart from these substantial costs, there is an unacceptable loss of early human life arising from the overall procedure of PGD.

As shown by the figures above, a very high attrition rate accompanies PGD, with under 3% of the total number of embryos created eventually leading to a pregnancy. Over half (56%) of all embryos are discarded because they test 'positive' while almost a quarter (24%) are lost, either from the diagnostic test or during the culture process of IVF itself. Such disregard for human life is totally unjustifiable and Pope John Paul II clearly identifies the main moral issue:

"...what is at stake is so important that, from the standpoint of moral obligation, the mere probability that a human person is involved would suffice to justify an absolutely clear prohibition of any intervention aimed at killing a human embryo.....The human being is to be respected and treated as a person from the

moment of conception.<sup>14</sup>

### ***Commodification of Human Life***

Undergoing PGD, and choosing to not implant certain 'affected' embryos has major philosophical implications as well.

Perhaps one of the most important is that society seems to be increasingly supportive of the notion that in order for meaningful human life to exist, certain minimum, 'normal' criteria must be met. Accordingly, if these arbitrary criteria are not satisfied, then life is just not worth embarking on. Rather than being absolute and irreducible, there is an emerging view that many genetic conditions are worse than life itself.

***There is an emerging view that many genetic conditions are worse than life itself***

Many clinicians and geneticists believe that it is better to not implant an embryo rather than bring an 'affected' individual, such as one with Down syndrome, into the world. A survey conducted in the UK confirmed this alarming trend, finding that 13% of Obstetricians agreed with the statement:

'that the state should not be expected to pay for the specialised care of a child with a severe disability where parents had declined the offer of prenatal testing.'<sup>15</sup>

Such attitudes can not go unchallenged. Mary Johnson, a prominent disabilities activist, counters very succinctly:

'A decision to abort (or not implant) based on the fact that the child is going to have specific individual characteristics such as mental retardation, or in the case of cystic fibrosis, a build-up of mucus in the lungs, says that those characteristics take precedence over living itself.'<sup>16</sup>

Such an outlook is simplistic, superficial and fails to recognise the

inherent diversity and sacredness of life itself. How can living with a disability, however limiting or difficult, be viewed as worse than not existing at all?

### ***Unfair Discrimination***

Another disturbing aspect of PGD is the implicit discrimination against those with the disabilities or conditions being tested for. As Zimmern states:

'if PGD is used as a tool to eradicate as many disabilities as possible in society, then it does discriminate against people with disabilities: those who are already living with disabilities and those potential babies who may have lived very successfully with such disabilities.'<sup>17</sup>

Disability groups are rarely, if ever, consulted by clinicians or those couples undergoing genetic tests for that condition.

A display of negative attitudes or intolerance for anything that deviates from narrow norms should be vigorously opposed. Potential parents, and indeed society as a whole, are faced with stereotypical

### ***PGD effectively transfers power away from prospective mothers to clinicians***

information regarding disabilities.

A disabled fetus represents for parents a problem that may have more to do with society and its collective values than with disability. Disabled children, notes Alison Davis, confront a hostile environment. Living with severe spina bifida, she explains:

'...if I lived in a society where being in a wheelchair was no more remarkable than wearing glasses and if the community was completely accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely

than the fact that I have spina bifida.'<sup>18</sup>

### **Future considerations**

PGD, and its increasing application across the board, causes prospective mothers to feel guilty should they decline PGD and then discover the fetus is affected by a genetic disorder. The very fact that a test is offered by doctors tends to suggest to mothers that their use is not only warranted but desirable.<sup>19</sup> Furthermore, once the test becomes routine, as PGD is rapidly becoming for certain subgroups, this effect is exacerbated. These mothers also anticipate being blamed by others for not taking the tests now available.<sup>20</sup> All these social pressures can coerce vulnerable women and leads one to wonder whether couples can easily give *free*, informed consent to PGD.

A more worrying implication underlying the increasing use of PGD is that it effectively transfers power away from prospective mothers to clinicians. They are legally bound to consider the interests of future children they helped create. Furthermore, society is increasingly being encouraged to medicalise, or offer treatment for, conditions or behaviour previously considered normal, or at least acceptable. It is of vital importance that we, as a society, do not allow PGD, and other new technologies, to decide fundamental ethical and social questions. It is imperative that we examine ethical issues raised by PGD *now*, in order to put safeguards in place for the future. After all, shouldn't we be attempting to eradicate the *intolerance* of differences?

### **ENDNOTES**

<sup>1</sup>Handyside, A.H. *et al*, 'Pregnancies from biopsed human preimplantation embryos sexed by Y-specific DNA amplification.' *Nature* 344 (1990) 768-70

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Michael Herbert



## Advocacy in Health Care

*This article offers a brief overview of advocacy in our society. It also explores the ethical challenges that are inherent in its application.*

There are some members of our community who are vulnerable, in terms of decision-making, for a variety of reasons. This may be because they have not yet reached maturity commensurate with making certain decisions (newborns and minors).

### *family is the obvious choice to make decisions*

It may be that they have been deemed previously competent, or never competent. Family is the obvious choice to make decisions on their behalf in all aspects of their life – of which health care is only a part. But not all our vulnerable people have family available, or willing, to make decisions on their behalf, which is why the concept of advocacy is integral to ensuring that

they are not disadvantaged in terms of their interests.

### What is advocacy?

Advocacy is not a straightforward concept to describe as its meaning may change in the context in which it is assumed or applied. As a theoretical concept its description is derived from the legal system where it is used to refer to someone who pleads the cause of another. Advocacy can also be the process of achieving a common goal in everyone's interest, carried out by different interest groups, be they individuals, the community, the legal system, or the government. In relation to health, this may mean patients and their families, legal and health professionals, as well as dedicated interest groups working

together to develop programs that ensure availability and access to high-quality health care for the community as a whole. The principles involved in advocacy include *rights* (human, legal and consumer), *social justice*, *empowerment*, and *participation*.<sup>1</sup>

From an ethical perspective one can't separate the act of advocacy from the person on whose behalf it is performed. Health professionals often assume this role either by sanction or because they believe it is a subsumed role in their ethic of caring. It has also been described as being paternalistic when emphasised from a professional model of practice that assumes that one is acting in the best interests of an individual.<sup>2</sup> Advocates must exert a degree of power in the exercise of advocating on behalf of someone (or

group) deemed in need of this service. Difficulties arise when advocacy is misapplied with outcomes incongruent with the patient's wishes or the supposed *best interest* principle.

## Principles that guide Advocacy

*Best interest* judgements have been used in medicine for decision making on behalf of the never competent and the previously competent, especially where their prior preferences cannot be determined. These are value-laden decisions, which may be dependent on the assessor's view. These views, in turn, may conflict with the views of others. *Advance Directives* allow some scope for autonomous and previously competent people to make known their preferences in regard to end-of-life care, use of medical technology and health care.

### *medical or treatment cannot be given without valid consent*

*Substituted Judgements* attempt to reach the same decision that the previously competent would have made when still competent – that is, respect for autonomy. However, these judgements made by proxy decision-makers have the potential to create ethical dilemmas in cases where decisions are made for individuals who have never been autonomous eg, newborns, infants, and the never competent.<sup>3</sup>

When seeking health care, individuals are expected to make their own health care decisions with laws and policies on informed consent protecting this autonomous right. Exceptions occur when competence is questionable. In these cases guardians and advocates may be used as substitute decision-makers. Problems can occur when health care providers believe that court appointed guardians lack insight into the particular situation, and question the decision made by the guardian. This may lead to legal recourse to override contentious decisions, especially when both parties argue that they are acting in

the patient's best interest.<sup>4</sup>

## Who makes decisions for those who cannot?

Who should make decisions when there are no advance directives in the previously competent and the never competent? The role of the decision-maker brings privileges with it and denotes a degree of power differential. Any relationship like this has the potential to be abused by either party depending on what each seeks to achieve. Beachamp and Childress propose a list of qualifications for those making decisions for incompetent patients: 'ability to make reasoned judgements, adequate knowledge and information, emotional stability, and a commitment to the incompetent patient's interests that is free of conflicts of interest and free of controlling influence by those who might not act in the patient's best interests'. Even applying these criteria is value-laden, because decisions on the capacity of a person (or organisation) to be the appointed advocate must also be made.

## Advocacy in Victoria

The Victorian Medical Treatment Act of 1988 provides for the appointment of an *Enduring Power of Attorney (medical treatment)* which comes into effect if the patient becomes incompetent. The Guardianship and Administration Act of 1986 allows an appointed agent to make decisions for another person who is not capable of making them for themselves. Medical or dental treatment cannot be given without valid consent, which is of concern for patients who cannot consent. This Act allows for someone called a *person responsible* to make medical or dental treatment decisions, but does not permit consent to withdraw treatment. If there is no *person responsible* known, or available, practitioners can proceed with treatment if they believe the treatment is in the best interests of the patient.<sup>5</sup>

The Victorian Civil and Administrative Tribunal (VCAT)

Guardianship List appoints guardians who make personal and lifestyle decisions, subject to limitations or plenary orders which allow all lifestyle decisions, except health care where there is an existing *Medical Enduring Power of Attorney* or a *person responsible* for people with a disability.

Its role is to protect the interests of

### *what harm is inflicted from the consequences of bad advocacy decisions?*

adults who are incapable of making reasonable decisions, with the Office of the Public Advocate (OPA) acting as advocate on its behalf. The adults referred to include people with intellectual disability, mental illness, brain damage, senility or physical/sensory disability. The Guardianship and Administration Act 1986 details the extent of authority of a guardian. It refers to the *best interests* of the represented person to participate as much as possible in the life of the community. Advocates must act in such a way as to protect the represented person from neglect, abuse or exploitation, and respect the wishes of the represented person.<sup>6</sup>

## Advocacy is not paternalism

Kottow suggests that paternalism has been dominant in medicine and values like autonomy and beneficence have been miss-assigned to the detriment of patient well-being - the belief being that it is acceptable to disregard a person's views in favour of promoting their health.<sup>7</sup> Johnstone suggests that people are denied equitable access to the quality and quantity of health care they need, the opportunity to make informed choices, and are harmed because of questionable practices in health care provision.<sup>8</sup>

Helping patients and families make decisions about curative to palliative care choices, and end-of-life decisions, may be interpreted as paternalism or even coercion by some. Another aspect, as suggested

by Galbally, is the idea that 'healthism' pervades our society along with a view that 'the health system should never let us die'.<sup>9</sup>

## Advocacy is not always good

Advocacy does not always protect the rights and interests of the people it intends to assist. We are subjected to media reports about individuals' denied some rights, or their autonomy disrespected, or their capacity over-ruled, by people or organisations in positions of power which allow them to do this. Public outcry sometimes over-rides these decisions and 'rationality' is restored. However, for all the bad advocacy that is publicised, it may be assumed that much more goes unnoticed. What harm is being inflicted from the consequences of bad advocacy decisions? In relation to popular bioethical principles 'bad' advocacy may directly contradict the principles of justice, beneficence, non-maleficence or respect for autonomy.

## Advocacy in Aged Care

Most people do not choose residential care for 'social' reasons. They do so because of chronic medical conditions and permanent disability. Federal government age and disability policies aim to provide services that enhance the quality of life for consumers, with the right of older people and people with disabilities to be supported in their own homes and communities encouraged.

The Victorian government also seeks to help older people live independently and remain connected with their families and their communities for as long as possible, as promoted through its *The Age to Be* document, citing that most seniors live at home (93%) with only 7% requiring residential care.<sup>10</sup> *The Code of Ethics for Residential Aged Care* aims to protect the frail and aged in care. It also specifies that the competent be self-determining.<sup>11</sup> Health professionals

have a duty of care to report cases of substandard or dangerous practice in these areas.

## Advocacy in Mental Health

Specific issues may relate to a moral dilemma between respect for autonomy and beneficence. The use of competency tests cannot be divorced from the ethical dilemma that is intrinsic to these. Paternalistic arguments favour decisions that go against the will of the person perceived to be making an irrational choice.

### *in quality of life decisions, the best interest principle is proposed to guide advocate decision making*

There is potential for other value-laden opinions to burden an already problematic choice. An example of this is when a severely depressed person makes a decision to refuse potentially life-saving surgery in preference to palliative treatment. Over-riding what is perceived to be a mentally irrational choice and performing the surgery is an example of strong paternalism. Many would see this as the preferred option, especially since severe depression is amenable to treatment. In supporting this model there may be a legitimate loss of autonomy.<sup>12</sup>

## Advocacy in the Care of Newborns

Newborns comprise a special client group given that surrogate decision making is inherent in all aspects of their life. Newborns and infants do not fit within the usual advocacy conditions given that they have never been autonomous, and decisions are made subject to considerations of their 'potential interests'. In quality of life decisions, the *best interest principle* is proposed to guide advocate decision making. In intensive care settings conflicts can arise about the rights of parents and the rights of the newborn.<sup>13</sup> An extreme example of

this may occur, for example, in separating vital-organ sharing conjoined twins, when it is foreseen that in doing so, at least one of them will die.<sup>14</sup>

## Should Health Care Professionals act as advocates?

Is there a case for doctors or nurses to take on an advocacy role? They may do so out of their deeply ingrained ethic of care. Both the Australian Medical Association (AMA) and the Australian Nursing Council (ANC) respective Codes of Ethics, make reference to respecting a patient's right to make their own decisions about treatment or procedures.<sup>15</sup> It has been suggested that giving doctors official status as advocates could increase their justification to act paternalistically. So then, are nurses better for the role? Nurses' role as advocate is unclear and seen by some as controversial.<sup>16</sup>

Nurses, like doctors, may have conflicts of interest with potential to create discordance over issues, especially if asked to advocate for controversial choices. Yet they assume the role in the belief that they act in the patient's best interests. Exposing problems in practice, referred to as *whistle-blowing*, has become a contentious issue with polarised views on whose rights are being exploited or abused, and whose practices (or non-practice) are being exposed.<sup>17</sup>

## Conclusion

Advocacy literature is subject to jargon. One can talk about individual advocacy as opposed to systemic advocacy. How might the concept of global advocacy fit in the picture? If parts of the world are intent on conquer and rapine, with consequences of whole societies disenfranchised or subject to 'cleansing' and their right just 'to be' negated, how can this be separated from individual rights and systemic rights? In Australia, the welfare system is protective of

individual rights on the one hand but sanction some practices which are transparently coercive (eg some mental health practices). We value democracy. Yet, paradoxically, our performance in terms of 'human rights' advocacy is questionable, especially in regards protecting our children, addressing the issues of indigenous health, and meeting the health care needs of asylum seekers.<sup>18</sup>

Advocacy is a worthy position for health professionals to support as long as their limitations are recognised. Paternalistic practices disguised as acts of advocacy should be exposed and the coercive care mentality pervasive in some health practices discouraged. *Best interest* judgements should guide decision-making, as long as the right of a patient to be self-determining, whenever possible, is respected.

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