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Abortion – Informing the Debate

The induced abortion debate is polarised, with the taking of nascent life often pitted against a woman's right to choose. There is often a lack of thoughtful discussion and a dearth of reliable figures so necessary for an informed debate. While it must be stressed that abortion involves deliberately terminating the life of an unborn child, it is misguided to simply condemn women who choose to abort. Alternative ethical decisions can be actively encouraged to support women carrying to term.

Overview

Throughout Australia, the Commonwealth Health Department has estimated the annual number of abortions to be between 70,000 and 90,000.¹ That translates to a ratio of one abortion in every four pregnancies, which is fairly low by international standards, with the US at 30%, while countries such as Bulgaria have recorded abortion rates of over 50%. However, it means that about one in three Australian women will undergo an abortion, making it one of the most common surgical procedures in the country.² The private sector provides terminations up to 18 weeks gestation while public sector services are available up to 20 weeks gestation or 22 weeks for foetal abnormality.³

Statistics

Health Insurance Commission (HIC) figures showed the number of Medicare funded abortions fell from 76,846 in 1997 to 73,191 in 2004.⁴ In Victoria there were 18,514 abortions carried out during 2002 and 2003.⁵ Abortion is not confined to one group – all socio-economic backgrounds, religions, races, levels of education and vocation are represented.⁶ Information obtained under the Freedom of Information Act reveals that in Victoria, more women aged 20 to had a termination at a rate of 2.8%. This was followed by those aged 25 to 29 (about 2.3%) and 30 to 34 (1.8%), although abortions were performed on at least two 12 year olds and more than 47 girls aged under 15 in Victoria.⁷ In 2002 and 2003 approximately 5% of abortions took place between 14 and 19 weeks into pregnancy.⁸ Evidence from Victoria suggests that the proportion of late-term abortions (ie. pregnancy beyond 20 weeks gestation) is very small,⁹ with around 600 being performed annually over the last eight years.¹⁰ In recent years the most common reason for late termination was the diagnosis of fetal abnormality.

Although the HIC collects data on medicare funded abortions, they cannot report on privately funded abortions nor do they collect data on publicly funded abortions in public hospitals. This is significant as it is estimated that a quarter of all abortions in Victoria are performed in public health facilities. A further complication is ambiguity in the medicare numbers used to itemise the procedure. Items 16525 and 35643 may result in abortions; however, descriptions of the procedures makes no moral distinctions. For example, no.16525 is simply management of 2nd trimester labour, *with or without induction*. The procedure may be carried out following miscarriage or to terminate a pregnancy. Any numbers or rates are therefore at best estimates, regardless of source.

The need for an informed debate

The National, Liberal, Labor and Democratic parties all

INSIDE THIS ISSUE

Abortion – Informing the Debate	1
Unhappy Children – Disorder or Defence	4
Highlights of Brian Pollard's Views on Palliative Care	7
Benefits and Burdens of 'Routine' Antenatal Screening	10

agree that the number of terminations in this country is too high. All seem to agree with National Senator Boswell that 'if we're going to have a debate on these issues I think we've got to get the correct information out.'¹¹ Parliamentary Health Secretary Christopher Pyne has called for abortions to be banned beyond 21 weeks and Special Minister of State Eric Abetz suggested limits to Medicare-funded terminations.¹² Boswell has also said: 'Abortion is a serious issue, whatever your ethical position, and authoritative information is absolutely essential to an informed debate.'¹³ Even proponents of abortion, such as James King, chairman of the Victorian Government's consultative council on obstetric and pediatric mortality and morbidity, supports better data collection.¹⁴ However, Premier Steve Bracks has refused to supply further information on state abortion statistics,¹⁵ and South Australia is the only state to make such information publicly available. It is good to have this public debate as it makes everybody more aware of what is involved in abortion, how it impacts on the pregnant woman as well as the loss the lives of so many unborn children in Australia.

Reasons

Reasons given for abortion vary greatly and the decision process is often complicated. What has been missing from the current debate on abortion is a real examination into the underlying reasons women choose to have the procedure. It is never an easy choice and yet this aspect is often ignored. Why *do* so many women choose to terminate today? Past studies have shown that 80% of women who have an abortion may well not have done so had they been better supported through difficulties arising from an unwanted pregnancy. Lack of counselling, no paid maternity leave, lack of sufficient childcare, and other financial burdens were all factors that contributed to their decision.¹⁶ Reluctance to be a single mother, interference with their education and/or employment,¹⁷ and pressure brought to bear by partners, friends or family are also reasons given. But while the predominant reasons are social pressure (57%) and financial limitations (28%), terminations are also 'sought after rape, incest, severe psychological trauma, or to save the mother's life.'¹⁸

Long term sequelae

Abortion does not solve all problems, but may in fact bring new ones. Numerous studies have shown that women are more likely to experience negative outcomes when the decision to abort was not freely chosen. Emotional problems including guilt, grief, depression and anxiety can result when pressure, whether by partners, family, counsellors or clinicians, is brought to bear on pregnant women to terminate.¹⁹ It has been documented for some time that women who terminate pregnancies commonly experience periods of distress and trauma. Psychological sequelae are primarily due to the inability

to cope with an unwanted pregnancy. They often include symptoms such as acute grief, depression and feelings of guilt. Furthermore, long-term sequelae occur in around 10% of cases, rising to 20% where the women terminated a previously wanted pregnancy following detection of fetal abnormalities.²⁰ The risk of harm is more prevalent in younger women, those with poor social support and those who come from cultural groups opposed to abortion.²¹ Although not always present, these downstream effects of induced abortion are not readily acknowledged in the debate on abortion.

Unified support for reform

Leaders of many religions have also voiced their concerns about the rate of abortion in Australia. An unprecedented recent meeting of religious leaders called for restrictions on late-term abortions, greater awareness of alternatives, and better information given to pregnant women by federal and state governments. The breadth of representation was impressive: Anglican, Catholic, Baptist, Presbyterian, Assemblies of God, Buddhist, Greek Orthodox, Hindu, Islamic, Lutheran, Mormon, Sikh, Salvation Army, and Wesleyan representatives all attended the meeting.²² All agreed that the government should remove the profit incentive from private clinics that do late-term abortions. They further suggested that the procedure be restricted to public hospitals where tighter controls and ethical reviews can be implemented.²³ 'For the first time in this country religious leaders have gathered to declare their opposition to abortion and to call for something better for women and their babies.'²⁴

What's needed – effective ethical education

A National Health and Medical Research Council (NHMRC) paper noted it was unlikely that there will be a significant reduction in demand for abortion services among young people without a major change in sexual behaviour and/or major technical developments in contraceptive methods.²⁵ However, greater support services for pregnant women who want to carry to term, but are subjected to grave financial or emotional burdens, may well offer a moral alternative to termination. While not wishing to promote fatherless families, it would be good to support single pregnant women and thereby reducing the number of abortions.

No doubt effective and ethical education would help reduce the number of abortions. The objectives and methods of some education campaigns are subject to constraints arising from different ideological and moral views reflected in the community. But there is no justification for excluding from Government funding educational programs which are inspired by the principles of Christian morality and designed to prevent abortion. Educational programs should help the young to under-

stand their own worth and dignity as persons, be permeated with a Christian vision of human sexuality and should not conflict with parental rights. Relevant facts may be provided if they are designed to suit students' stage of development and maturity. Knowledge of facts alone is insufficient to prevent abortion. Respect for one's sexuality is respect for the person. The ideal of virtue, including chastity, should be inculcated.

John Howard recently said that 'a greater understanding of the implications of sexual behaviour...can have an impact on the abortion level.'²⁶ The young should be informed of the implications and likely consequences of their behaviour in a way that does not appear to condone immoral acts. Often even highly resourced programs do not mention or promote abstinence and never discuss the serious emotional issues emanating from sex and intimate relationships. Risks of pregnancy apart, educators could not advocate the use of contraceptives or condoms for premarital sex without being seen to condone sexual immorality. Religious schools should adhere to programs approved by their respective Church authorities. Urgent action is needed because many teenagers are entering into sexual relations earlier than in previous generations. Nobody desires to have an unwanted pregnancy. An ethical, comprehensive educational program should reduce the likelihood of this occurring. Young people may well not realise what they are becoming involved in, and this may be one of the reasons why sex education is still failing adolescents with disastrous consequences.

What's needed – a change in attitude

A change in attitude is also sorely needed in our society. Today, many young mothers are looked down on. They ought to be praised for making a courageous decision to carry to term, particularly in the current climate. Undue pressure is brought to bear by friends and family to terminate, with the obvious implication that it is easier to terminate than to carry to term today. And in practical terms this is often true. What real choice are 'pro-choice advocates' standing for if options are so heavily weighted in one direction?

We could do well if both young mothers and fathers are encouraged and supported much more, both emotionally, financially and otherwise. Many face hardships but these are often societal in origin. While giving birth when young is associated with lower levels of education and employment, this need not be the case. With better support there is no reason why mothers, whether young or not, have to experience such disadvantages. Perhaps greater services could be made available to them and their babies. For example, HECS fees could be waived, or free childcare could be provided on-campus to those women in need. This may be seen as radical to some but why not encourage and provide helpful alternatives? Women ought not be forced into a position where it be-

comes difficult to make an ethical decision.

The Catholic Church in Scotland established a positive initiative in 1997. Pregnant women of any religion, race or background were offered assistance to help them carry the baby to term. As well as counselling and emotional support, women were also offered help in navigating the social welfare system and even in some cases financial support. If we as a society are genuinely concerned about the high rate of abortion in Australia, we should endeavour to offer alternatives. Centacare, the Catholic family service, offers pregnancy counselling services regardless of race or religion. Their counsellors offer confidential advice about adoption, social security entitlements, legal issues, community support services and even where to obtain baby clothing and equipment.²⁷

Conclusion

It is quite clear that there are many ways in which we can reduce the current number of abortions in this country and we ought to do this relying on the best evidence available, looking carefully at the needs of women and taking a national approach to this problem.²⁸ Greater care and assistance needs to be extended to support pregnant women, regardless of their circumstances. And further research is also needed; in particular, the reasons why women chose to terminate, and data about their age, education, income and level of support need to be examined. Surely it would be better to know these things if we as a society want to effectively help pregnant women become successful mothers. At the same time, the message given by society to pregnant women and mothers ought to be positive.

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Unhappy Children - Disorder or Defence

There is increasing evidence suggesting that children are not happy. Is unhappiness a disorder that needs a remedy? Children and young people are usually passive and trusting recipients of these remedies, since many are powerless to resist and probably would not, even given the capacity to do so. Why should children be sad? Children through the ages have been the unwitting victims of society's mores, empire building, cultural experimentation and more recently, genetic manipulation.

Worry and depression in children is common

Mental health disorders account for nearly 12% of the global burden of disease and is maximal in young adults, the most productive section of the population.¹ In Australia, mental health and behavioural problems are the major burden of disease for young people aged up to 24 years.² A recent report from America stated that for the first time, spending for psychotropic drugs has exceeded the cost of antibiotics and asthma medications for children under the age of 19 years.³ This trend is emerging in Australia.⁴ Indeed, like so many other aspects of life, a market has been created to treat mental health disorders that have emerged since the medicalisation of behaviour and mood.

Worry seems to be common in children aged between 8 and 13 years with a minority exhibiting pathological variants of worry and depression.⁵ Infants can even be shown to be suffering depression, with a link to later developing Attention Deficit Hyperactivity Disorder (ADHD) postulated.⁶ The neurobiology of infant attachment is said to effect brain development. Adverse early life experiences may predispose the child to exhibit depression.⁷ Research has shown an association between a childhood history of anxiety disorder or major depression with later multiple suicide attempts and personality psychopathology in adulthood.⁸

Depression risks and consequences

Besides individual and peer factors, the generic risk factors for children becoming depressed include exposure to social disadvantage and economic deprivation, as well as impaired parenting and family conflict.⁹ A history of vic-

timisation and poor social relationships may predict the onset of emotional problems such as depression in adolescents, particularly girls.¹⁰ There is also evidence that children with depression may base their conceptions of happiness and wellbeing in relation to goal choice. That is, they see their happiness as an end-point of achievement or acquisition.¹¹

Whatever the reason, the increase in the prevalence of mood disturbances in young people is unlikely to change in the short-term. Investing in means to minimise the effects of depression and proactive changes to prevent the onset of depression is urgently needed. The long-term consequences of unrelieved anxiety and depression may be detrimental to a young persons adult life.¹² Debate continues over the evidence to support the theory that stress begets illness. Certainly some recent research suggests that this can be borne out with older people.¹³ Other research shows that adolescent stress and depression may impair immune status.¹⁴

Unfortunately, many of the known risk factors are not easily amenable to change, such as socio-economic disadvantage, unless a complete cultural revolution occurs which ensures all people are equal. There are physiological factors which may also prohibit change. For example, the age a child reaches puberty can be associated with the child's mental status. For example, early maturing females and late maturing males are at greater risk of developing some psychopathology in early adulthood.¹⁵ On the other hand, adversity in early life may be a factor in young girls maturing earlier than their forebears.¹⁶

Being sad can be helpful

Westerners might be trying too hard to fix normal variations of life that don't need fixing. Humanity has proven its resiliency by its progress thus far despite periods of natural and manufactured cataclysm. Indeed low moods can be protective in some situations, such as allowing a person to disengage from unproductive efforts, as a way to cope with unpropitious situations and giving freedom to move onto something better.¹⁷ For example, it is proposed that a woman's capacity to experience emotional responsiveness once had evolutionary advantage as some sort of survival mechanism.¹⁸

The rise and rise of interest in children's well-being

There was a time, generally speaking, when childhood was less distinct from adulthood and some families regarded their children as mere chattels that could be traded, sold, or worked for the family's economic or political advantage.¹⁹ Whilst it is certain that many children over the ages have suffered because of their circumstances, nurturing children's mental health was probably not a priority given the certainty that many children would not outlive their childhood. The modern world, however, is very considerate of children's basic human rights and seeks ways to determine, preserve, recover or enhance children's physical and mental well-being. Paradoxically, efforts expended in striving to attain this well-being may in fact be jeopardising a child's health in other ways. Children may be developing depression because of the pressure to achieve.²⁰

Our modern lifestyle makes it difficult to ignore technology, which virtually brings the reality of strife, terror, hunger and poverty into our private lives. For much of the world's population these are lived realities with the drive for basic survival paramount. In Australia, survival is not so much a basic urge, but there are other dilemmas which burden our youth. In particular, the enticing and elusive lure of a shallow, exploitative and commercial material world which values idealised attributes, such as beauty and wealth, disregarding those who lack either or both.

Certainly, there are marginalised groups of children in Australia, who are burdened with poverty, homelessness, institutionalisation, detention, abandonment or abuse over which they have no control. Some amongst these groups will be resilient but many will perpetuate the cycle that marginalised them in the first place. Efforts to reduce inequality would surely reap generational benefits, both for the economy and humanity. Whilst governments can't fix all the problems they have the power to increase funding to mental health services generally and those targeting young people specifically.

Managing the sadness epidemic

Cognitive-behavioural treatment (CBT) of children and adolescents with anxiety and depressive disorders is currently the treatment of choice.²¹ The problem with this is that such treatment is labour and resource intensive, access is inequitable, and the benefits may take time to accrue. Hence the trend to treat children with pharmacy products, despite their known and unknown risks.²² Whatever treatments are used there is also the problem of accessing appropriate health services and the ability to pay for some treatments. Servicing the mental health needs of children is an example of the phenomena known as the inverse care law - that is, those most in need, such as the marginalised groups mentioned previously, are less likely to access or receive services.²³ This breaches the bioethical principle of justice.

Whilst the advent of living in a truly equal society seems unlikely, it doesn't exclude efforts to minimise the effects anxiety and depression have on children. Unfortunately there are treatment controversies in the child mental health area, which is ironic since so much effort has been invested in medicalising variations of mental health states in the first place. It is imperative, however, that the best interest of the young person should be considered in treatment choice, especially with evidence that mood disorders may have long-lasting brain effects which demand that early identification, prevention and treatment are important.²⁴

Eliminating sadness is an ethical dilemma

The search for genetic markers for sadness and depression is gaining momentum as evidence of links between certain genes and depressive disorders mounts, although such associations have been hypothesised for many years.²⁵ Whilst conclusive evidence is lacking, the potential to be screened for genetic markers for depression is looming, with all the ethical implications this entails. Will a potential risk for sadness be another excuse to deny certain people eligibility to be born? If humanity has remained viable despite an inability to be constantly happy, how will a society without the propensity to feel sadness survive? Whilst this is unlikely, since humans are more than their genetic make-up, it is worrying that some sectors of society believe that it would be useful to know in advance if one is likely to be depressed later in life. Might knowing that a risk exists precipitate a self-fulfilling prophecy of depression?

The power of social capital and resilience

Family can be a powerful physic. Unfortunately there are many children and young people that lack 'family' in both its literal and figurative sense. Loving and supporting parents are often necessarily and busily engaged in work and social commitments. Like many children, parents too are

under pressure to achieve. Many struggle to provide basic needs. The average family size has fallen over time, which may effect the capacity for a child to engage in play activities with other children. There are numerous early intervention schemes and initiatives to strengthen and support parents, even encourage families to have more children. Yet many of the risk factors for depression are extrinsic to the individual, for example, poverty and discrimination.

Of course, it would be irresponsible to assume that young people lack capacity to be happy and healthy without intervention. Research shows that resilient youth withstand the effects of early adverse life events because they receive guidance, support and supervision by their parents and live in higher-functioning families.²⁶ The concept of developing social cohesion and capital as a means to improve mental health is a popular movement.²⁷ Efforts to enhance, generate or provide surrogate sources of this support for those who lack them may do much to prevent or minimise the harm associated with depression during childhood.

Opinions may vary about whether sadness is a disorder or a defence mechanism. The answer is probably spread throughout the nature versus nurture debate. There have been major social changes in the last hundred years, which have transformed the concept of family. Children and young people are no longer pawns or possessions. Tailored efforts to alleviate or eliminate sadness, anxiety and depression in the individual child is a worthy objective because of the ongoing health and societal benefits for the rest of their life. Making many risk factors for depression redundant through social and economic reforms would benefit humanity.

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The Symposium on "Stem Cells, Research & Ethics" on February 23, 2005 was well received. See attached flyer for information concerning the Centre's book "*Stem Cells, Medicine, Law and Ethics*".

Highlights of Brian Pollard's Views on Palliative Care

*In this article I wish to briefly present the highlights of the significant and valuable insights on palliative care for health professionals published by Brian Pollard MB BS(Syd), DA (Syd) FANZCA. GradCertBioeth in his excellent book, *The Principles of Palliative Care. An Introduction*.*

What is palliative care?

Dr Brian Pollard begins his book with a brief account on the emergence of palliative care resulting from the dedicated work of English social worker Cicely Saunders.¹ She became a nurse and then a doctor before founding St Christopher's Hospice, which opened in London in 1967. Pollard then explains the meaning of palliative care quoting the World Health Organisation's definition of palliative care as 'the active care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life of patients and their families. Many aspects of palliative care are applicable earlier in the course of the illness in conjunction with anti-cancer treatment. ... Palliative care affirms life and regards dying as a normal process ... it neither hastens nor postpones death'(10). He notes that palliative care is not restricted to the last stages of the care of the dying. It is then a part of medical treatment in general. Although it employs low technology, it can be labour intensive (11). He rightly says 'when patients cannot be made better, they must be helped to feel better'(12). While palliative care has been traditionally provided in hospices, it is now provided in general hospitals - some with special wards, and also in the community, as an outreach service of a hospice or a hospital. In rural areas it has proved its worth with trained nursing teams working collaboratively with general practitioners.

A team approach is essential for palliative care, with trained nurses having most contact with the patients, thereby providing most of the care and valuable observations for doctors and patients' families. Nurses know their contribution is significant because they often see immediate results in improved patient outcomes (15-6). Palliative care differs from other nursing care because the incurable and progressive nature of the illness seldom allows thoughts of foreboding death to be absent for long. Symptom control and comfort care are the number one priority. This means patients' preferences and views need to be sought since the relationship with their carers is more of a partnership than 'that of an expert and client'(17).

Control of physical symptoms, especially severe pain

Truth telling is as important in palliative care as it is for other medical treatment. Doctors may need to elicit the truth carefully from their patients as they may be inclined to exaggerate or understate their degree or type of pain due to their condition. 'What is pain for one is discomfort for another'(19) Doctors also should reciprocate by telling their patients the truth in order to develop mutual respect between themselves and their patients. Patients should know that in about 97% of cases, with proper treatment, pain need not remain disablingly severe. It would be inhumane and unnecessary today to prescribe the period of time between doses of analgesics so long that patients in chronic pain are left to suffer pain before the next dose is due. Referring to severe pain, Pollard says that 'traditional medical fears of overdose, tolerance and addiction ... and their likelihood become insignificant in importance when contrasted with the alternative outcome, namely that of under-treatment'(23). Severe unrelieved pain in patients with reduced life expectancy should be viewed as a medical emergency that needs immediate treatment.

When pain cannot be reduced even by the intervention of an expert in pain control, terminal sedation may be worth initiating, provided the usual analgesics are given, sedation is just sufficient to induce a light sleep and the patient agrees after a clear explanation has been given. Upon waking, the patient could indicate whether, and when, such sedation should continue for pain relief.

Control of emotional symptoms, such as fear and anxiety

The ignorance of patients about their illness or the possibility of relief of pain may be the cause of fear and anxiety. At times it may be necessary to ask questions of patients to see if they have a correct understanding of the significance of their ailment. A doctor may know a patient's fears are groundless, but they are real for the patient and should be taken seriously. A patient, without saying a word, may really be consumed with dread for cancer, when in fact the cancer is non-existent. Listening is important to discover what are the patients' real fears so that they may be allayed. Other patients may worry about the effect of their illness on family members or their conflicts of opinion about their illness or even what some patients

falsely believe to be unresolved old family quarrels. Once concerns or issues are suspected, teased out and raised to the surface, adequate remedies can usually be found.

Drugs may alleviate physical ailments but not emotional anguish, spiritual problems or the lack of an understanding of the very meaning of life and ultimate human destiny. Empathy and support are always helpful for these kinds of suffering, but it may be up to others like social and pastoral workers or chaplains, not doctors, to provide directly the required support by way of human understanding, sympathy, counselling or spiritual advice. Successful outcomes in palliative care require the collaboration of a skilled team to identify the real causes of patients' suffering before their significance for patients can be grasped and then be satisfactorily resolved. Pollard says 'the warning of Cassel, an expert on suffering should never be forgotten 'the sick person is seen as a well person with a disease' when in reality he is better viewed as 'qualitatively different, not only physically but also socially, emotionally, and even cognitively.'(28). It sometimes seems that a dying patient's autonomy is intact but in fact it may not be. Pollard comments: 'Decisions or wishes of these patients which are out of character for them should not therefore be routinely accepted at face value, but need to be thoroughly tested by every means possible' (28).

Effective communication

Health professionals need to actively seek the information they need to understand the patient's condition and fears, and in plain language tell family members what they need to know. While patients' preferences should be respected, health professionals should protect patients against the consequences of choices that would obviously be contrary to their own best interests (30). As Pollard rightly says: 'The factors that will maximise a patient's chances of a successful outcome do not include who decides the treatment, but depend on that decision being the best in the circumstances, followed by the most competent delivery of that treatment (29).

Honesty

It is important to always remember that patients have a right to know the truth about their condition, especially as they approach the end of their lives. It may usually be presumed that this information may be shared with family members, unless patients ask for it to be withheld. At times communicating the full truth may be counter-productive if patients are unable able to cope with it for the time being. The full truth told all at once and at the wrong time could cause as much as harm and anguish as saying nothing. While most patients questioned when they are well, say they would want to be told the full truth if they were dying, some dying patients who 'are strug-

gling with what may have recently overturned all the usual certainties of their life' (31) may find the burden too much. It is the dying patient who needs to be respected in relation to the degree of truth telling, without however, deliberately lying to deceive them.

Family, social and cultural issues

Family members may tend to forget their loved ones earlier in their life, but they are very concerned with their care during their dying stages and after death has occurred.. They do not forget perceived insensitivity or neglect in nursing or medical care of the deceased (35). Family carers of the dying are often full time workers who do not spare themselves in attending to the needs of their dying relatives. In doing so, they may even neglect their own health and wellbeing. Health professionals need to keep an eye on the health of these relatives and counsel them accordingly. Family members who are caring for a dying relative at home need to be guaranteed that their relative can be readmitted to their hospice or hospital should this become necessary.

In some cultures, family members are regarded as the dying person's primary carers. They expect doctors to report to them directly and not to the patient. In such cases, it is necessary for health professionals to clarify the wishes of their patients . They need to find out if they wish to abide by their family's traditional culture in relation to their health care, or to have their autonomy respected like other members of the community in a western culture, i.e., to be treated as an autonomous patient for all relationships with their health professionals (36).

Personal , religious and cultural traditions need to be respected in relation to modesty, religious practices and last rites. Christians may wish their minister of religion to be called. Catholics in particular would like to have their priest called for the administration of the last sacraments while they are still conscious. Traditional Jews usually do not wish to be told of a bad prognosis. They do not accept the deliberate performance of any act to shorten their natural life. Traditional Moslems see it as wrong to struggle against dying: death is to be accepted as God's will. After death, only Moslems are to handle the body which is to be buried and not cremated. The custom is for burial to take place as soon as possible and this may preclude an autopsy. As far as possible, health professionals should respect these traditional Islamic requirements.

Dying with dignity

Pollard takes the dignity of human life to mean 'intrinsic worth or value'. Ethics requires the life of each human being to have supreme and equal value. In this same sense, palliative care proclaims the 'affirmation of life'(39), regardless of the situation or the quality that a particular life may happen to be at a given time. Human

dignity demands respect and that the dying 'are valued, their suffering is relieved, their wishes are sought and respected and they feel sure they will not be abandoned'(39). Pollard comments that nobody destroy someone who is valued (40).

The law and medical decisions near death

Pollard holds that adherence to Australia's laws will generally result in a satisfactory outcome. The following statements sum up his sound legal positions:

'Every competent, informed, freely-choosing patient has a right to refuse treatment, except for suicidal motives, even though it is sustaining life.

Criminal and civil liability for withholding or withdrawing treatment will not arise if a fully informed patient refuses the treatment.

A doctor may not do anything to put a patient's life at additional grave risk, except with the person's consent, and/or for a grave reason.

A doctor is not obliged to provide, or continue to provide, treatment which is excessively burdensome, or is unwanted, or has no reasonable prospect of providing a benefit to the patient, that is, is not reasonable treatment. Such treatment is medically futile, and may be defined as treatment which has no recognised capacity to cure the illness, to restore function or to relieve distress adequately, now or in the future.

Doctors incur civil or criminal liability if they deliber-

ately withhold or withdraw treatment which they have a legal duty to provide, that is, treatment that is appropriate in the circumstances and is not medically futile in terms of the definition above.

Where doctors are not under any duty to treat, recognised by the law of homicide, their failure to save or prolong life will not be regarded as the cause of death.

Where doctors do not continue futile treatment, even when they know that the patient will die if it is not continued, they will not be regarded as in breach of their duty of care.'

Conclusion

Throughout his book Brian Pollard shows his deep respect for all patients, but especially for those in their dying stages. His published insights demonstrate his own dedication to the humanity and dignity of patients until death comes. They are always seen as valued members of families with whom they share a religious faith which should always be respected. Because Dr Pollard's book is now out of print, it is hoped these highlights will help health professionals and others to appreciate his practical wisdom and advice for the loving and expert care of the dying.

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¹ Dr Brian Pollard, *The Principles of Palliative Care. An Introduction*, Sydney: published by Brian Pollard, 2002, 6-9. Hereafter references to this book will appear in the text.

Benefits and Burdens of 'Routine' Antenatal Screening

With the increasing arsenal of antenatal screening technology available today, many parents are faced with difficult decisions or months of worry about the welfare of their baby due to unexpected findings. The role of antenatal screening can be confounding rather than comforting for many confused by what they believe is routine care. The limits of what is considered normal keeps narrowing. What is considered a minor variance or a major anomaly seems to be merging. And, society seems less tolerant of any differences.

What is Screening?

Firstly it is useful to consider what the aim of screening is. Generally it is the practice of offering a test or investigation to apparently healthy individuals in order to detect unrecognised disease or its precursors, with the intention of improving the outcome for individuals identified in this way.¹

Antenatal screening and testing

Antenatal screening can be done for both maternal and foetal reasons. Antenatal screening and testing can be

classified as non-invasive or invasive. The former includes urine testing, various blood tests, ultrasound, Doppler scans, and foetal monitoring, as well as screening for domestic violence and depression. Invasive tests, such as chorionic villus sampling (from placenta), amniocentesis (from the fluid around the foetus), and cordocentesis (from umbilical cord) may pose a risk of foetal loss from the procedure.² New screening tests for genetic disorders are being developed, such as testing foetal cells trapped in the mother's cervix early in pregnancy,³ and a blood test that can isolate and then screen for chromosomal abnormalities in foetal cells found in maternal blood.⁴ Three and four dimensional ultrasound technology is being used to detect foetal anomalies and monitor foetal behaviour.

(3D looks like a photo and 4D looks like a video).⁵

Pregnant women are usually screened for gestational diabetes, pre-eclampsia and certain infectious conditions. If the screen ultimately leads to a positive diagnosis, there are effective treatment or management options for that woman. Screening for foetal conditions, however, can raise ethical challenges. Many parents and health professionals consider foetal screening as a tool of reassurance that a foetus 'is normal'. However, the aim of screening is to seek abnormalities in order to act on that information. It is argued that it is cheaper to prevent the births of individuals with certain genetic disorders than to care for them so that screening for these disorders is held to be justified. Terminating a foetus with a proven or suspected abnormality is considered a form of 'prevention'.⁶ Though this kind of ethic is not applied in all maternity care.

Whilst antenatal testing is reassuring to prospective parents if given appropriate counselling and ongoing support should a foetal anomaly be found, as is the practice of some maternity care providers, such as Catholic health care, it is not always the case elsewhere. Indeed it is reported that at all stages of screening, counselling is systematically biased toward encouraging women to take up the screens and tests and have an abortion if an abnormality is detected. The literature suggests that the primary purpose of antenatal diagnosis is to relieve parents of anxiety and inform parents of the birth of an affected infant, to allow in-utero treatment, or delivery at a special centre for immediate postnatal treatment, or (the most common option) allow termination of an affected foetus.⁷

Antenatal screening for Down Syndrome

Screening for foetal anomalies, can be problematic and may not fit comfortably with the criteria for screening low risk populations. Consider the effort expended in screening for chromosomal abnormalities, in particular Down Syndrome. The ideal of population screening is early detection with a view to commencing early treatment. The purpose of a commonly offered antenatal screening regime, ultrasound scanning and/ or maternal serum screening, is to detect foetuses with Down Syndrome or structural malformations. However, at present, there is no *treatment* for Down Syndrome and some maternity care providers regard *prevention* as terminating the pregnancy.⁸

Many women remain ill-informed and may misunderstand the implications of antenatal ultrasound and serum screens offered to detect Down Syndrome. A French study identified that almost 60% of maternal serum screen providers imposed screening without giving the woman a chance to refuse. Almost 40% of women who participated in this study were unaware of the risk of miscarriage after amniocentesis, which was offered if abnormal serum screen results were detected.⁹ A Canadian study found

that almost 50% of its participants did not view ultrasound as a screen for anomalies, suggesting that informed choice was lacking.¹⁰ Compromised informed choice is a finding in other studies looking at antenatal screening for Down Syndrome.¹¹

Ultrasound screening

Whilst the consensus is that ultrasound medical diagnosis is safe there are some people who consider the increasing use of ultrasound as an enormous uncontrolled experiment.¹² Ultrasound is used extensively in obstetric medicine. A recent review suggests that multiple scans during pregnancy may be associated with a small but insignificant effect on foetal growth but otherwise pose little risk.¹³ However, the use of ultrasound in pregnancy has escalated over the years without evidence that its increased use improves maternal, foetal or newborn outcomes. Curiously Australia spends more on *routine* obstetric ultrasound than on labour and delivery.¹⁴ Practising defensive medicine to reduce the risk of litigation may be a major reason why antenatal screening and testing is a growing area.¹⁵

A particular concern about the obstetric ultrasound is that it may be considered an indicated diagnostic test for one purpose, such as gestational age assessment, while at the same time serve as a screening tool for problems such as foetal anomalies.¹⁶ *Soft markers* found during antenatal ultrasound screening are minor anatomical variations indicating an increased likelihood that the foetus may have a chromosomal abnormality. Unfortunately women are sometimes inappropriately counselled and misinformed about risks on the strength of ultrasound results alone and healthy foetal lives have been terminated.¹⁷

Voluntary or coerced

A substantial systematic review of the psychosocial aspects of genetic screening of pregnant women and newborns identified that there are inadequate levels of knowledge for decision making, and that social and cultural inequalities exist in knowledge about testing. Public understanding of the basic concepts associated with screening was found to be poor. However, the review suggested most women held positive attitudes towards antenatal screening but 30% receiving a screen-positive result expressed regret about their screening decision.¹⁸

Unfortunately, some of the practitioners who advise pregnant women about the risks of genetic conditions, such as Down Syndrome, have been found to lack understanding about the condition themselves.¹⁹ Of particular concern is a study that shows that a woman's intention to terminate a pregnancy because of foetal abnormality was not related to their overall knowledge about disabilities but rather their knowledge about the perceived inadequacy of disability related services. They lacked information about

quality-of-life issues for individuals with disabilities, and wanted to know about the positive as well as the negative aspects of giving birth to a child with disabilities.²⁰

Not many women refuse some sort of antenatal screening and testing if offered, as they want reassurance that their baby is normal. Parents value the images ultrasound provides. The fact that many believe these screens are not only routine but are done for reassurance rather than to detect anomalies, which is the purpose of screening low-risk populations, suggests that there is a general lack of informed consent for these screens in the first place. Of course, some women forgo some screening knowing that termination would never be an option for them. Others decline antenatal screening and diagnosis not because they are against abortion, but because they have concerns about the health and well-being of their foetuses.²¹

Preventive eugenics?

Are invasive diagnostic tests, such as amniocentesis and chorionic villus sampling, which are offered following a positive antenatal screen, morally licit given the potential risk of foetal loss? Pope John Paul II states: 'When they do not involve disproportionate risks for the child and the mother, and are meant to make possible early therapy or even to favour a serene and informed acceptance of the child not yet born, these techniques are morally licit'.²²

Stainton suggests that arguments in favour and opposed to antenatal testing mistakenly presuppose that there is no moral status attached to the foetus.²³ Just because it is possible to screen for certain conditions does not necessarily mean that we should. This discussion has focused on maternal and foetal screening, yet increasingly, technology is being used to screen embryos for a variety of conditions before they are implanted. Scientists euphemistically call this type of screening 'embryo selection', when in fact a majority of embryos are rejected. In applying pre-implantation genetic diagnosis (PGD) prospective parents *choose* to implant only 'normal' embryos rather than those found to carry actual disorders.

What is particularly abhorrent is the systematic drive to screen out people with differences. Not all these differences are overwhelmingly burdensome for society, as many are compatible with a long life in valuable and rewarding ways. The statutes that allow this are being stretched. It is possible to screen out those with an increased but not necessarily actual risk for developing certain conditions later in life. How many of these individuals, had they been allowed to actually exist, would have chosen non-existence in the first place? - which is itself a specious argument since they had no choice at all.

Again, the assumption is that the world not only devalues certain populations but would be better off without them in the first place. This attitude is rightly highly conten-

tious and offensive for people who have these differences, and to those who love, live, work, play and care with them and for them. Use of some artificial reproductive technology may be legal, but it is not always ethical. Enhancing future babies through the use of gene therapy and embryo engineering is unlikely to benefit those with actual disorders but, as recent history suggests, will more likely be used indiscriminately in an era of creating the 'boutique' or 'designer baby'.²⁴

The value of 'routine' antenatal screening is being questioned.

There is the ongoing problem of pregnancy technologies being used beyond their original intention, also known as 'function creep'. Whilst the benefits seem clear for use in high-risk situations, many technologies are now being used routinely - sometimes with unfortunate consequences. Routine ultrasound before 24 weeks gestation has not been shown to reduce perinatal mortality, but is considered of benefit for gestational age assessment, inductions of labour for post-term pregnancies, detection of multiple pregnancies, and earlier detection of clinically unsuspected foetal malformation.²⁵

Even what is thought fundamental in antenatal care is being reconsidered.²⁶ Checking urine for protein can be a poor predictor of pre-eclampsia in the absence of hypertension and can possibly be eliminated from routine care without adverse outcomes for women.²⁷ Routinely screening all pregnant women for gestational diabetes is not supported by scientific evidence. Indeed gestational diabetes is said to be 'a diagnosis looking for a disease'.²⁸ There is a higher rate of caesarean deliveries in low-risk patients when continuous, rather than intermittent, foetal heart-rate monitoring is practised, despite lack of evidence to support the use of this technology in this manner.²⁹

Parents need encouragement to make informed decisions about their family needs. Antenatal screening and testing is often seen as a rather innocuous and celebratory event. It is certainly a huge commercial and costly enterprise at the expense of other areas, such as disability, mental health and aged care which always seem to be underfunded.³⁰ Even so, consent for any antenatal screening and testing must be fully informed and those who decline supported in their decision. Parents who receive a positive screen or abnormal test result need non-directive counselling, support and time to make decisions.

Improved funding for disability services and positive information about disabilities in general would help eliminate the stigma that seems to be eroding the tolerance and generosity of society. As newer technologies emerge to screen earlier and for more differences the distinctions between what is normal and not so normal appears to be a scientific or economic decision rather than a humanitarian

one.

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