

Chisholm Health Ethics Bulletin

Vol 8 No 3

AUTUMN

2003

The Impact of Demoralisation on Decision-Making in End-Of-Life Care - A

A paper presented at the Challenges in End of Life Care, Conference October 31, 2002

Medical decision-making in end-of-life care involves complex interactions between the patient, doctor, multidisciplinary team and the family of the patient. The endeavour to preserve the autonomous choice of the patient interacts with the ethic of care and the necessity for competent medical practice. While the recognition of depression is one clinical challenge, the state of demoralisation in the patient has recently been described as a common influence on the development of a desire for death. I am grateful for the opportunity to talk to you today about the potential contribution of demoralisation, and on the capacity of the patient to give informed consent to a "managed death" in the setting of physician-assisted suicide or euthanasia.

Acceptance of Dying

Firstly, let me establish the normality of acceptance of dying within the modern practice of palliative care in Australia today. Clive Seal (1995) has described the current Western ethos of the "heroic death", in which awareness of dying is faced by the patient with courage. This mental attitude of acceptance of dying can be expressed as, "I'm ready to die." There is no desperation in such patients. Acceptance of

dying is possible without evidence of demoralisation.

Non-Caring Attitudes to Life

Let us turn to the question of non-caring attitudes to life. Medicine, and indeed Psychiatry, have been slow to develop a taxonomy of disorders of hope or disorders of loss of meaning. The paradigm of mood disorders has prevailed and subsumed hopelessness within it, but without attention to the existential or spiritual realms. Yet the loss of purpose or meaning in life is not uncommonly encountered during palliative care, and is clearly deserving of a better focus. There have been a number of terms in the literature which capture some of these non-caring attitudes to life. These include notions of existential despair, spiritual torpor, mopishness and boredom, acedia and demoralisation.

Acedia, for example, was a term used in the early Christian church to reflect a tedious meaningless loss of hope and despair. Its use was more complex than that of personal sloth. The 4th Century monastics in the desert saw acedia, the expression of doubt that there was any point to life at all, as sinful because of its fundamental break with God. However, the Dominicans in the 16th Century suggested separation of acedia from the state of depres-

sion, but generally the two were confused throughout subsequent centuries. Similarly, there is quite strong literature on the mental state of demoralisation.

A clinical example of a demoralised patient will assist our understanding of this state. An elderly veteran suffered multiple skin carcinomas of his head and neck, such that over time he suffered the surgical loss of not only his nose, but both his ears. Now as the tumour spreads, enlarged lymph nodes in his neck and the base of his skull have contributed to the development of a facial palsy. He is deeply embarrassed by his appearance and yet avoids the medical prosthesis that has been attached to a pair of spectacles to give him the appearance of a normal nose. In his shame, he has become housebound, isolated and bored

FEATURING

The Impact of Demoralisation on Decision-Making 1

Legal Issues at the End of Life 4

The Myth and Malady of Maternal Mood Disorders 6

Ethical Issues in ADHD: Diagnosis and Management 9

with life. He openly states that life is pointless and he wishes that he could hasten his death yet he is not clinically depressed as is evident during his interaction with his family where his love for, and delight in, his grandchildren is exemplified.

Demoralisation

The nature of this mental state of lowered morale spans a spectrum from disheartenment to demoralisation. A patient who is disheartened expresses a mild loss of confidence, and as they start to lose hope dependency develops. Once hope is lost, a stage of despair is reached. Once meaning is lost in addition to hope, then the person has "given up" and can be seen as deeply demoralised. I want to argue that the severe end of this spectrum of mental states is pathological in its nature, because it is maladaptive, a source of considerable personal distress, and because it leads to greater harm through deterioration into a desire to suicide. It is the morbid nature of this state of demoralisation that calls for medical or psychological intervention.

We can understand the pathway through which demoralisation develops by following both the external environment of the person and their corresponding internal world. Firstly, they encounter a stressful event or situation which they may interpret as producing a sense of threat. If they perceive that they cannot change this situation a perception of helplessness emerges. When they perceive that they cannot influence or change their circumstances, a sense of personal incompetence develops, in which a sense of 'stuckness' becomes entrenched. They may appear to others to be a failure and this corresponds with an inner world of shame and growing isolation. Life in such circumstances loses any sense of purpose and as the person despairs, the meaninglessness of life dominates, such that there seems no

point to continue one's existence.

Normally the hope that a person carries serves as a source of optimism and attempts to influence, and indeed ameliorate, any progression down this pathway towards demoralisation. Similarly, the individual's spirituality and set of beliefs that render meaning to their world can significantly influence their response to such stressful events, well illustrated by the progression of disease such as cancer towards one's eventual death. Hope and meaning have the power to counter demoralisation, but their absence contributes substantially to its development.

Given this, we have suggested the following definition for a clinical diagnosis of Demoralisation Syndrome. The key to this lies in the affective symptoms of existential distress, and in particular, hopelessness is combined with meaninglessness or loss of purpose in life. Cognitive attitudes of pessimism, personal failure, helplessness and a sense of being trapped or of lacking a worthwhile future, are also present. Thirdly, associated with these, is a lack of drive or motivation to cope differently. Social alienation, isolation or a lack of support are commonly associated features. These phenomena need to persist over a period of 1 - 2 weeks to warrant the clinical diagnosis of Demoralisation Syndrome.

Differentiating Demoralisation from Depression

A key aspect to the understanding of this morbid mental state of demoralisation is its differentiation from depression. While clinically it is a harbinger of a major depression, it is not always the case that such co-morbidity develops. Depression and demoralisation can remain quite distinct phenomena. The core feature of depression in modern psychiatric practice is anhedonia, in which there is a loss of pleasure or interest in life's activities, as experienced both in the present and

in the future. This contrasts with demoralisation, for such an individual can enjoy consummatory pleasure, but they lose anticipatory pleasure through their hopelessness and meaninglessness. Thus, the demoralised person can smile, laugh and demonstrate a broad range of affects appropriate to the context of their social world. Because the demoralised can report recent activities which bring pleasure, and demonstrate interest in these activities, they do not meet DSM-IV criteria for major depression. Having emphasised the potential and independence of demoralisation and depression, we also need to acknowledge that in the medically ill these two states can exist comorbidly. It is the demoralisation which generates the desire to hasten death rather than the anhedonic features of depression.

A number of clinical associations of Demoralisation Syndrome occur, for it is commonly found in the elderly, those with bodily disfigurement and chronic physical disability or illness; it is also found in the mentally disabled and in patients who fear dependency on others or carry a concern about being a burden. It seems likely that demoralisation will be found equally distributed between the genders, but will be more common in the socially isolated and in those who have a perception or fear of loss of dignity. While we have been talking thus far of the demoralised patient, we should also note that carers and families can also become demoralised.

For the past 25 years, psychiatric research has shown that hopelessness is an independent and more powerful predictor of suicide than depression. Aaron Beck first demonstrated this in 1975. Since that era the prominence of hopelessness as a predictor of suicide has been seen in studies of adolescence, the elderly, patients with cancer, HIV-positive patients and those with a range of serious medical and mental ill-

nesses. What has not been well studied, however, are the existential and spiritual domains, so that we know little about the contribution of meaninglessness and pointlessness to the development of suicide. Our construct of demoralisation combines hopelessness with meaninglessness in what we perceive to be a clinically useful diagnostic category.

The impact of demoralisation on the capacity to give informed consent

Having thus described the state of demoralisation, let us now consider its impact on the capacity that a patient has to give informed consent to any treatment and, indeed, when the decision-making is about taking a "treatment" whose goal is to deliver a 'managed death' (eg physician-assisted suicide). The patient's competence to make such a decision is crucial.

There has been considerable debate about the nature of informed consent in choosing suicide when a patient suffers from mild or sub-syndromal depression. This contrasts with the generally accepted view that severe depression interferes with capacity to consent. The question is the extent to which Demoralisation Syndrome morbidly colours judgement and also interferes with a rational decision-making process. I want to suggest to you that demoralisation very much interferes with a normal consent process.

When we consider the nature of such choice, we are helped by what Colin Murray Parkes has described as the "assumptive world" (1975). This is more than a person's moral and normative beliefs, and indeed more than their character. The assumptive world locates a person's sense of purpose and their worth; it represents their sense of global meaning; it carries their generalised hope for life's future and their particular hopes in the here and now. The assumptive world forms the cognitive context in which personal

choice is exercised. I want to argue that demoralisation can cause a temporary breakdown of a person's "assumptive world" and thus interfere with their usual capacity to exercise choice.

Now Grisso and Applebaum (1998) have described 4 competencies necessary for a patient to give informed consent. These are:

1. The capacity to understand pertinent information;
2. The capacity to appreciate the significance of data for one's own situation (a state which will be influenced by the person's "assumptive world");
3. The capacity to deliberate on the risks and benefits, thus reasoning logically; and
4. The capacity to choose and exercise personal agency.

When we consider the mental state of the demoralised person, it can be argued that they have a disordered relationship to their future which will impact on any decision made in the present. Thus if the person has decided that there is "no hope in the future", and this is their appreciation of their world, can they make a competent decision regarding their future? It is doubtful that they can for their decision will be substantially influenced by their negative mindset. Having a disordered relationship to the future means that any decision that is taken relating to that future may be later viewed differently when hopelessness and pointlessness have passed. Such reasoning leads one to conclude that any choice to suicide made by a demoralised patient (e.g. in the setting of requesting physician-assisted suicide), will not involve a competent consent to the inherent treatment. When patients are seriously medically ill, they are vulnerable through having a reduced ability to understand detailed clinical information. They are often found to have limited insight into options for symptom relief. Furthermore, they are subject to the influences of others, be they

family members or our colleagues within the medical treatment team. When the clinical outcome involves the potential for loss of life, there is a further requirement to set the threshold for certainty in such decision-making very high. If there were to be any likelihood of informed consent being limited, there is a moral need to exercise caution in not proceeding with that potential treatment. A demoralised patient's decision-making should, in short, not be considered competent.

Demoralisation is contagious

There is an easy transmissibility of demoralisation between the patient, doctors and nurses, the multidisciplinary team, the family and the community.

Important research has been recently conducted by Brian Kelly and colleagues at Mt. Olivett Hospice in Brisbane. They studied a cohort of 256 patients and independently surveyed 252 doctors, mostly General Practitioners, who had referred the patients to the palliative care service. Some 15% of these patients indicated a persistent wish to hasten death. Independently of the patient's assessment, and with no knowledge of what the patient had declared, a second research assistant identified that specific attitudes in the doctor corresponded with the presence of a wish to hasten death in the patient. These included the doctor's willingness to hasten death, a doctor's sense of pessimism and awareness of distress in the patient, and the doctor's reduced experience or training in psychological care of such patients. Here we have evidence for the role of countertransference reciprocally influencing the doctor and the patient in the thinking about hastening death. This is quite frightening clinical material because there is a highly statistically significant, yet independently derived, correlation between the patient's wish to hasten death and the presence of equivalent sentiments in the doctor. Not only is

this evidence of the contagious nature of a demoralised state, but it also points to the potential vulnerability of the patient, if their doctor starts to think in similarly demoralised ways.

Demoralisation can also spread through families. They can experience distress at poorly controlled symptoms and carry a sense of helplessness at the existential plight of their relative. Some will perceive loss of their relative's sense of dignity, while others will feel the strain of care provision and perceive that the patient is indeed a burden. A number may carry a negative perception of what the future will be like. We can be sure that the more dysfunctional the family, the more intense their sense of distress and demoralisation is likely to become.

Conclusion

Where countries or states have introduced legislation for physician-assisted suicide and euthanasia, they have thus far recognised the potential of severe depression to impact upon clinical decision-making and required that depression be treated in such circumstances. In this paper, I am arguing that the clinical state of demoralisation is equally pertinent because it can interfere with the competence of a patient to give informed consent. Demoralisation is a state that can be actively treated with a broad range of therapies, and when relieved, a person's interest in life-sustaining therapies is restored. Demoralisation interferes with the personal autonomy of the patient because they lose their capacity to give informed consent. Further research is called for to establish the prevalence of demoralisation, and validate its diagnostic features. Specific em-

pirical work is needed to clarify the influence of demoralisation in clinical decision-making. It appears that as many as 10% of palliative care patients may become demoralised at different points of their illness journey. The Demoralisation Syndrome has a satisfactory face, predictive and construct validity, which suggests its utility as a relevant psychiatric diagnosis for use in palliative care.

*Professor David Kissane E
Director, Centre for Palliative
Care, University of Melbourne*

Legal Issues at the End of Life: A Guardian's Perspective

A paper presented at the Challenges in End of Life Care, Conference October 31, 2002

Amongst those immediately involved with people at the end of their lives, we can identify a number of perspectives - medical, legal, economic, social, personal, family, ethical and philosophical. Most professionals working in this area will draw on a number of perspectives even though their focus may be largely in one area. Thus a doctor will be mindful of the legal and social and philosophical aspects of a person's care towards the end of their life as well as the medical aspects. My way of knowing about the end-of-life is as a legal guardian, that is a substitute decision-maker appointed by a Tribunal to make decisions for a person in a way which reflects as far as possible their values and respects their autonomy. Some of these decisions are end-of-life decisions and a guardian must, amongst other things, be very con-

scious of and operate within the legal framework. But we must also recognise that the law does not contain everything we need to know or understand about the end-of-life and in many very important areas it says nothing at all.

Legal framework

It seems to me that the purpose of the law at this time is to empower the person receiving treatment and care and to prevent undue interference in the relationship between doctor and patient in determining what care and treatment should be provided. A sound legal framework is one which supports and promotes care and treatment for those at the end of life and protects those who are providing that care and treatment.

Our law is based on principles which uphold the intrinsic value of human life and doctors have a particular responsibility to preserve hu-

man life. However this is not an absolute value and in medical law it is modified by the liberal values of self-determination, human dignity and privacy.

The overwhelming majority of judicial decisions also support the liberal view of the fundamental importance of self-determination. Both ethical and legal principles require patients to provide an informed consent to their doctor before a medical procedure is undertaken. Consequently if a medical procedure is conducted without an informed consent being obtained (or alternative legal procedures being followed if a person is not capable of providing consent) the medical practitioner could be liable for medical trespass.

To look more specifically at the law relevant to the end-of-life we need to look to both common and statute law. Common law is made up of the judgments made in particular cases which set precedents for decision in

future cases and from which lawyers provide guidance to professionals on whether practices are lawful.

Medical Treatment Act 1988

Statute law is established by Act of Parliament and applies only to the country or state where that parliament has jurisdiction. The *Medical Treatment Act 1988* (MTA) in Victoria is very important legislation but is not, contrary to popular view, legislation only about terminal illness or people nearing the end of their lifespan. The MTA establishes

The right of a competent person to refuse medical treatment

The right of a competent person to appoint an agent to make medical decisions if the person becomes unable to do so herself.

The responsibilities and limitations of an agent making decisions for a person who is no longer competent.

That treatment without informed consent is medical trespass.

That a registered medical practitioner acting on a refusal of treatment certificate is specifically protected from legal action.

The law places no limits on the rights of a competent adult to refuse treatment, except that a Refusal of Treatment Certificate must be signed voluntarily, with understanding and relate to a current condition. Limitations are however placed on an agent or a legal guardian refusing treatment under the Act. Treatment can only be refused if

the treatment itself would cause unreasonable distress to the patient or

if there is evidence that the person would not consider the treatment justified.

A further limitation on the power of an agent is that the Guardianship Tribunal may suspend or revoke an EPA(Medical Treatment) if it deter-

mines that it is not in the best interests of the donor for it to continue.

Palliative care

The Act specifically excludes palliative care from the definition of medical treatment and defines palliative care as the reasonable provision of food and water and pain relief. There has been a great deal of debate on whether the reasonable provision of food and water includes artificially provided nutrition and hydration such as naso-gastric feeding and PEG feeding. Although not specifically tested in Victoria, legal judgments and medical practice supports the view that artificial nutrition and hydration are medical treatment and thus can be refused or withdrawn in some cases. This was clearly established in the Bland case in Britain where Anthony Bland remained in a persistent vegetative state following the Hillsborough stadium football disaster. The court decided that it was not in his best interests for treatment (the provision of food and water by artificial means) to be continued which had the effect of artificially prolonging his life. Palliative care as defined in the Act also includes pain relief and it makes sense that a person acting as the agent or guardian of another person should not be able to withhold or withdraw pain relief from the person who is actually experiencing the pain.

There has been some confusion about whether a competent person can refuse palliative care. Whilst the Medical Treatment Act cannot be used to refuse palliative care (food, water, pain relief), a competent person also has rights under common law and their right to do so under common law is clear. At common law the patient has the right to refuse any care or treatment. The reason why an agent cannot refuse palliative care for another person is because agents have no common law rights. An agent draws authority only from the statute which sets up the Power of Attorney

and in the MTA, agents are not given the right to refuse palliative care.

Advance directive and living wills

Another area of confusion is the Advance Directive (sometimes called a living will) The advance directive has no legal status in Victoria (although some might argue that a refusal of treatment certificate is a very limited form of advance directive). Legally, they may be taken only as an indication of a person's views and anticipated wishes. However, most of us make decisions on the basis of how we feel about something rather than what we think about it and none of us are very good predictors of how we would feel and what we would want in a situation we have not yet experienced. Recent research indicates that most people overestimate their negative response to having a terminal illness or disability and nursing staff will attest to the human capacity to come to terms with severe illness and find meaning and happiness in the final stages of life.

Common law

There is very little common law in this area in Victoria. I believe that there are two main reasons for this. First, most end-of-life decisions are made by patients, doctors and families by agreement of all concerned within the context of hospital policy, medical ethics and the limitations set by law. Second, cases involving people unable to make their own decisions which, until the late 1980s may have been decided by a court, are more likely now to be decided by an agent appointed under the MTA or a health care guardian appointed by the Guardianship List of the VCAT. These cases are not reported and do not establish common law precedents

Guardianship

A guardian appointed under the *Guardianship and Administration*

Act 1986 is required to act in a represented person's best interests, take account of their wishes and choose the alternative least restrictive of their freedom. A guardian is, naturally, also required to act according to law and so in Victoria must also act within the MTA. Guardians are not appointed in every health care situation where the person is incompetent to make decisions for themselves. Many situations are dealt with by consensus and some people have appointed an EPA (Medical Treatment). There are also some consent provisions which allow a "person responsible" to consent to medical treatment where a patient is unable to do so. A guardian is generally appointed when there is disagreement about what decision should be made or the situation is ethically contentious. In 70% of cases when a guardianship order is made, the Public Advocate is appointed as guardian. In end-of-life cases the percentage would be much higher. An example may illustrate the role of a guardian in end-of-life decision making.

Case study

Joe was a 72 year old man who had a severe stroke at the age of 67. He was physically completely dependent, incontinent and lived in a nursing home. He was mentally alert and appointed his wife as his Enduring Power of Attorney, not realising, and not being advised by his solicitor that this only gave her authority to look after his financial and legal affairs. He said frequently to his wife that he did not wish to go on living like that. Joe then developed an aneurism and was rushed to hospital in great pain. At first he refused an operation and then later

changed his mind. After six days Joe was still unconscious in intensive care in the hospital. His condition was poor but there was a 40% chance that he would survive and if so was likely to be more disabled than previously. The Public Advocate was appointed to decide whether treatment should be withdrawn. After an extensive process of consultation and confirmation of the situation as it had been presented the guardian finally decided that treatment should be withdrawn as, in the terms of the Medical Treatment Act, "there were reasonable grounds for believing that the patient, if competent and after giving serious consideration to his health and well-being would consider that the medical treatment was unwarranted". Treatment was withdrawn and Joe died later that day.

It is important to note the basis for the decision in this case. The guardian was required to act in Joe's best interests as well as to respect his right not to receive treatment which he would regard as unwarranted. The treatment was not considered futile by medical staff, although it might have been argued that further treatment would be of no benefit to him. His change of mind about whether he wanted surgery was given lesser weight by the guardian because of medical advice that it was likely to have been influenced by the pain he was experiencing and could therefore be seen as not constituting an informed consent. The decision was made largely on the basis that his views were clear, that he had already experienced disability and illness and had discussed specifically with his wife what he would wish to happen in such cir-

cumstances.

Conclusion

Until about 100 years ago, most people died from what are now preventable causes and understandings about natural death were academic and of interest only to philosophers. In some ways we seem to have come full circle. Many deaths are now preventable in the short term because medical science has given us the possibility of some control over the manner and time of our death. Questions about the end-of-life and about death in the human experience are in the popular literature and culture. So we debate whether we would want "to be kept alive on a machine" and watch MDA, currently popular on ABC television, where the interaction (or clash) between law and medicine is the central theme.

What then can we conclude about the role of the law at the end-of-life? I said at the beginning of this talk that the purpose of the law is to empower the person receiving treatment and care and to prevent undue interference in the relationship between doctor and patient. Law in Victoria goes a long way towards meeting this standard. Our challenge is to understand and use it.

Barbara Carter
Senior Guardian,
Office of the Public Advocate
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The Myth and Malady of Maternal Mood

There has been much written about what some researchers call the medicalisation of unhappiness. Many normal female physiological, and increasingly psychosocial as-

pects of child bearing and rearing, have been medicalised. This article briefly discusses the issue of postnatal depression (PND).

Research shows that women, in general, are more likely than men to develop a mental illness. Our society uses the term 'depression' lightly to explain a variety of mood states not

necessarily having any correlation with a mental illness, eg. 'bad news depresses me!' It could be argued that many people experience some symptoms of depression yet would not consider themselves to have a mental illness. Terms that define mental illness are cultural definitions placed on behaviours that in other times may have been normal, functional, rational and reasonable and symptoms now considered as evidence of mental illness have in the past been regarded as religious afflictions, sins, or lack of self-control

There has been a degree of complicity over the insidious encroach of medicine into women's reproductive biology. Historically, women's madness was linked to sexuality, and associated with menarche, menstruation, pregnancy and menopause.² Women were denied not only the vote, but also any participation in public office, and were considered to 'lack virtue' if they tried.³ Perhaps these attitudes stemmed from the erroneous perception that women were irrational. At the dawn of the last century women were incarcerated in hospitals for the insane for physical causes that included pregnancy, parturition and the puerperal state.⁴ Others spared the asylum were given what has been termed 'the rest cure' - a period of enforced isolation from all cares and responsibility.

Many women continue to be socialised into dependent roles, and feel powerless to escape the constraints imposed by patriarchal dominance. Expectations that a woman is biologically programmed to be a nurturer, and happily so, is shattered by the cataclysmic change that parenting brings. The stay at home mothering role is often devalued, yet the working mother may feel guilt. A happy medium seems unattainable.

Women are now more readily consigning some of their parenting role to others, and seek help when unable to cope. Support was once the purview of the extended family, but tra-

ditional family structure and basic financial support has changed over the years with many families now reliant on non-family support. Distress engendered by changed family dynamics may be construed as evidence of mental illness by a public unable or unwilling to alleviate it.

Mothering and mental health

PND is the most prevalent mood disorder associated with childbirth and affects up to 15% of childbearing women. PND is similar to depression occurring at any stage in life and is characterised by irritability, anger, having low energy levels, loss of interest and feelings of guilt.⁵ At the clinical level PND is categorised as a 'mild mental and behavioural disorder associated with the puerperium'.⁶

PND is regarded as a major national health problem, yet research has found that mothers can have relatively good mental health between birth and six months.⁷ This doesn't surprise those who subscribe to the view that the added stress of newborn parenting exacerbates normal levels of anxiety and deplore labels of depression being inappropriately applied.

Increasingly, the non-western world is also reporting that depressive symptoms related to the period after childbirth is prevalent.⁸ PND in migrant women is associated with social isolation and pressure to fulfil 'traditional' mother and wife roles.⁹ In western society, there have been many revolutions in childcare practices. It is not remarkable, therefore, that women don't feel confident about fulfilling the 'perfect' motherhood role that society promotes. Indeed, it is not only mothers who suffer, as there is evidence that partners of women identified as having depressive moods after childbirth may also develop depressive symptoms.¹⁰

Is PND a normal physiological event or a mental

illness?

PND is now regarded as almost a normal response to childbirth. Stone suggests that:

"... given the particular stresses in our society that a woman faces when she becomes a mother, such as social isolation, exclusion from the work force, financial dependence and loss of identity, it is worth questioning whether it is in the best interests of a woman to be also given an illness label, such as PND, or whether a non-medical approach towards helping women to deal with these kinds of feelings may be a more constructive alternative".¹¹

Services targeting postnatal women have proliferated, especially mother-baby / parenting units offering parent support. Some also offer valuable treatment options consistent with the mental health philosophy, as genuine depression is amenable to treatment. These units generally report positive outcomes.¹² What is of concern is why these units (many privately funded) are becoming mainstream. Does providing services create a need to seek out clients? Does taking an issue out of the domestic environment and into a medical institution necessarily constitute best practice?

Lack of sleep is a major differential diagnosis and predictor of PND.¹³ There is also an association between depressed maternal mood and problematic childhood sleep behaviour, though less clear is which way the association is influential.¹⁴ Support and help may be enough to help some families through these normal crises. Other families may suffer needlessly because of pressure to 'snap out of it' in cases where there is failure to diagnose and treat 'true' depression.

Pitfalls of predicting PND

Known risk factors for PND are a personal history of depression, depression during pregnancy, difficulty

in marital relationships, lack of support, and stressful life events.¹⁵ Alternatively this can be expressed in terms such as life stresses and lack of social support contributing to behaviour and symptoms regarded as manifesting as PND.

Some reports suggest that screening for PND using questionnaire-based psychometric scales can predict the likelihood of a woman developing PND,¹⁶ whereas others clearly refute that there is evidence to support the use of universal screening.¹⁷ Whichever model is used it is imperative that a diagnosis of PND not be accepted on the basis of a screening tool alone.

If screening tools are the mechanism in which risk factors are identified then women should be informed about the consequences of scoring positively. The commitment to use screening tools must be secondary to a commitment to act on them appropriately by responsible referral for diagnosis and treatment. There is evidence that alternate pathways for why women develop a depressed mood after birth exist, and their experience should not always be seen as an expression of mental illness per se.

Is PND stigmatising?

The potential for creating stigma is a problem inherent in many psychometric screening tools. How might the prospect of a positive result be in itself predictive of actually developing some 'mental illness' symptoms? Equally problematic are the missed diagnosis and the potential to prolong the distress. Other concerns about screening are whether women would actually access treatment, and whether screening would dramatically increase the requirement for treatment.¹⁸

The National Health and Medical Research Council (NHMRC) acknowledge that the stigma of mental illness, culturally inappropriate measures, and under-reporting of symptoms may cause inaccurate as-

essment of PND.¹⁹ Does having something to blame for how they react to the stresses associated with motherhood in fact make some mothers feel better? It is suggested that very few of the many women who report having PND are diagnosed by a health professional.²⁰ If we accept that PND is indeed a mental health illness, why are we so casual with its diagnosis?

Some women who do have depression may not seek treatment because of the stigma associated with mental illness. Unlike having a mild dose of flu, the repercussions of mental illness may affect some individuals' future prospects in a society, which is uncomfortable with such diagnosis. If we accept that PND is a mental health illness and not merely a normal response to the pressure of mothering, then we should ensure that there is professional diagnosis, treatment and ongoing support.

Another aspect of maternal depressive moods is the legal implications. The much-publicised Andrea Yates case in the United States is a prime example. Yates drowned her five children. She was sentenced to 40 years imprisonment for Capital Murder. She had pleaded not guilty by reason of insanity due to postpartal depression.²¹ There are correlates in Australia. PND has also been implicated with increased risk of unexpected death in infancy.²² There is speculation that some of these deaths are actually murders.²³ Historically the maternal mental state has been used in defence of infanticide. The current law in Victoria allows for the indictable offence of infanticide within 12 months of a woman giving birth.²⁴ If PND can potentially be cited as a mitigating factor for committing infanticide, might it allow, eg, road rage, theft, and child abuse, among others.

PND is not just another women's health issue

Despite a new century and millennium women are still stigmatised as

being gullible to the effects of their hormones. PND has been the subject of research for many years and it is disturbing that much of it relies on mother's self-report and screening tools as the only reliable indication of having PND. It appears that many women accept this mental health illness label and reject the possibility that they may simply be reacting normally to the pressure of newborn parenting. However, for others, clinical depression is a significant disease with the potential for serious repercussions, including death by suicide.

The effects of PND are far-reaching, so reducing it to just another women's issue would be irresponsible. Yet so much is still unknown about why depressive moods in women appear to be more prevalent in our society. Can this issue be separated from societal and environmental, and increasingly global contexts, as a purely medical condition that needs medical treatment? The research literature expounds prolifically on possible endogenous causes of postnatal depressive moods, yet the cause of depression, in general, is unknown, and quick-fix cures are unlikely to endure in a disease known to remit and recur.

Conclusion

What is apparent in the literature is that depressive symptoms following childbirth are common. What is unclear is whether this in fact represents a normal physiological state or a malady. The global burden of depression is seen as a major issue in our society. Health professionals may be loath to diagnose mental illness because of their own socially contrived beliefs about mental health in a society that prefers to keep those so diagnosed hidden. Depression is amenable to treatment. Promoting professional diagnosis of any mental health illness is important.

Women continue to bear the brunt of paternalistic attitudes that seek to regulate their biology and psyche.

The future mental health of our mothers is a concern as there has not been general consensus about PND, either as a state that is unique, or one that should be seen as part of the spectrum of depressive illnesses that doesn't arbitrarily discriminate for the postnatal period. Perhaps an attitudinal shift is needed in our society where instead of giving mental health illness labels to coping behaviours we actually applaud and support woman's resilience in adapting to change.

ENDNOTES

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Anne Moates E

Ethical Issues in ADHD: Diagnosis and

This article discusses the growing disquiet in both the medical establishment and the community at large about the accurate diagnosis and appropriate treatment of Attention-deficit/hyperactivity disorder (ADHD).

What exactly is ADHD?

ADHD is characterised by inattention, hyperactivity, impulsive behaviour and academic

underachievement (American Association of Psychiatrists, 1997). The currently accepted diagnostic criteria (DSM-IV)¹ state that symptoms should be present before 7 years of age and be more severe and/or frequent than those typically seen in children of the same age. Symptoms should be pervasive, existing in at least 2 settings, typically the home and school. Significant clinical impairment in the child's social, academic, or occupational functioning is the prevailing hallmark of ADHD.

About 30% to 40% of children with ADHD have an associated disorder or comorbidity, most commonly oppositional defiant disorder, anxiety disorder, conduct disorder, or learning disorder.² Although individual risk varies greatly, children with ADHD are at a higher risk than other children for a wide range of learning problems, substance abuse, and difficulties in future relationships, including work and marriage.³ Finally, a child's specific symptoms and their severity usually vary ac-

ording to the category of ADHD.⁴

Recent findings about the nature of the disorder are of further concern. ADHD was once believed to disappear after childhood but longitudinal studies suggest symptoms and resulting impairment persist into adulthood. For instance, one study that followed 140 children with ADHD found marked increases in behavioural, mood and anxiety disorders as well as increased impairment in cognitive, school and family functioning after four years of follow-up.⁵ It is now thought that around one third of those children with ADHD continue to be affected by the condition into adulthood.⁶

Unfortunately, ADHD, like many other psychiatric conditions, relies solely on a clinical judgement: there are no objective laboratory tests to substantiate such a diagnosis. And the current diagnostic parameters used for assessing ADHD are certainly one of the most controversial aspects of the debate today. The picture is further complicated by the numerous changes in the definition of the disorder over the last twenty years. Although a few researchers still question the existence of ADHD, most now consider this position to be extreme: there is now general consensus that as currently defined, adults, and more commonly, children diagnosed with ADHD comprise a diverse group sharing a cluster of symptoms.⁷

The diagnostic criteria, however, are not only being ignored by many clinicians, but are proving quite inadequate and rigid in many cases. A study performed by the Pediatric Research in Office Settings (US) network found that the DSM-IV criteria were used by only 38% of the clinicians surveyed.⁸ Although these criteria have been improved, and remain the best diagnostic tool to date, they are still somewhat vague and subjective in nature. Furthermore, whereas most parents, teachers, and physicians can determine whether a child's behaviour is qualitatively abnormal, it is sometimes difficult for

them to determine whether the child's behaviour is quantitatively abnormal for the child's age and level of maturity.⁹ Most youngsters show some degree of inattention, impulsivity, and hyperactivity, but the child with ADHD is typically more inattentive, impulsive, and hyperactive than most children of the same age.

ADHD is clearly not an "all-or-none" phenomenon, but rather presents as a degree of behavioural variation that falls outside the normal spectrum for that age. Unfortunately, the DSM-IV criteria fail to recognise this continuum of behaviours naturally seen in children.¹⁰ This is problematic and raises grave concerns about misdiagnoses and unwarranted treatment of children and adolescents. Urgent research needs to be done to accurately define and characterise ADHD.

Prevalence and possible causes

The significant obstacles to reliable diagnosis have also made accurate estimates of ADHD prevalence difficult to determine. Reliable information on the demographic distribution of ADHD, particularly for socioeconomic factors, is not available. The child and adolescent component of the National Survey of Mental Health and Wellbeing, conducted in 2000, revealed that 14% of individuals in this age bracket within Australia suffer from mental health problems. Estimates of those affected by ADHD vary from 3% (1996, National Health and Medical Research Council) to 11% (2000, Minister for Health and Aged Care) of all children and adolescents. Regardless, ADHD is the most common mental disorder among this age group. Indeed, many specialists believe there may well be more than one child in every classroom affected by ADHD.

The underlying causes of ADHD are unknown. Surprisingly, this has not been vigorously researched to date. Boys are identified with ADHD at least four times as often as girls.

This is consistent with the sex ratio found in many other developmental disorders. Reports suggest low birthweight babies born between 1500g and 2500g are at an increased risk of ADHD.¹¹ Higher prevalence rates have been reported among urban as opposed to rural children.¹² Cigarette smoking during pregnancy has also been linked to an increased risk of ADHD.¹³ In addition, there now appears to be a genetic component, with around 30% to 40% of ADHD children having a parent with ADHD,¹⁴ but the jury is still well and truly out. More investigation is needed, and urgently, into the prevalence and underlying causes of this disorder.

Stimulant Medication Treatment

The wide range of disruptive symptoms associated with learning, behavioural and emotional problems, family stress and the chance of the condition persisting into adulthood, often combine to produce considerable pressure on health professionals to treat these "problem" children, and quickly. Set against this scenario is the mounting public concern over the apparent growth in the number of affected children and the rocketing prescription rate of stimulant drugs used to manage the condition.

The use of stimulant medication is the most common medical treatment for ADHD. Throughout 10 countries recently surveyed, the consumption of stimulant medication increased on average 12% per year. More worryingly, from 1984 to 2000, legal consumption of stimulants, predominantly prescribed for ADHD, within Australia increased 26% per year, with Australia and New Zealand ranked third overall in its rate of consumption.¹⁵ The reasons for this huge increase are not clear. However, contributing factors may be laxer prescribing standards here and a broader diagnostic definition than that found in other countries.¹⁶

While these medications have been shown to be effective in ameliorating primary symptoms, they are relatively useless at overcoming children's social difficulties, which commonly persist. New research shows that it is these social difficulties caused by ADHD that most distress those suffering.¹⁷ Despite these concerns, "stimulant medication remains the single most powerful intervention we have for treating ADHD," said Dr Fischer, a researcher into the disorder. "Putting a child on a stimulant medication is a very difficult decision for parents to make, even if children have substantial problems at home and at school."¹⁸ Alternative treatments, and a more comprehensive, integrated approach, is therefore needed to treat ADHD more successfully.

Another concern arising from the widespread use of stimulants is their apparent abuse by children. What is particularly disturbing are the recent reports of prescription drugs being sold or traded in Australian school grounds. A paediatrician recently reported the disturbing finding that children without ADHD were using medications to enhance concentration during exams.¹⁹ Perhaps schools nationwide should adopt the Queensland Health Department initiative--basically that children should not carry their medication at any time. Rather, ADHD medication should be regulated and administered by adult supervisors at school. Another strategy would be to give doctors and pharmacists access to online information concerning past prescriptions before filling out new ones. Such guidelines would surely help minimise the abuse of prescription medications.

Prescribing medication to children under 6 years of age is also highly contentious. This is because there is a very wide range of behaviour normally displayed at this age and it is particularly difficult to distinguish (if at all) behavioural patterns that are deleterious to later development.

If in doubt, clinicians should err on the side of caution, always keeping the patient's best interests paramount. Perhaps a wait-and-see approach, or short-term trial, would be preferable to immediate and prolonged stimulant medication in borderline cases. This is also pertinent when financial considerations have a bearing on the treatment option taken. Health insurance companies often find the option of stimulant medication cheaper than employing a psychotherapist to treat a child with ADHD.²⁰ In each case, clinicians should be ever careful that parent's impatience, anxiety or wishes do not trump the child's welfare.

Behavioural Therapy

Behavioural therapy is defined as the broad set of specific interventions that modify the physical or social environment to promote changes in behaviour. It is usually effective in helping parents and family members manage the child with ADHD. Because of the high toll that the condition exerts on family life, behavioural therapy should be strongly recommended for most patients and families with ADHD.²¹ Working with parents and teachers to change the child's environment is critical to the success of behavioural therapy; they remain the best source of information about children with ADHD. Behavioural treatments are effective in improving both the behaviour and academic performance of these children.²² Studies of different management regimes have shown that combined behavioural and pharmacological treatments for ADHD have been the most effective in reducing symptoms of ADHD.²³ Although more difficult and onerous, behavioural therapy should be more widely utilised.

A better future

ADHD must be seen as a complex, chronic condition that will require long-term follow-up to monitor the safety and efficacy of treatment

strategies. Individualised treatment must be family-based and coordinated with other specialists and school programs in order to optimise the use of available resources and to help ensure success. Nevertheless, "our poor understanding of the pathophysiology of ADHD, the absence of an operational definition of the disorder, and the lack of consensus regarding the clinical and behavioural symptoms required for its diagnosis have made it difficult for the paediatrician to properly evaluate, diagnose, and treat the condition. As a result, ADHD is often overdiagnosed and overtreated, and occasionally missed."²⁴

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Michael Herbert E

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Website: www.mercyhealth.net/chisholmhealthethics/

The Centre is funded by Catholic healthcare institutions in Victoria.

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Director/Editor:

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Research Officer:

*Michael Herbert BSc(Hons)
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