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Mental Health: Posing Extra Problems for Accepted Ethical Standards

Mental illness creates additional ethical difficulties for many accepted standards in medical practice including; confidentiality, consent and competency. It is an area of health that requires increased education.

Before exploring the additional ethical dilemmas created by mental illness it is important to understand what is meant by the term as well as related concepts such as mental health and mental disorder. These terms have been increasingly used to describe the myriad of mental health problems that are currently having a greater impact on society than ever before. This increase may either be because of an increase in the prevalence of mental disorders or because we no longer segregate people who suffer from mental illnesses and as a result we as a community are more exposed to their existence.

According to the *Mental Health Statement of Rights and Responsibilities*, **mental health** can be understood as 'the capacity of individuals within the groups and environment to interact with one another in ways that promote subjective well-being, optimal development and use of mental abilities (cognitive, affective and relational) and achievement of individual and collective goals

consistent with justice.'¹ That same document provides an account of both a mental health problem and a mental disorder as two distinct categories. Firstly, a **mental health problem** is 'a disruption in the interactions between the individual, the group and the environment producing a diminished state of mental health.'² Secondly, a **mental disorder** 'may be defined as a significant impairment of an individuals' cognitive, affective and/or relational abilities which may require intervention and may be a recognised, medically diagnosable illness or disorder.'³ The Australian Institute of Health and Welfare provides a more general account of a mental disorder by saying a mental disorder is 'the existence of a clinically recognisable set of symptoms or behaviour associated in most cases with distress and with interference with personal functions.'⁴

Fighting a losing battle. Unfair opposition.

Not Dated, Neurosis

Painting on paper, gouache 510 x 758 mm

The Cunningham Dax Collection of Psychiatric Art 2000.118

FEATURING

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These accounts of mental illness and mental disorder include 'classic' mental health problems such as schizophrenia, bipolar disorder (manic-depressive), panic disorders, anxiety disorders and other psychiatric disorders. However, the definitions also seek to include some of the most common psychiatric disorders in the community, including major depression and substance abuse and dependence.⁵ The diagnosis and prognosis of these disorders varies dramatically. While some can be adequately managed with psychotherapy or counselling others require pharmacological management. Drug treatments can sometimes be inadequate in controlling the disorder and its symptoms as well as being associated with unwanted feelings and side-effects, such as 'not feeling in touch with reality' or feeling very

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distant.

The variety and complexity of mental health problems create unique dilemmas for health care professionals and health care policies. Not all mental health problems can be treated under the same set of guidelines nor can they merely fit under the same umbrella as other health care issues. In this article I will seek to identify the areas of difference that mental health creates for several ethical principles and look at why mental health education is invaluable.

Confidentiality

The principle and reasons for medical confidentiality have been discussed in past issues of *The Bulletin*, so I will not explore them again, except to say that medical confidentiality is generally accepted as playing a very important role in maintaining a trusting health care professional-patient relationship⁶.

Often one of the most important aspects of treatment for mental health problems is the relationship the patient has with their health care professional. People with mental illness see a variety of health care professionals in Australia with two-thirds of mental health problems treated solely by general practitioners. The other third of patients seek specialists' help either in the form of psychiatrists or psychologists.⁷ It is, however, important to note that only a third of persons with mental disorders actually seek help for their condition.

patients with mental health problems need to rely on confidentiality

Patients with mental health problems need to rely on confidentiality in order for their relationship with their health care professionals to be open enough to allow effective dialogue and to be therapeutic. The dilemma regarding confidentiality arises when a disclosure is made to a health care professional during a confidential discussion which raises a potential risk to either the patient themselves, their family or the community at large. This situation creates a very difficult balancing act between the value and importance of maintaining confidentiality in both the individual instance as well as its importance and value to the community, and the potential harm posed to individuals. It is important to factor in both the likelihood of the possible harm as well as how severe the threat is. Unfortunately, there is no magic formula and each case needs to be evaluated on its own merits. However, if it is judged that confidential information should be disclosed then it should be done in a sensitive and very restricted way. In other words discretion is required in order not to jeopardise the essential role confidentiality plays in mental health care relationships. Maintaining confidentiality wherever possible is also necessary if we are to see an increase in the number of people with mental health problems

seeking appropriate treatment.

Consent and Competency

Informed consent is another important aspect of all interactions that individuals have with their health care providers. Simply providing information to patients is not sufficient to ensure informed consent. Patients must understand what is involved in a proposed treatment or therapy, what the possible side effects or complications might be and what is required of them in order to ensure that treatment is effective. Improved medications for mental illness are leading to a better quality of life for many sufferers. However, some are not receiving up to date specialist treatment and may be prescribed older-generation drugs that have greater side effects, some of which may be irreversible.⁸ It is essential that people with mental health problems receive up to date information about the best possible treatment for their condition and potential improvements in the future. Information about psycho-active drugs must be presented in plain language and in an easy to understand format. Many of the medications available have side-effects which may make patients feel distant, slow or simply not themselves. If patients are aware that the drugs are responsible for causing these sensations then they can work towards ways of coping with them.

Some mental disorders can lead to questions about the competency of

simply providing information to patients is not sufficient to ensure informed consent

patients. That is, is someone who is suffering from a particular mental disorder sufficiently competent to consent or reject treatment or to know what is in their best interest? A further complicating factor is that the episodic nature of many mental health problems means that, while competent most of the time, some

patients will experience periods of psychoses, during which they are perhaps not competent. If a patient has consented to a treatment option while competent but rejects the same treatment on another occasion it can be very difficult for the health care professionals involved. It should be up to the judgement of specialists in the area to decide in which instances a patient should be treated against their current wishes and such a judgement should be based on what the patient, if they were competent, would want. Obviously, competency and informed decision making are important not only for treatment of a person's mental health problem but also for other treatment they may be receiving such as dialysis.

Models of Care

There has been a dramatic shift in the model of mental health care used in Australia from a live-in, hospital style of care to more community-based, out-patient care. While this move has been assessed as generally improving the quality of lives of people with mental illness, it is a mode of care which demands adequate funding to ensure success. Community based programs allow people with mental disorders to

effective treatments need to be clearly identified and promoted

establish a sense of belonging that is often pivotal in their recovery. Mental disorders account for approximately 20% of the burden of disease in Australia and yet only 5% of the health budget is spent on services to the mentally ill.⁹ I am not suggesting that simply increasing the amount of money spent on mental health will further improve the standard of mental health care. However, increased spending might allow already established and successful programs to reach the two thirds of people with a mental illness who are currently not receiving any treatment.¹⁰ Mental health treatments are not more costly or ineffective than other medical

treatments, although this is how they are often perceived. Effective treatments need to be clearly identified and promoted and made easily accessible to those who need them.

Prevention

Prevention of some mental disorders requires education of the community about the nature of anxiety, depression and substance abuse, and about what can be done to prevent these disorders from occurring. Messages such as 'face fears' and 'be active if depressed' are just as

early intervention can succeed before the disorder has even developed

important as 'don't dive into shallow water'. If family members and friends can identify the early warning signs of mental disorders much of the trauma and anguish of mental health problems may be avoided. Resource material discussing mental health issues should be readily available with recognised prevention strategies and treatment options endorsed by bodies such as the National Mental Health Strategy. Identifying at risk groups, and in particular at risk individuals, is essential because early intervention can succeed before the disorder has even developed. Prevention programs in schools would perhaps have the greatest effect with the peak prevalence of mental disorders occurring in the 18-24 year old age group.¹¹

Conclusion

It is estimated that 17.7% of Australian adults experience symptoms of a mental disorder at some time during a 12-month period.¹² With such a high prevalence of mental disorder it is becoming increasingly obvious that it is an area of health which affects the entire community. Some mental disorders are not preventable and must be dealt with in a reactive and compassionate way. Disorders such

as schizophrenia and other forms of psychoses are not curable but with new medications they are very treatable. It is not enough that treatment options are available. The community must be made aware of all clinical advancements in this area so that people with mental disorders who have not found satisfactory treatment options in the past might try to seek treatment again.

For mental disorders that are preventable such as anxiety and substance abuse, everyone needs to become vigilant so that those individuals who may be at risk are identified early. The community readily endorses many safety messages through advertising campaigns and the area of mental health should not be treated any differently. Education is needed to highlight the value of protecting one's own mental health. The types of messages that need to be promoted include; if you feel depressed you do not isolate yourself, monitor your dependence on substances such as alcohol, and that if you do feel 'at risk' then help is available and that accessing such assistance is not stigmatised. There are many myths surrounding mental illness and to dispel these will also require education. People with mental disorders can recover and those who are undergoing treatment can take part in community life in many valuable ways. Part of the responsibility for improving the lives of those with mental disorders rests on all of us. We as a community need to be well informed about our own mental health, the risks to it and how we can best offer our help and support to those with mental disorders.

ENDNOTES

¹ *Mental Health Statement of Rights and Responsibilities*, Commonwealth of Australia, 1995.

² *Mental Health Statement ...*

³ *Mental Health Statement ...*

⁴ Australian Institute of Health & Welfare, *Australia's Health 1998: the sixth biennial health report of the Australian Institute of Health & Welfare*.

Canberra, AIHW, 103.

⁵ NA Keks & GD Burrows, 'The essential practice of mental health care', *Medical Journal of Australia Practice Essentials*.

⁶ *Chisholm Health Ethics Bulletin*, 1/2 (1995), 5/2 (1999).

⁷ G Andrews et al, *The Mental Health of*

Australians, Mental Health Branch, Commonwealth Department of Health and Aged Care, April 1999, 39.

⁸ Sarah Stock, 'Out-patient care proves a winner', *The Weekend Australian* 5-6/8/2000.

⁹ *The Mental Health of Australians*, 38.

¹⁰ *The Mental Health of Australians*, 39.

¹¹ *The Mental Health of Australians*, 8.

¹² *Australia's Health 199,8 104.* ✚

Tracey Phelan

Risk

This article will examine the concept of risk and how because of its subjective nature it can be perceived differently. Some of the ethical issues related to risk information will also be discussed.

We live in a society that has become more and more aware of the risks associated with particular actions and behaviour, the use of certain technologies and the living of specific lifestyles. Rather than rely on destiny we are encouraged to make our decisions by using probabilities about the future so that we can have some control over the outcomes and therefore take some responsibility for them.

Risks to health are increasingly being explored as more and more links are being discovered between certain factors and behaviours, and any diseases that may subsequently develop.

Risk

Risk may be described as 'a concept used to give meaning to things, forces, or circumstances that pose danger to people or to what they value. Descriptions of risk are typically stated in terms of the likelihood of harm or loss from a hazard and usually include: an identification of what is "at risk" and may be harmed or lost (e.g., health of human beings or an ecosystem, personal property, quality of life, ability to carry on an economic activity); the hazard that may occasion this loss; and a judgement about the likelihood that harm will occur.'¹ Risks are usually measured numerically, in terms of a probability, which refers to some adverse event. Risk is a combination of uncertainty and adversity, the perception of which is believed to influence subsequent decisions.² Some-

thing is perceived as risky because the outcome to which it has been linked is considered adverse, bad, onerous, burdensome or undesired.

In health there are two types of risk. Firstly, there is the risk posed by a health danger to populations by environmental hazards such as pollution, nuclear waste or toxic chemical residues. This health risk is external in that usually the individual has little or no control over it. The individual cannot eliminate the risk, but they can remove themselves from it, thereby controlling their exposure if they have the resources and the knowledge. The second type of health risk is that present as a consequence of lifestyle choices made by the individual. This type of risk is internal as the individual has control over it and the behaviour is modifiable. Lifestyle risk is easily identifiable in behaviours such as smoking, unsafe sex, certain diets and lack of exercise. Increasingly, however, risks such as those posed by possible

risk is a combination of uncertainty and adversity

genetic inheritance and even those presented by the birth of a child with a congenital condition are being seen as controllable and even preventable. A study that looked at women attending genetic counselling for hereditary breast/ovarian cancer found that those who were identified as at risk not only assumed responsibility for their own and others' genetic risks, but also perceived themselves

as having an obligation to others to manage these risks. The feelings of responsibility expressed by these women to find out their risks could ultimately have influenced their autonomy insofar as it constrained their choices, especially their right not to know about their genetic risks.³

Faults of nature can no longer be

lifestyle risk is easily identifiable in behaviours such as smoking, unsafe sex, certain diets and lack of exercise

seen as the main cause of risks to our health. Many current risks have been created by humans. Modern technology saves us time and energy. The fast food generation drive in their cars and wait only minutes for their dinner. Obesity and lack of exercise are risk factors for heart disease and other illnesses.

Some 'risk' factors that have always been present, or at least have been around for a long time, are now being acknowledged as possible threats or risks to health. They are often the side effects of developments that have mainly been viewed as benefits to humans. The increasing emphasis on 'risks' must be seen in the light of changes in scientific thinking. Previously it was determined that a disease had only one cause whereas now with the increase in chronic disease there has been a paradigm shift to the belief that there are multiple causes and effects *and* that there is uncertainty.⁴

Characterisation of Risk

'Risk characterisation should be a decision-driven activity, directed toward informing choices and solving problems.'⁵ The aim of risk characterisation is to describe the possibility of a hazardous situation in an accurate and thorough way that is relevant to decision-making. The significant concerns of the relevant parties need to be addressed and the information must be presented in an understandable and accessible way. An adequate risk analysis and characterisation should entail incorporating the perspectives and knowledge of the interested and affected parties from the beginning so that the risks can be understood. Risk characterisations often focus on a single outcome but many risk decisions have multiple outcomes so there are usually several attributes and kinds of information that need to be synthesised.

risk characterisations often focus on a single outcome

The different language that is used to communicate risk and probability reflects our beliefs and values as to what constitutes adversity and undesired outcomes. If we say that there is a 25% or 1 in 4 *probability* or *chance* that something will occur, this could imply non-adversity. The emphasis would seem to be on the 75% or 3 in 4 probability or chance of something *not* occurring. However, if we say that there is a 25% or 1 in 4 *risk* of something occurring then it is usually understood negatively, that is, that the outcome is adverse.⁶ It is almost insinuated that the outcome must be avoided. It is a very negative characterisation. Presenting risk information in mortality rates characterises a risk in quite a different way than if the information was conveyed using survival rates.

Risk Communication

The effective communication of risk is fundamental to informed decision making. Risk communication can be mass in that it is between an agency

and the public via the media where there is no opportunity to ask questions or qualify information or, it can be individual on a one to one basis during which there should be plenty of time for clarification and understanding.

Measuring the effectiveness of risk communication is difficult, as there needs to be consensus about the most effective outcomes. If judged by 'professionals' this may mean knowledge, accurate risk perception (as ascertained by them) and appropriate behavioural change, but if judged by patients this may include 'satisfaction with the communication process, actual involvement in the decision making, a better understanding of the risks and benefits of the different options, helpfulness of the information to the decision-making process, or certainty that the best choice has been made.'⁷

Risk Perception and Context

Cultural, social and institutional factors affect how people recognise and use information on uncertainty. 'Understanding depends not only on the inherent features of a risk, or even the experience and expertise of the analyst attempting to characterise it, but also on the social context of the risk analysis and the associated deliberative process.'⁸ Risk percep-

people's diverse values and life directions mean that they may perceive 'dangers' differently

tions are embodied in complex systems of beliefs, values, and ideals that constitute a culture. People's diverse values and life directions mean that they may perceive 'dangers' differently and behave in varying ways. Defining risk can become a way of explaining the failure of existing political or social relationships (especially in the area of large public risks such as the possibility of chemical spills), of delegating blame and voicing mistrust. Whether we distrust or dislike the organisations

or institutions that put us at risk impacts on our perception of risk. The complex social attributes of risk are reflected in the diversity of approaches that characterise the expanding risk assessment field.⁹ It is the individual for whom the risk

the acceptable risk to benefit balance must be determined by the individual

may be relevant who has to perceive it within the context of their lives and then make a decision according to their values and life plans. The significance of an actual numerated objective risk may be quite different from the subjective risk perceived by the recipient of the information. The acceptable risk to benefit balance must be determined by the individual. There are problems however with people who seem to be aware of the relative risk of specific activities or behaviours when talking about them objectively but when this knowledge is applied to their own behaviour they underestimate the risk. Teenage smoking and unsafe sexual practices are two pertinent examples of behaviours that are acknowledged by young people to be risky but where they personally don't feel they are at risk.

Prenatal Screening and Testing and Risk

Prenatal screening and testing is all about risk. Prenatal screening, whether serum or ultrasound, is about identifying pregnancies where there is risk of the baby not being 'normal'. A numerical estimate that has taken into account maternal age, gestation time and other factors puts the pregnancy in a high or low risk category for certain abnormalities. A decision then has to be made about whether more certitude about the presence or absence of the particular abnormality is desired. Prenatal testing using chorionic villus sampling or amniocentesis, while bringing certitude about such conditions as Down's Syndrome, carry the risk of miscarriage of a 'normal' baby. In

some instances the numerical risk of miscarrying, as a result of one of these procedures, may be the same as that of having a child with Downs Syndrome. The risk/benefit balance must be carefully analysed.

In a study that analysed the feelings and views of women who refused prenatal serum screening it was found that these women felt there was a range of risks produced by the information discovered by the test. These included stress, abortion and miscarriage and amniocentesis.¹⁰ Interestingly, the women in the study were concerned about the inaccuracy of the test because of the likelihood of false positive results and actually saw the risk of getting a false positive finding as being higher than the risk of there actually being something wrong with the foetus. Notions of 'risk' accounted for the decisions made by both groups of women in this study, those who had serum screening and those who did not. The difference however lay in their perceptions of 'risk'. For those who had the screening test the risk lay in not knowing or not having information about the foetus whereas for those who refused the test the 'risks' were created by the information that the test could provide.¹¹

A study by Marteau et al¹² found no

societal values and its degree of acceptance of disability can greatly impact on women's beliefs and values

relationship between the pregnant woman's perceived risk of having a baby with an abnormality and their actual risk. The perceived risk of having an abnormality is almost a universal worry for pregnant women and, according to Judith Searle¹³ this is related to the context of the risk and women's underlying values and beliefs. Societal values and its degree of acceptance of disability can greatly impact on women's beliefs and values. 'Understanding of the sociocultural context in which pregnant women perceive their risk is paramount to addressing their con-

cerns and to avoiding a conflict of expectations and subsequent discontent.'¹⁴

The Ethics of Risk

It could be argued that the dissemination of information about risks is an ethical imperative based on the individual's right of self-determination. It is therefore the responsibility of epidemiologists to provide accurate estimates about risk factors and their association with diseases so that the individual can make an informed decision about the way that they choose to live. While there will always be conflicts over the significance of risks, the adequacy of evidence, the methodologies for evaluating and measuring risk, and the severity of health effects it is the responsibility of government and public health authorities to warn the community about health risks without causing unnecessary panic.

The emphasis on risks, especially in the area of health, could be seen as

we can be responsible and morally accountable for the outcomes

an attempt to increase control and personal responsibility and to attribute blame. Escalating risk awareness is increasing the numbers of the *worried well*. What we eat, where we work, whether we exercise and how much or how little, our sexual behaviour, whether we procreate and under what conditions, what sort of holidays we choose, whether we sit in the sun and, any other behaviours we adopt, have all been subjected to risk estimates. Evaluating these risk estimates and making 'rational' decisions based on them is seen as the responsibility of every *reasonable* person. The evaluation of risks is seen as a necessary foundation for health awareness and 'responsible' behaviour change. If we control our behaviour and make lifestyle choices based on valid and reliable information then we can be responsible and morally accountable for the outcomes and if they are undesirable we may be blamed. Smoking in today's

risk enlightened environment is not tolerated to the extent that it was decades ago when information about its effects was unknown. Smokers pay higher insurance premiums and it is not unheard of that they may be refused certain operations if they continue smoking. It is a contentious point as to what is the responsibility of a publicly funded health care system when a person has knowingly taken risks with their health and then requires expensive treatment.

Risk discourse that emphasises lifestyle risks, serves as an effective agent of surveillance and control that is difficult to challenge because of its

some risks are tolerated in order to gain other benefits

goal of maintaining the standards of health, if health is understood to be the absence of disease and prolonging life. However, a broader definition of health that also encompasses self-realisation, personal fulfilment, quality of life, coping and psycho/social/physical functioning may not be achievable if we are increasingly encouraged to evade risks. According to Førde 'a growing intolerance to risks and uncertainty is hardly the best basis for self-realisation and coping as long as uncertainty, unpredictability and risk are an inherent part of any human life that is worth living.'¹⁵

Conclusion

We have to make sure that health by its narrow understanding is not worshipped as a principal life value. There are very few things in life that are purely 'healthy' or 'unhealthy' and many of the identified risk factors are factors of everyday living. The discourses of risk produce risk themselves as they construct boundaries and connections that define safety and danger. People's ethical evaluation of taking a risk can consciously or subconsciously be influenced by their chosen way of life. Some risks are tolerated in order to gain other benefits.

ENDNOTES

¹ Paul C Stern and Harvey V Fineberg (eds), *Understanding Risk : Informing Decisions in a Democratic Society*, (Washington D C: National Academy Press 1996), 215 & 216.

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³ Nina Hallowell, 'Doing the right thing: genetic risk and responsibility', *Sociology of Health & Illness* 21/5 (1999) 597-621.

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⁹ Dorothy Nelkin, 'Communicating Technological Risk: The Social Construction of Risk Perception', *Annual Review of Public Health* 10 (1989) 98.

¹⁰ Susan Markens, C H Browner and Nancy Press, 'Because of the risks: how US pregnant women account for refused prenatal screening', *Social Science & Medicine* 49 (1999) 360.

¹¹ Markens et al, 'Because of the risks...', 366.

¹² T M Marteau, J Kidd, R Cook et al., 'Perceived risk not actual risk predicts uptake of amniocentesis', *British Journal of Obstetrics & Gynaecology* 98 (1991) 282-286.

¹³ Judith Searle, 'Fearing the Worst - Why Do Pregnant Women Feel "At Risk"?'', *Australian & New Zealand Journal of Obstetrics & Gynaecology* 36/3 (1996) 284.

¹⁴ Searle, 'Fearing the Worst.....', 285.

¹⁵ Olav Helge Førde, 'Is Imposing Risk Awareness Cultural Imperialism?', *Social Science & Medicine* 47/9 (1998) 1157.

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Deirdre Fetherstonhaugh

What do Adult Children Owe Their Ageing Parents in Matters of Health Care?

This article discusses the duty of adult children to provide for their parents in relation to health care as well as its limits bearing in mind their need to provide for their own children.

Currently in health care there are strong economic pressures to find ways to have children provide care for aged parents. These pressures display a mix of financial, ideological and charitable motives. If children are to shoulder this burden three basic questions must be answered: (1) What kind of moral obligation do children have toward the welfare of their elderly parents? (2) What are the limits of this obligation? (3) Even if children do have some significant duties to parents, is it still legitimate to ask the state to take over much of the direct financial burden

all the evidence points to the fact that children and families remain the principal source of emotional support and companionship for the elderly

of care?

Reference is frequently made to the changed social environment in which the elderly now find themselves. Two myths must be debunked. The first is that the caring family has dis-

appeared among all the changes. The second is that the elderly are now more isolated from their children than ever before. Rather, all the evidence points to the fact that children and families remain the principal source of emotional support and companionship for the elderly. Within society it is generally accepted that respect and care are owed to the elderly. Giving a coherent and satisfactory explanation for this phenomenon is more difficult.

One Contribution

The American bioethicist, Daniel Callahan, has explored these issues and in doing so has focused on three dimensions of the parent-child relationship. The first thing to note is the role friendship and gratitude have in the unique child-parent relationship. Other writers take it further when they assert that grown children are obliged to befriend their parents.¹ The love expressed in this friendship is a mutual one. Callahan dismisses this understanding. Many adult chil-

dren, he reminds us, do not view their parents as friends. Nevertheless they respect and love them. Another explanation of the parent-child relationship concentrates on the gratitude that is due. It, too, has difficulties similar to the friendship model. Gratitude is ordinarily judged to be due when a benefactor has gone beyond the requirements of ordinary duty. In some cases parents may have merely done their duty but in such a grudging way that gratitude scarcely arises.

A second dimension of the parent-child relationship is located in the dependence of the elderly on their families. Callahan has asked whether dependence alone creates the obligation to care. He turns to the practical and specific demands that parents make on their children. On a scale of moral priorities it would be difficult to argue persuasively that persons in a middle generation are obliged to deprive their dependent children of necessary financial support in order to support

their elderly parents. Children have a claim on their parents which their parent's parents cannot equal. In ordinary terms, then, the primary economic duties of adults are directed to their own children rather than to the needs of their parents. Physical help and affection, however, are another matter. In making this distinction Callahan argues that an inability to provide one particular kind of care does not exempt children from providing other forms of care. When different forms of physical help may be difficult to give adult children are called on to offer the affection, emotional and psychological support so often craved by elderly parents. The third dimension of the parent-

children have a claim on their parents which their parent's parents cannot equal

child relationship considered by Callahan arises from the impact of chronic illness on ageing persons and the need to set limits to family obligations in such situations. The burdens that chronic illness impose create enormous pressures on families. This, in turn, confronts traditional moral expectations about family life. Currently the trend in health care delivery is to locate care of the chronically ill and the frail elderly within the domestic setting. This policy assumes that families, with minimal social support, will be able to manage such care. It is further assumed that family members have the moral, psychological, and spiritual strength to sustain such care. Callahan questions such assumptions, especially when a frail, sick, or demented parent requires many months or years of demanding and stressful care.²

Ethical dilemmas arising from the need to care for elderly parents are directly connected to the fundamental question as to how commitments to family members can be justified. These demands do not neatly fit contractual frameworks. Contemporary moral thinking emphasises the fact that a moral act arises from a free, autonomous choice. Non-contractual

moral obligations thus become highly problematic. They violate human autonomy falling as they do within the realm of supererogation. This is commendable, virtuous and edifying if freely chosen, but is not demanded in the name of morality. This philosophical approach which clearly demarcates these two dimensions of human activity is not primarily selfish. Rather it stems in great part from the inability of philosophers to establish a solid moral basis for self-sacrificial behaviour that springs from contextual, rather than from contractual demands. A more fundamental problem is that the ground for self-sacrificial morality

cannot be sustained by will alone. A presumption of much secular, individualistic morality is that one ought to do one's duty, and that good reasons for moral behaviour are sufficient motivation. One need only make up one's mind to act in a certain way, will to so act, and the actions will follow. But there are too many good-willed but still angry caregivers around to sustain that view. It is psychologically naive. It takes account neither of our emotions (which colour our judgment and will from the inside) nor of the social setting of our actions (which influence our judgment and emotions from the outside).³

Callahan's point is well made. He has concluded that significant self-sacrifice is only possible if under-

self-sacrifice is only possible if understood within the context of an entire way of life

stood within the context of an entire way of life, and a way of life set ultimately within some scheme of religious or higher meaning. The care of another must be transformed from a stark and unpalatable moral demand, he argues, into a satisfying moral vocation, one honoured by the community and returned in kind when the caregiver himself or herself comes to need care.⁴

Daniel Callahan is a notable exception in modern philosophical ethics in his concern to investigate familial relationships. Intergenerational obligations have attracted little study in recent ethical literature.⁵ This is somewhat anomalous since much of our daily living occurs within the context of family networks. This gap in modern Anglo-American philosophy ignores the social and biological contexts of human existence in favour of the Enlightenment view of the human self. Atomist rational beings, virtually unconnected to others in any essential manner, have little or no need for a theory of filial relations. In either its Kantian or utilitarian forms, post-Enlightenment moral thinking has adopted an impersonal standpoint which overlooks the tendency 'to treat preferentially people to whom we are related by special ties of affection, such as parents, children, spouses, friends, and lovers.'⁶ The *moral point of view* has gone too far in the direction of impartiality. As a result *special relations* have been ignored, or at least overlooked. From the perspective of strict universal impartiality such relations are instances of merely irrational sympathies. A moral philosophy that emphasises the social contract is primarily concerned with what we owe to one another as strangers rather than what we owe to friends or kin. Indeed, "all so called 'special-relations' such as husband-wife, father-daughter, brother-sister are seen as ethically anomalous."⁷ The moral field is one in which all persons, no matter how distant, have absolutely equal claim on the moral agent. From this viewpoint morality thus becomes a matter of transcending the familial.⁸

Elements in a Public Discussion

Two facts counter the paucity of philosophical thinking on intergenerational obligations.⁹ First, we must recognise that adult children generally fulfil their duties to their parents. Data on the informal care of

the elderly substantiates this. Second, post-Enlightenment philosophical reflection has overlooked the significance and influence of the Judaeo-Christian moral tradition. The commandment: 'honour your father and your mother that your days may be long' has governed family life within the Jewish and Christian communities down through history. This commandment together with the directive that 'each person shall revere his mother and his father' has been the basis of the Judaeo-Christian understanding of the duties owed by children to their parents.¹⁰ Public discourse about the duties of adult children toward their ageing parents can be pursued in a way con-

younger adults have an obligation to make provision for their old age

sistent with the current familial practice and the Judaeo-Christian tradition. To do so a central place must be given in the discussion to what it means to be a good human being. Such persons discriminate among the moral demands that arise from human needs and human relationships. As one of the participants in the public discussion of intergenerational obligations theologians propose three insights more generally accepted in the human community. The most basic of these is the fundamental dignity of each individual human being. The unfolding of each person's life-story occurs in the context of a network of relationships. For each person to live the good life it is necessary for him or her to take proper account of these relationships throughout the whole of life. Adult children continue to have an obligation to care for the parents who have benefited them significantly in their early years. This obligation, as Callahan has observed, goes beyond merely material care and calls for a wider range of human supports. When the demands of caring for an ageing parent become such that they conflict with the adult child's obligations to his own family then the latter duty may be judged to take precedence. It

is at this point that the state has an obligation to provide the necessary care which now exceeds the resources and capacities of adult children.

Theological emphasis on human responsibility which is frequently framed in covenant language also contributes to a richly textured understanding of the human person. Each person, whether elderly parent or adult child, is an interdependent individual called not only to care for themselves but also for one another. One implication of this interdependence is that younger adults have an obligation to make provision for their old age. Contributing to superannuation throughout one's working life exemplifies prudence and responsibility regarding the financial needs and burdens of later life. From this viewpoint no one individual or group is exempted from responsibility for the common good. This is so because our interdependence as human beings and the expression of this solidarity with one another structure all our dealings in the human community. At times it is necessary to discriminate between the demands of the common good and the needs of the individual. While solidarity points to social cohesiveness, epitomised in family relationships, subsidiarity makes clear that the responsibility children have

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Conclusion

What do the children owe their parents in matters of health care? The

discussion of intergenerational obligations above suggests a number of conclusions. (1) The responsibilities of both adult children *and* ageing parents play an important role when discussing the duties of adult children toward their ageing parents. (2) Priority must be given to the dignity, participation and interdependence of *all* persons involved, and (3) a view of social life must be encouraged that respects the status and competencies of the individuals who work together within society. What adult children owe their ageing parents must be viewed alongside the obligations of ageing parents to their children and society in general.

ENDNOTES

¹ Cf J English, 'What Do Grown Children Owe Their Parents?' in *Having Children: Philosophical and Legal Reflections on Parenthood*, edited by O O'Neill and W Ruddick, (New York: Oxford University Press, 1979), 351-56.

² D Callahan, *Setting Limits. Medical Goals in an Aging Society*. (New York: Simon & Schuster, 1987), 91-96.

³ Callahan, 'Families as Caregivers: The Limits of Morality', *The Archives of Physical and Medical Rehabilitation*, 69 (1988): 326-327.

⁴ Callahan, *Setting Limits*, 106.

⁵ S G Post, 'Filial Morality in an Ageing Society', *Journal of Religion and Ageing* 5:4 (1989): 17.

⁶ J Blustein, *Parents and Children: The Ethics of the Family*, (New York: Oxford University Press, 1982), 174.

⁷ S Hauerwas, *A Community of Character: Towards a Constructive Christian Social Ethic*, (Notre Dame: University of Notre Dame Press, 1981), 171.

⁸ Post, 'Filial Morality...', *Journal of Religion and Ageing*, 17-18.

⁹ Cf S Post, 'What Children Owe Parents: Ethics in an Aging Society,' *Thought*, 64 (1989): 320-324; S V Brakman, 'Adult Daughter Caregivers', *The Hastings Center Report*, 24:5 (1994): 28.

¹⁰ Lv.19:3; cf Post, 'Filial Morality...', *Journal of Religion and Ageing*, 24. ✚

Laurence J McNamara CM, STL, MLitt
(Oxon), PhD
Lecturer in Christian Ethics
Catholic Institute of Sydney

Ethical Issues in the Use of Sedation in the Care of the Terminally Ill

The aim of this article is to show that although in the majority of cases the appropriate use of sedation in the terminally ill patient is not an ethical issue, in a small proportion of patients the decision to use sedation involves ethical considerations. This is demonstrated by analysing a case study taken from the palliative care setting.

Amongst some ethicists, health care practitioners and the public there is some confusion regarding the purpose of sedation in the care of the terminally ill patient. On the one hand, proponents of euthanasia see sedation as a means whereby a patient's death may be hastened, and many of the public may also hold this belief. On the other hand professionals working in the area of palliative care see sedation as a tool to relieve distressing symptoms and do not consider it as a means of hastening death, although it might do so.

It is important to define the term sedation and to understand the conditions for which it is used. I would suggest that sedation in the care of the terminally ill patient can be defined as the prescription of sedative drugs where the primary aim of the management strategy is the relief of distressing symptoms, and where reducing the level of consciousness is necessary and unavoidable.¹ It has been shown that for the majority of patients with terminal restlessness in the terminal phase of their illness, sedative drugs (benzodiazepines such as clonazepam and midazolam) are necessary to control their symptoms.² Woodruff defines terminal restlessness as 'muscle twitching, multifocal myoclonus (spasmodic jerking of muscles) and occasionally convulsions, usually in a patient with impaired conscious state. Moaning, grunting or other distressed vocalising can occur.'³ However, before ordering sedation for terminal restlessness it is important to rule out other treatable causes. Some reversible conditions such as hypercalcaemia (a life threatening metabolic disorder associated with cancers) and infections may mimic the effects of advanced cancer, and these conditions

should be sought and treated.⁴ Woodruff notes that terminal restlessness is different from terminal anguish which is characterised by extreme emotional or spiritual turmoil. However, Burke acknowledges that terminal anguish may exacerbate terminal restlessness.⁵ It is relatively easy to assess the need for sedation for relief of terminal restlessness. It is more difficult, however, to make ethical decisions regarding the use of sedation for terminal anguish.

there is an inter-relationship where unrelieved pain exacerbates other problems and where pain may be caused or aggravated by other causes of suffering

A central concept of palliative care is the concept of total pain or total suffering and this refers to the sum of physical symptoms, psychological problems, social difficulties, cultural factors and spiritual concerns. There is an inter-relationship, where unrelieved pain exacerbates other problems, and where pain may be caused or aggravated by the other causes of suffering noted.⁶ Although it can be argued that sedation should not be a treatment for pain, when the concept of total suffering is taken into account, it can be seen that refractory pain may have elements of psychological, social and spiritual issues which may be appropriately alleviated with some level of sedation.

It could be said that the intended purpose of sedation is to calm the patient, and the reduction of consciousness or drowsiness is in some instances a necessary means to achieve the primary purpose of alleviating distress. It is very important to know that sedation can be at different lev-

els so that a patient may be only mildly, moderately or deeply sedated. As various issues are resolved (eg anxiety and fear) the need for sedation may be lessened or cease. In the palliative care setting deep sedation is never the goal of care *per se* but may be the means chosen and justified for the proportionate reasons of controlling symptoms of terminal restlessness. It is a misconception that in the palliative care setting sedation is used at the same time as the deliberate withholding of artificial hydration and nutrition. It is well documented that the diminished desire to eat and drink is a natural physiological part of the dying process.⁷ This brings us to a discussion of the case study.

Case Study

Frank is a 61 year old man. He is unmarried and lives alone out of town. He does not have a close relationship with his two sisters, and has requested that they not be informed of his admission to a palliative care unit. Neither does he have close friends, but he has a good relationship with one of the district nurses who was visiting him at home. He was diagnosed with cancer of the

in the palliative care setting deep sedation is never the goal of care per se but may be justified for controlling symptoms of terminal restlessness

larynx approximately two years ago. Though he underwent a total laryngectomy, followed up with radiotherapy, his tumour recurred some 12 months later. As time passed he experienced problems caused through the continued progression of the disease, including increased neck pain

and facial swelling. Whilst at home, just prior to his admission to the palliative care unit, Frank experienced two sudden and acute episodes of bleeding via the mouth. This, together with his other problems of neck and facial swelling, led to his admission.

Planning for discharge began after successful control of Frank's pain, though only a slight reduction of facial swelling was achieved. Discharge unfortunately did not transpire because of a sudden large haemorrhage. Unexpectedly, Frank survived this but over the next two-to-three weeks his condition deteriorated, both physically and psychologically. However, he was still able to walk around independently until a week before his death, and continued to enjoy visits from the district nurse.

Discussion to sedate Frank began following his major bleed, but at this time it was decided against sedation, in part because of an assessment that he maintained some pleasure in life through his friendship with the district nurse. The discussions were prompted because of staff observation of Frank's increased anxiety levels and agitation following the bleed. He also showed signs at this stage of some confusion and even paranoia. On two occasions nursing staff felt physically threatened by Frank's behaviour. It was also known that he had been aggressive on one occasion to a district nurse who was visiting him in his home. Frank was included in the discussions, and at this stage requested only mild sedation.

However, over the next couple of weeks, increasing anxiety, irrationality and confusion, signs of developing dysphagia, (inability to swallow) and increasing respiratory distress all became major concerns. Although death was likely in a few weeks, he was not observed to be in the end stage.

That is, Frank was still able to walk around and talk with staff and the district nurse. However, he was be-

coming incoherent. Frank's anxiety became overwhelming and he had a very justifiable fear of another catastrophic bleed being the way he would die. The decision to deeply sedate Frank was made after all other treatment proved ineffective to relieve his severe distress.

The plan for deep sedation was discussed with Frank but it was clear

it is unethical to deeply sedate someone who is alert and can still walk and talk unless this is necessary and without earlier informed consent or notification

his response was incoherent. Effectively, the decision was made by staff, following discussions with the district nurse. He died peacefully one week after deep sedation was commenced.

An Ethical Commentary

The ethically significant features of this case are that Frank is not assessed as being in the end stage, but perhaps he is a number of weeks away from death. The decision to deeply sedate Frank requires ethical analysis, as it is unethical to deeply sedate someone who is alert and can still walk and talk, unless this is necessary and without earlier informed consent or notification. Patients who are enduring great pain or suffering may be asked if they wish to be sedated (feel sleepy) for some hours, the day or most of the day. This leaves periods of alertness so that they know they are still being cared for and loved. In some severe cases, they may wish to be sedated for longer periods as required.

Other ethically significant factors include his deteriorating physical condition, especially respiratory distress that could not be easily palliated, and his horrific memories from the previous bleed giving rise to mental anguish. Frank is no longer able to cope with the burden of his disease and inevitable death. In the staff's judgement, Frank is under an excessive physical, psychological and

spiritual burden. It is important to note that in Frank's case mild sedation combined with his increasing confusion left Frank unsteady on his feet and at risk of falling; it also was observed to exacerbate his confusion and distress. In the circumstances, and given that all other forms of care have been tried, it is morally permissible to deeply sedate Frank as a last resort. Respect for Frank's dignity and alleviation of his distress are the primary focus of any further form of care. Generally, throat tumours are difficult to palliate well with frequent problems of pain control, local ulceration, offensive odour, interference with eating and drinking and respiratory obstruction.

As noted, a key notion of palliative care is the concept of total suffering. This includes an inter-relationship between physical, spiritual and psychological factors. The decision to deeply sedate Frank was taken in his best interests, and may be justified in view of his terminal distress without his explicit consent at the time. The sedation of Frank without his present informed consent is ethically acceptable if this has been discussed and attained at an earlier period in therapy.

In Frank's case the relationship between what is done, why it is done and the circumstances can be ethically evaluated as follows. What is done: an order for sedation via continuous infusion is written by the doctor, and the nurse follows the order setting up the infusion, which is the external cause that brings about the sedation. This intervention is morally legitimate and is permissible because it does not belong to a classification of actions that are described as wrong in themselves independent of their consequences.

Why it is done: to calm Frank from terminal distress and to enable him to die with dignity. The intention/purpose of the staff is not to deliberately will and cause Frank's death in order to end his suffering. Intention identifies what our concrete aim is,

and what we aim to do is usually what we take steps to bring about. The purpose of sedating Frank is to effectively alleviate his symptoms of terminal distress even though there is a reasonable risk that sedation might hasten his death.

Other forms of care have been tried and found inadequate. In these circumstances, where Frank is suffering unrelieved symptoms and terminal anguish, sedation is given to relieve Frank of an excessive burden. The grounds for this ethical evaluation are found in the health care teaching of the Church. John Paul II

it is not right to deprive the dying person of consciousness without serious reason

in *The Gospel of Life* (n65) reiterated the words of Pius XII that in answer to the question ... 'Is the suppression of pain and consciousness by the use of narcotics permitted by religious morality... if one foresees that such use will shorten life?'. Pius XII answered 'if no other means exist, and if, in the given circumstances, this does not prevent the carrying out of other religious and moral duties: yes'. (It is unconscionable to sedate someone without their consent as it prevents them from satisfying their family and moral duties and preparing to meet their God).

John Paul II stated in *The Gospel of Life* (n65) that in such a case death is not willed or sought; there is simply a desire to ease pain effectively. The same could be said for other symptom management. This case study does not highlight the problem of pain and narcotics but the problem of severe agitation and the use of sedatives. John Paul II quotes Pius XII 'it is not right to deprive the dying person of consciousness without a serious reason'. This case study focuses on what may constitute a serious reason.

In conclusion, sedation is a tool in the management of patients' symptoms. When it is used for the purpose of alleviating symptoms in terminal restlessness it is ethically permissible. It is hoped that by focusing on a case study it has been shown there are difficult situations when professionals, families and patients working together can make a wise judgement regarding the use of sedation near the end stage of an illness.

ENDNOTES

¹ P Stone, C Phillips, O Spruyt and C A Waight. 'Comparison of the Use of Sedatives in a Hospital Support Team and in a Hospice,' *Palliative Medicine* 11, 2 (1997) 141. Stone *et al* give a similar definition but omit to place the emphasis on relief of symptoms being the primary

goal with reduced consciousness being sometimes an unwanted outcome.

² Roger Woodruff, *Palliative Medicine: Symptomatic and Supportive Care for Patients with Advanced Cancer and AIDS* (3rd edn. Melbourne: Oxford University Press, Australia, 1999) 268.

³ Woodruff, *Palliative Medicine ...*, 267-268.

⁴ R J Dunlop, J E Ellershaw, M J Baines, N Sykes and C M Saunders, 'On Withholding Nutrition and Hydration in the Terminally Ill: Has Palliative Medicine Gone too far? A Reply,' *Journal of Medical Ethics* 21, 3 (1995) 141-143.

⁵ Alexandra L Burke, 'Palliative care: An Update on "Terminal Restlessness",' *Medical Journal of Australia* 166, 1 (1997) 39-42.

⁶ Roger Woodruff, *Cancer Pain*, (Heidelberg, Vic: Aspergilla, 1996) 2.

⁷ Michael Ashby and Brian Stoffell, 'Artificial Hydration and Alimentation at the End of Life: A Reply to Craig,' *Journal of Medical Ethics* 21, 3, 135-140. For a discussion of the role of dehydration in the dying patient, see Richard Wade, 'Artificial Hydration in the Terminally Ill Patient, Is There a Moral Obligation?' *Chisholm Health Ethics Bulletin*, 3, 4 (1998) 10-12. ✦

Richard Wade BEd, STB, MA, MTheol, DTheol

Lecturer in Christian Ethics
Australian Catholic University, Ballarat

Caroline Chisholm Centre for Health Ethics

7th fl., 166 Gipps Street East Melbourne Vic 3002

Tel (03) 9270 2681

Fax (03) 9270 2682

email: ccche@mercy.com.au

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