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Potential Benefits of Cloning Technology

The technique which created Dolly, the world's first clone of an adult mammal, has potential benefits for medicine. Although the cloning of humans is unethical and undesirable further research and technological advances should be pursued to make the most of this new technique.

Embryonic Cloning – Artificial Twinning

Identical multiple births, identical twins and triplets, have always been a part of natural reproduction. The early embryo splits into two or more embryos and the result can be several genetically identical people. Once it was possible to successfully create embryos ex vivo (outside the body), using artificial reproductive techniques, it was only a matter of time before these artificially created embryos could be split to form multiple identical embryos. This method of producing multiple copies of the same embryo, artificial twinning, is a kind of cloning, embryonic cloning, and has been used successfully in animal breeding since the late 1980's. Embryonic cloning, raises several ethical questions which include the following. What benefits might be gained by this method of cloning? Is mimicking the natural occurrence of twins in artificial reproduction morally problematic? Are there moral difficulties with cloning over and above those associated with artificial reproduction in general? Does it make a difference if the identical embryos are implanted at the same time or whether some are cryopreserved (frozen) to be implanted at some later time for a second attempt at pregnancy?

These questions require detailed and informed debate. One suggested benefit of artificial twinning is that it allows preimplantation genetic testing to be conducted on an embryo which need not be implanted because a genetically identical one can be. The 'cloned' embryos are genetically identical so any information gained from preimplantation tests on one embryo directly relates to the untested embryo. If the tests show no genetic abnormalities, the embryo which has been unaffected by the tests can be implanted.

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St John of God Healthcare, Geelong.

FEATURING

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Although embryo biopsy, testing one cell which has been removed from the embryo, can provide the same information and be performed on an embryo without serious detrimental effects, there are still those who believe that an untested embryo is preferable for implantation. Other possible benefits of embryonic cloning include creating multiple embryos from just one artificially created embryo, and this would reduce the number of eggs required for artificial reproduction. Egg collection requires hormonal stimulation cycles to mature several eggs at once, and a minor surgical procedure is required to retrieve them. The fewer hormonal treatment cycles required the better because the long term effects of the treatment are not known. Making multiple copies of the one person is not a practice which is morally or socially acceptable nor is it legal. At present all forms of cloning, including embryo splitting, are banned in Victoria by the *Infertility Treatment Act* 1995 s.47. Similar legislation applies to other states in Australia and other countries including the United States, Germany, Denmark and France.

"making multiple copies of the one person is not morally or socially acceptable"

Nuclear Transfer of Embryonic Cells

In the early 1970's Steen Willadsen created sheep chimeras by mixing together cells from two different sheep embryos. In 1984 he moved the nucleus from embryo cells into unfertilised sheep eggs, which had had their nuclei removed, and implanted the resulting cloned embryos into surrogate mothers. Two lambs were born using this technique, the first mammals to be cloned from foetal cells. Willadsen also went on to create inter-species chimeric animals, for example sheep-goats and sheep-cows. Without publishing his work Willadsen also managed to clone cows from cattle embryos which ranged from 60 to 120 days gestation. He was really the first to successfully clone from differentiated cells – cells with specific functions such as skin or liver cells.

Nuclear Transfer of Adult Mammalian Cells

Ian Wilmut, an animal embryologist and Keith Campbell, a cell biologist, co-created the world's first clone from adult genetic material, Dolly the sheep. Dolly's creation and birth were kept secret from July 1996 until February 1997. The announcement provoked outcry. The delay in making Dolly's birth public makes us wonder what other *break throughs* have occurred in artificial reproduction and cloning without public knowledge and scrutiny. Do scientists want to have a complete understanding of their success before publishing research or are they afraid that the community will disapprove of what they are doing? Once human cloning becomes scientifically possible do scientists hope people will accept it the way they have accepted other technological possibilities?

"Dolly was cloned from adult differentiated cells"

Before creating Dolly, Wilmut and Campbell developed a cloning technique using foetal skin cells. Their technique involved starving cells until they were on the verge of death. At this point the cells were all synchronised in what is known as the 'GO stage'. The cells interrupt their normal growth cycle and enter a state of suspended animation. Biologists have called this the GO stage or 'Gap Zero' phase. By starving the foetal skin cells that Campbell wanted to use, the cells entered the GO state. They were then transferred to enucleated eggs – eggs with their genetic information removed. Fourteen embryos were created in this way which resulted in five pregnancies. In July 1995 the surrogate ewes went into labour and two lambs survived. The two lambs were named Megan and Morag. This achievement, cloning from foetal cells using nuclear transfer, went largely unnoticed.

How does Dolly differ from Megan and Morag? Dolly was cloned from adult differentiated cells (somatic cells) unlike Megan and Morag who came from foetal cells. Somatic cells are all the cells within the body except the germ cells – the egg and sperm. In somatic cells proteins coat the DNA (deoxyribonucleic acid) in the nucleus of the cell. These proteins mask up to 90 per cent of a cell's genes, leaving exposed only those genes which the cell needs in order to survive and perform its specialised functions – for example as a brain or liver cell. Cloning from these differentiated cells involves enticing the DNA to lose these proteins so the cell can return to its undifferentiated state. This means the cell can be reprogrammed to return to a multipotential embryonic cell – a cell with all the genetic information needed for a person unmasked.

Dolly was cloned from cryopreserved cells that had been taken from the udder of a six year old Finn Dorset sheep. The udder cells were starved so that they too would enter the GO phase. Campbell then sucked the nucleus out of a ewe's egg, so that it had no genes at all. Then he injected an udder cell under its membrane. To allow the chromosomes to move into the egg and fuse, the egg and the udder cell were jolted for a few microseconds with a burst of electricity to open their pores. The egg then had the nucleus of the udder cell as its nucleus. The electric shock activated the fused cell to commence embryonic development.

It was a tedious process and only 29 embryos resulted from 277 udder cells. The newly created embryos were implanted in surrogate mothers. The ewes chosen to be surrogate mothers were of a different breed to the newly created embryos, so the offspring looked remarkably

different to the ewe that gave birth to it. Only one pregnancy was established. In July 1996 Dolly was born, the first mammal cloned from an adult.

Possible Benefits of Cloning Somatic Cells

The possibility of cloning from individuals' somatic cells may be extremely beneficial to medicine. Two major potential benefits of nuclear transfer would include the production of transgenic animals and gene therapy. Transgenic animals possess foreign DNA such as a sheep with some human DNA. A transgenic sheep could be created to produce proteins in its milk which are beneficial to humans. Creating a transgenic sheep would involve inserting a sheep cell which has been genetically manipulated to code for a particular human protein into an enucleated egg. The resulting embryo and sheep would then produce the human protein in its milk. Removing proteins from the milk is a relatively inexpensive procedure making the manufacturing of beneficial human proteins very economically attractive.

Gene therapy is another potential benefit which could result from the techniques used to create Dolly. Gene therapy is a form of treatment for people suffering hereditary diseases. It involves injecting 'healthy genes' into the bloodstream of the patient. Currently the 'healthy genes' come from a donor which means the recipient's body can reject the genes as it would any other foreign body. Using the nuclear transfer technique may mean that one day, with much further research, it might be possible to take a cell from a patient, correct it for the genetic abnormality, place it in an enucleated egg, grow new cells in culture and then transfer these cells into the patient. Using the patient's own cell would overcome the problem of rejection and make gene therapy far more effective.

Cloning Humans

The technology developed to produce Dolly may or may not be able to be applied to humans. At present the technique has only been used successfully with ruminants (cattle and sheep). It has been unsuccessful with rodents which have been the usual model for understanding cell differentiation and tissue formation in humans. It is still unclear whether humans will fit the ruminant or the rodent model. If the technique used to clone Dolly cannot be applied to humans, another method of cloning may be developed. However it is performed, the cloning of humans is

"a clone of a human adult would be a person with their own consciousness"

unethical. Every person has the right to have two biological parents, a mother and a father, to result from a combination of genetic material rather than just be a replication. Although identical twins have the same genes they are a mixture of their genetic parents and how they will develop, where their talents lie and what they will look like in their old age are all a mystery. A clone of a human adult would be a person with their own consciousness and beliefs, which would make them unique, yet they could literally 'see' their possible future self in the person from whom they were cloned. This would cause certain psychological harm as well as impact on how they were treated by others. The cloning of humans should be banned because its possible benefits fail to outweigh the harm done to the clone, the risk to genetic diversity and the potential abuse of any cloning technology.

Conclusion

The potential benefits of cloning techniques to both human gene therapy and the creation of transgenic sheep, make further research in the area appealing. The cloning of cells for gene therapy, using any technique, seems ethically acceptable. Creating cells in this way would not involve artificially creating or harming a human embryo. The development of transgenic animals using nuclear transfer would also be acceptable as long as the sheep created are not disadvantaged or harmed in any way. Embryo splitting appears to have some possible benefits but, along with using nuclear transfer to clone humans, it is not ethically acceptable. Deliberately manufacturing embryos and humans who are genetically identical to already existing individuals (adults or embryos) threatens personal identity. Creating clones which do not have their own unique genetic identity places unrealistic expectations on them and their development. Individuals formed from the 'random' composition of genes are free to develop in their own way. No one like them has ever existed before. Their future development whether good or bad is relatively unknown. This unique identity is valuable to us all and is something that should be maintained. The banning of cloning human individuals is essential but that should not be at the expense of other potentially valuable uses of the technology.

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From the Director

Our recent submission to the Medical Practitioners' Board of Victoria arguing against late terminations of pregnancy fell on deaf ears. Let's hope the Premier has more success in this important issue.

This issue of our *Bulletin* completes our third volume. Quite a number of topical issues have been thoroughly researched and written up in a reader friendly style. Naturally the hospitals supporting our Centre receive a substantial number of copies. It is subscribed to by many other hospitals, nursing homes, health care organisations, schools, seminaries, theological colleges, universities and individuals.

After publishing the *Bulletin* for three years it is timely to review it. The Centre's Board of Management recently approved to simplify the *Bulletin's* title: it was too long for any librarian's computer. Beginning from Volume IV, Spring issue, its name will change to *Chisholm Health Ethics Bulletin*. The Board also agreed it would be better to include precise bibliographical references in End Notes rather than simply supply a list of source material used.

Suggestions sought. I would like to invite readers who wish to help us to improve our *Bulletin* to write to me with their comments. I would appreciate suggestions for future topics for articles. It is important that our articles be well researched. Up to now most of our articles are about 2,000 words in length. We are prepared to include shorter articles if we are given this indication. It is a matter of knowing if subscribers prefer to keep all our articles at about 2,000 words long or to vary the length of research articles in each issue – say 500 words, 1,000 words, 1,500 words and 2,000 words. If you send in your suggestions for the *Bulletin* it would be helpful for us if you also indicated whether you are a private subscriber or a member of a hospital, university or school community.

Enclosed in this *Bulletin* you will find the registration form for our conference on 6 August 1998 on "Aboriginal Health: The Ethical Challenges". Also please return the enclosed invoice for your subscription for Volume IV of our *Bulletin* from July 1998 to June 1999.

Norman Ford SDB

Gene Therapy, Patenting and Genetic Research

In this last article on genetics and the Human Genome Project I look at the ethical issues involved in gene therapy. I then move on to discuss the vexed concepts of ownership and patenting of genetic information.

Introduction

In the last Bulletin article I identified two kinds of potential issues with regard to the Human Genome Project (HGP). The first is concerned with the ethical and moral questions raised by the existence of the HGP itself. In my discussion I looked at the risks of our society putting too much importance on genetic research. In particular, I looked at the way that the DNA molecule is now being seen, in the words of Nelkin and Lindee, as the secular equivalent of the human soul and that, consequently, in the mind of the general public, genetic research will eventually be able to solve all health and social problems. There is concern that the scale of the project, and the financial resources being poured into it, may outweigh the benefits that will be received, particularly given that the beneficiaries, in the main, will exist in the future.

The second potential issue raised by work on the HGP is the use to which the resultant information may be put. This is seen as being of particular concern, given that genetic diagnosis

"the patient's own malfunctioning genes will be altered and reinserted back into the body"

may reveal genetic abnormalities or potential problems for which there is, as yet, no treatment or therapy. Consequently, there is worry about the issues of confidentiality and discrimination, particularly with regard to who may have access to genetic information about individuals. While it is understandable that a potential insurer, or even employer, may see access to genetic information about clients or employees as necessary, there is still some fear that people may be discriminated against because of their genetic makeup.

Gene Therapy: Somatic and Germ Line

Given these legitimate concerns, the subject of gene therapy, although not actually part of the HGP in itself, is worth discussing. Strictly speaking, the HGP is the sequencing and mapping of the human genome. But, having mapped the genome, the next logical step is to determine the function and variation in expression of the mapped genes, thus allowing researchers to devise new drugs, immunotherapy techniques and avoidance of the environmental conditions

that may trigger genetic disease. Eventually, this will lead to the possible replacement of defective genes through gene therapy, the greatest promise of benefit from genetic research.

Currently, research efforts are being made into somatic cell (body cell) therapy, a therapy that involves treating a genetic disease in the body cells of a living individual by introducing functioning genes. Eventually it is hoped that rather than using functioning genes from donors, the patient's own malfunctioning genes will be altered and reinserted back into the body. Genetic diseases being researched into in this manner include cystic fibrosis, muscular dystrophy, hereditary cancers and cholesterol problems, emphysema and coronary artery disease. However, somatic cell gene therapy alone, while helpful for an individual, does not prevent the hereditary genetic disorder from being transferred to

"somatic cell therapy is not seen as being ethically problematic"

the next generation.
Germ line gene therapy, on the other hand, could involve the insertion of a corrective gene into sperm, eggs or early embryos. Consequently, it means that the inserted gene is not only incorporated into the individual but could be passed on to future generations. Theoretically, it could eventually eliminate targeted disease-causing genes from the human gene-pool.

Research into gene therapy is already occurring. According to Walters and Palmer, the first sanctioned human somatic cell gene therapy experiment began in 1990. This involved isolating T cells (a type of white blood cell) from a little girl suffering ADA deficiency (an immune system problem), inserting properly functioning ADA genes from a donor into those T cells, and then reinfusing them back into the little girl. The functioning genes were carried through her body by an engineered retrovirus. The procedure was a success. Although the child remains on treatment drugs, these have been reduced by more than half.

Ethical Issues

Traditionally, according to Chalmers et al, an ethical line has been drawn in gene therapy between germ line and somatic cell techniques. Somatic cell therapy is generally not seen as being ethically problematic, provided the technique is thoroughly researched and safe. Indeed, it is largely seen by ethical commentators as being morally desirable because it will help to relieve individual human suffering. Walters and Palmer have identified 28 policy statements throughout the (mostly western) world from the years 1980 to 1993 representing multiple professions, religious traditions and cultures. All 28 suggest, and I agree, that somatic cell gene therapy for the cure of serious disease is ethically acceptable.

However, ethically, germ line therapy is problematic because of uncertainty about the long-term effects of the therapy. In particular, a concern is expressed that while the known disease may be eliminated, the individual, or their offspring, may become more susceptible to some other disorder. Essentially, the procedure may create new problems due to the fact that genes often control several functions and correcting one may adversely affect others. In other words, the therapy may result in unforeseeable harm rather than good. For example, it was discovered that some sufferers of Sickle Cell disease in Africa also have a natural immunity to certain types of malaria. It is unknown what would occur to this immunity if Sickle Cell disease was eliminated. As a result of these unknowns, and their possible harmful consequences, the National Health and Medical Research Council in Australia has currently rejected germ line gene therapy. In this, they adopt a similar position to other countries.

Therapy or Enhancement

Walters and Palmer, however, argue that there is nothing wrong with germ line techniques as such, stressing that "we think that the same sophisticated techniques that were employed to introduce the new genes will be able to be used to remove [side effects] or to compensate for their presence in some other way." In addition, they suggest, if such techniques are able to correct serious genetic defects then it should not be regarded as unethical tampering. Instead, they suggest that the ethical line that should be drawn is between therapeutic and enhancement techniques.
Interestingly, the confusion between

"ethical line should be drawn between therapeutic and enhancement techniques"

somatic and germ line, therapeutic and enhancement, seems to be perpetuated by some ethical commentators. Peters, for example, stresses that "somatic therapy should be pursued, but enhancement through germ line engineering raises serious questions about protecting human dignity." I think that we must ensure that we understand the distinction between therapeutic and enhancement therapy, whether somatic or germ line. Germ line therapy could provide the same benefits as somatic, provided enhancement techniques are avoided, and provided they cause no harm. According to Peters, the U. S. Catholic Health Association states that as "germ line intervention is potentially the only means of treating genetic diseases that do their damage early in embryonic development. . . . this is a goal toward which biomedicine could reasonably devote its efforts." However, it is difficult to see how we can ensure these benefits without experimenting on human embryos.

Therapeutic gene research, whether somatic or germ line, provides the possibility of alleviating human suffering. Enhancement therapy however, although presumably a very long way in the future, raises the

spectre of eugenics, threatening human dignity in the quest to "improve" heredity.

Ownership

Surprisingly, perhaps one of the most contentious issues that has now arisen from the issue of genetic research is based, not on the ethics and morality of such research itself, but on the issue of *ownership* of the resulting data. Given the enormous quantity of data involved, and the growing number of private companies funding human genetic research, the possibility for commercial gain has increased exponentially. McNeil points out that "the Office of Science and Technology has said that the Human Genome mapping program has enormous potential not only for the improvement of health but also for *wealth* creation." And Macer reiterates that many countries joined the HGP because they recognised its potential economic benefits and they feared that they would be refused access to the U.S.-based databases.
In such a climate it is, perhaps, natural that investors wish to see their investments protected.

"most contentious issue is ownership of the resulting data"

There are actually two issues involved here. One is a political one, concerning access to the information gleaned from the HGP. At one stage there was a suggestion that only those countries that are participating in the HGP should be allowed access to information concerning the mapped human genome. The Human Genome Organisation (HUGO) is vigorously opposed to such a move, and in this I agree. The human genome represents *all* human beings and those countries which, for social or financial reasons, are unable to participate, should not be discriminated against, or deprived of its potential benefits.

Patenting

The second issue is concerned with the possible financial gains available from genetic research. Consequently, a debate over whether genetic discoveries can be patented has raged in the U.S., Europe, and now Australia. In order to be patentable, something must be useful, non-obvious and novel (involving an inventive step). Traditionally, phenomena of nature have not been patentable and consequently, as a natural occurrence, DNA has not been considered as patentable. Recently, however, natural discoveries, in which there has been "some human intervention" have been considered as satisfying the criteria for patenting, particularly if they involve something more than simply a "discovery". For example, the discovery of a link between a particular gene and a genetic disorder is not patentable: however, a way of diagnosing or locating a genetic defect may be.

"a link between a particular gene and a genetic disorder is not patentable: a way of diagnosing or locating a genetic defect may be"

Beyond this though, lies the question of whether human genetic material is the sort of product that *should* be owned and patented. How ethical is it to allow a financial benefit for something that may be derived from humans? As Hanson points out, many religious critics have argued that granting "ownership" in something as essentially human as DNA offends the notion of human dignity. The concept of the commercialisation of human genes prompts concerns about promoting a materialistic conception of life.

However, it must be understood that it is not ownership of a particular *gene* that is granted. Instead, what is granted in a patent application, argues Nicol, is "ownership of information derived from that gene and the commercial application of that information." Additionally, a patent only lasts a limited period of time – 16 years in Australia – after which anyone may use or exploit the invention.

Another way to look at patenting and commercialisation is to see it as keeping genetic research in the public arena. Patent law can only protect an invention if the invention is publicly disclosed. In fact, Nicol claims that the *refusal* of patents on various genetic discoveries has driven much of the research and information underground in an effort to protect discoveries. In addition, allowing information protection provides an incentive to invest in research that may ultimately benefit society. Already, in Australia, there is public debate over the problem of lack of funding and incentive for scientific endeavour.

Conclusion

When weighing up the issues of patenting and ownership, we perhaps need to come down on side of patenting for purely pragmatic reasons. Unfortunately, it is possible that the days when scientific discoveries were freely shared are gone. If we wish genetic discoveries to be shared, and to remain in the public arena, then it appears that we may have to provide protection for the financial investments involved. We do not live in an age where companies, or even governments, will fund research and expect no financial return.

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Anna Stokes

The Elderly and Autonomy

Mrs Darcy is an 82 year old lady experiencing obvious increasing frailty who lives on her own. She has, until recently managed on her own with community support. She is fiercely independent having raised her children on her own after her husband died in his thirties. Two weeks ago she slipped over and fractured her arm. Five years ago, her daughter convinced her to wear a medical alert alarm which she activated when she fell over. She was admitted to hospital, underwent the appropriate treatment and now her children want her to sell her house and move into supported accommodation in an attempt to prevent any further falls. Mrs Darcy is adamant that this is not what she wants. There is no suggestion that she is mentally incompetent and she seems to be aware of the risks involved in remaining in her own home. Her children and health professionals fear for her safety.

Mrs Darcy is not a real person but there are many elderly individuals in the community just like her who live alone and are unable to continue to function independently in their own homes without putting themselves at some degree of risk of injury or accident. With increasing age, elderly people often have decreased energy capabilities and restricted mobility, their sight and hearing may be impaired and their reflexes when performing such actions as driving may be somewhat dulled. Yet, for all their lives these people have been able to meet their own needs and been in control of their lives. They have made autonomous choices about their families, their careers, their values, their health and the course of their lives and these choices have often involved risks. The sorts of choices made and the risks that they have considered worth taking throughout their lives, reflect the values which they hold dear, and are part of their identity as autonomous individuals. Problems arise however, when older people insist that they are capable of living independently and their family or other interested people do not think that this is safe. According to Virginia Rice et al "personal control and autonomy are powerful components in terms of life satisfaction, survival, and how one defines one's role in society." Taking away a person's autonomy may take away their will to live. There are, therefore, many issues which need to be analysed when the question is raised as to whether an elderly person should move into long term supported residential accommodation.

Autonomy

Autonomy, according to Mildred Hogstel and Alice Gaul, may be defined as a "form of personal liberty based on respect for persons, in which individuals have the right to determine their course of existence, as long as that right does not infringe on the autonomy of others." However, for a person's decision to *be* autonomous they must be free from coercion and pressure and be aware of, and accept the ramifications of the decision that they make. The rationality of their decision and perhaps their competency to make decisions, may be questioned by others and *this* is where dilemmas arise. Whether a decision is an autonomous one is a different issue from whether it is considered by others to be rational. Subjectivity cannot be dismissed. We can respect peoples' autonomy to make decisions about indulging in risky behaviour such as sky diving, motor car racing or living alone in a house where there is a danger of falling

"whether a decision is an autonomous one is a different issue from whether it is considered by others to be rational"

and breaking bones. We accept their decisions when we know that they have not been forced to act in this way and, if they are fully aware of, and accept any consequences. However, from an onlooker's perspective the decision may not be seen as the right one but this is not a reason for questioning the competency of the decision maker. Just because there are inherent risks in a behaviour or course of action, it doesn't mean that those risks have to be avoided. According to Tom Beauchamp and James Childress "A general presumption exists that

adults are competent to make their decisions, and when those decisions are unproblematic (in part because they concur with professional judgement), no motive exists to challenge competence." This would seem to be an accurate statement especially in reference to situations where elderly people wish to stay in their own home but health care professionals are of a different opinion.

It also cannot be ignored that people may be competent to make autonomous decisions in some areas of their life but not in others. A person may be able to make autonomous decisions about what they will eat and when, but they may not be able to decide what to do with their finances.

"an obligation based on reciprocity would imply a duty"

In the specific case of whether or not a frail elderly person should live independently, one also has to consider whether the exercising of their autonomy by staying in their own home, infringes on the autonomy of those who assist and support that person. Whether or not family members even have a moral or familial obligation to care for their elderly relative is a contested issue. It is more or less generally accepted that when a couple have children, their first priority should be to care for those children to the best of their ability. Reciprocity on the part of those children once they have grown and it is the elderly parents who require the care, is not such a commonly accepted concept. An obligation based on reciprocity would imply a duty, a debt to repay, and if that debt could ever be repaid, then no further obligation would exist. Yet, how can anyone settle with their parents for all the benefits that they received when a child? However, an obligation based on gratitude would suggest that caring for an elderly parent is a response of appreciation and goodwill. For behaviour to be based on gratitude implies that there is something to be grateful for. In this case, according to Sarah Vaughan-Brakman the conditions necessary for gratitude on the part of the child include "that parents provide benefits of life and/or caregiving to their children, voluntarily, benevolently, primarily for the sake of the child alone and that the benefits provided are considered socially valuable."

When relatives *do* provide the ever increasing levels of assistance required to keep an elderly person in their own home, they may experience quite restrictive limitations on their own life in order to maintain that help. It is predominantly women, daughters and daughters-in-law, who provide this care and who try and balance these responsibilities with those of raising their own children and holding down employment. This can be very difficult and may prove very stressful. If there is an equal or even more compelling obligation to meet, such as caring for young children, then, perhaps adult children have to work through their priorities. This may mean that the obligations to the younger generation which are forward flowing may to some degree override those to the older generation.

Beneficence and Non-maleficence and the Right Action

Using the principles of beneficence and non-maleficence in order to determine the right course of action is problematic in that one has to determine what are the harms and what is the good. Is the good what the person themselves, or what someone else sees as being in their best interests? In the situation of the elderly person who wants to live independently but who may be at risk of falls, fires or malnutrition, one could say that supporting the autonomous choice of that person to remain at home supports the principle of beneficence, but in doing so, one is accepting the fact that harms may occur. In much ethical analysis the prevention of harm may be seen as more imperative than the promotion of good. A relevant point which should be considered is what is the likelihood of a harm occurring? Are the risks high? Has the elderly person fallen several times before, set the kitchen alight, or is it just an unsubstantiated fear that they may do so in the future which has raised the issue of whether the person is capable of staying in their own home? Forcing an elderly person to change their living arrangements, just so that their relatives can feel secure and comfortable is not a legitimate reason or motive for the elderly person to have to move.

"what are the harms and what is the good"

Paternalism

Paternalism is when someone decides to override the autonomous decision of another, or actively ensures that a person has no opportunity to make a decision, so that the person then has no control over a course of action which affects them, either in a specific situation, or in the way in which they live. Paternalism derives from the belief that someone feels that they know better about how someone else should live or what should happen to them in a specific circumstance. Whether or not paternalism is ever justified is open to contention. Theoretically, the person overriding the autonomous decision and known preferences of another feels they can justify their involvement or 'taking over' by insisting that their intention is to benefit the other person and to avoid harm. According to Beauchamp and Childress "Paternalistic acts typically involve force or coercion, on the one hand, or deception, lying, manipulation of information, or nondisclosure of information on the other."

"whether or not paternalism is ever justified is open to contention"

Beauchamp and Childress make a

distinction between 'weak paternalism' and 'strong paternalism'. Weak paternalism is when a person is supposedly being protected against their own nonautonomous action which is so judged because the individual concerned has not been adequately informed; they are not aware of all the facts; they may be experiencing severe depression; or a severe addiction prevents free choice and action. In other words, it is thought that the ability of the individual concerned, to make an autonomous decision is compromised. Strong paternalism on the other hand, even when intended for the perceived good of the individual, is when someone else takes control and intervenes, despite the fact that the person's own risky choices and actions are informed, voluntary and autonomous. While strong paternalism may perhaps never be justified, even weak paternalism has its problems. Severe depression or addiction may prevent fully autonomous choices but the determination of whether some-one is adequately informed, can be open to many interpretations. Is explaining risks and likely consequences enough? How does one know whether there is a full understanding? Perhaps, because the possible risks do not seem as significant, or, when balanced against alternatives, they do not have so much importance as they do to the onlooker, it is surmised that the individual concerned is making an irrational decision because *they* do not think that they should avoid the the risk of harm.

"choices and actions are informed, voluntary and autonomous"

According to Beauchamp and Childress, those who feel that paternalism is justified, do so because of the following reasons. Firstly, "the harms prevented from occurring or the benefits provided to the person outweigh the loss of independence and the sense of invasion caused by the intervention". Secondly, the person's physical and mental condition critically affects their capacity to make an informed choice. Thirdly, it is thought that the intervention would be universally justified given the same circumstances in other situations and fourthly, the person mostly affected who benefits from the paternalistic intervention has consented, will consent, or would, if rational, consent to those actions on their behalf.

The Common Good

There is also a conflict between collectivism or the common good, and independence. There is a tension between respecting the rights of people, in this case elderly people to do what they please (without harming others), and recognising the needs of society to maintain or reduce health care costs, in this case by reducing the numbers of admissions to acute care facilities. It could be argued by some that society has the right to expect people to take care of themselves if they are able, and to avoid becoming excessive burdens in terms of health care costs and care requirements by seeking help when necessary and avoiding risky situations. However, why should old age and frailty determine the loss of independence? The elderly obviously do not have a long future to look forward to, to plan, or to strive for. Yet, having worked all their lives, maybe raised a family and looked after themselves financially, it is not much to expect that if capable they should be able to determine how and where they spend their remaining years.

"to take care of themselves if they are able"

Admission to a long term accommodation institution involves giving up control over most of your life. Even with the best of intentions, care facilities have rules and regulations which although hopefully aimed at the common good of all those who live there, set the agenda for most of the remaining life of those admitted. No wonder many people fight to the end to remain in their own homes where they can be surrounded by as much memorabilia as they desire; where they can eat and drink when and what they please; where they can lock the door and where they can come and go as they please.

Conclusion

Issues surrounding the balance between respecting the autonomy of the elderly and minimising risk are complex and extremely difficult to resolve. It is often a dilemma between the elderly person and their immediate family or health care professionals, all of whom care for each other and hopefully want the best. There are no obvious answers and no one answer or solution can be generalised to apply in every situation. However, given that an autonomous decision is one made without force and coercion and one made with the full understanding and acceptance of any consequences, then it should be respected despite what others think is in the best interests of the decision maker.

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Artificial Hydration in Terminally Ill Patients: Is There a Moral Obligation?

A significant number of patients, family members and professionals in today's health care environment struggle over what is appropriate and ethical management for the terminally ill patient. Generally, for critically ill patients difficult choices have to be made about introducing, withholding, or ending life support measures such as mechanical ventilation, cardiopulmonary resuscitation, antibiotic therapy, tube feeding and artificial hydration. This article will look at the complex issue of withholding artificial hydration from the terminally ill patient who is at the end stage of the illness. In the terminally ill patient the end stage generally lasts several days but it may last from a number of hours to a couple of weeks. The focus here is on the last few days. It is not an an issue if it is a matter of hours.

For professionals working in the field of palliative care, whether, or not, to use measures of artificial hydration at the end stage of the patient's illness is not generally seen as an ethical issue. However, in the acute hospital setting many professionals have concerns about the issue of continuing hydration in patients until the end. It is also true that people with little knowledge of the clinical features of dehydration in the terminally ill patient at the end stage fear that failure to provide artificial hydration is either incomprehensible, unnatural, cruel or a means to hasten death artificially.

"health care professionals are aware that feeding and giving fluids involve emotional and symbolic concerns of care"

None of these are in fact true. In the palliative care setting there are particular circumstances where decisions involving whether or not to hydrate individual patients by artificial means are complex. Furthermore, all health care professionals are aware that issues surrounding feeding and giving fluids to patients involve emotional and symbolic concerns of care for both families and carers. There is no doubt that the issue of hydration in the terminally ill demands investigation and public discussion. Perhaps the greatest need is for more widespread general awareness of the acceptability of not hydrating terminally ill patients at the end stage of their disease. This principle can be applied not only to terminally ill cancer patients but to those patients in acute hospital settings who are clearly dying from other causes.

Identifying the End Stage of Dying

From the outset it is important to look at how the end stage of dying and the variables of the situation can be recognised. Secondly, it is essential to note the differences made to a patient's comfort by either administering or withholding artificial hydration in the end stage. It is also necessary to consider the circumstances under which artificial hydration constitutes good medical management of terminally ill patients.

"dehydration at the end stage is a natural physiological part of the dying process"

The end stage for terminally ill patients is usually preceded by some days or even weeks of increasing drowsiness, occasional disorientation, limited attention span followed by a diminishing desire to eat, and finally to drink, until the patient gives up eating and drinking altogether. In fact it is the observation of palliative care professionals that many patients become unable to swallow in the last couple of days. Of course the process of dying is individual and for some people there is very rapid deterioration. However, for palliative care professionals it is usually clear when a patient is at the end stage of their disease. Although drowsiness may be increasing and food and fluid intake decreasing, many patients at this stage can be easily roused and can communicate with family and carers. It would be true to say that the majority of patients, though dehydrated at this stage, do not become unconscious until a matter of hours before their death. Dehydration at the end stage is a natural physiological part of the dying process.

Dehydration and its Benefits

Jackonen (1997) gives a definition of terminal dehydration as any disorder of salt and water depletion that occurs in the last several days of life. She gives an informative report of three categories of terminal dehydration. The most important point she makes is that the dehydration most commonly occurring in the terminally ill is not associated with intense thirst. A number of authors outline the benefits of withholding artificial hydration. Woodruff (1993) states that dehydration in the dying patient is beneficial in a number of ways. A reduction in urinary output reduces the need for patients to move on and off bedpans in order to urinate. It avoids the need to catheterise patients to manage this problem. Decreased gastrointestinal secretions can reduce nausea and vomiting. Decreased pulmonary secretions reduce breathlessness and congestion, the latter associated with the death rattle which is distressing for patients' families. Furthermore, reduced oedema (excess accumulation of fluid) surrounding a tumour, if present, may reduce pain. There is also a reduction in peripheral oedema, for instance in the hands. This is an important factor for families at a time when they want to be

particularly close and hold the hand of the person dying.
However, it is important to point out

"dehydrated terminally ill patients are in less distress and less aware of pain than artificially hydrated patients"

that Woodruff's criteria are not absolutes. Individuals differ, have different pathologies and may not always react in the same way to hydration at the end stage. However, in a review of the literature, many authors consistently state that both research and case study evidence show that dehydrated terminally ill patients are in less distress and less aware of pain than artificially hydrated patients. Conversely, artificial hydration of patients at end stage can cause the opposite effects, and distress to the patient and family. Dryness of the mouth appears to be the only symptom of dehydration at the end stage. This can be palliated by regular and simple mouth care, an aspect of care of which families often choose to be a part. According to Woodruff and other authors, dying patients do not complain of thirst and this is borne out by case study evidence.

It is important to distinguish between appropriate use of artificial hydration in palliative care and its inappropriate use at end stage. Artificial hydration is administered either intravenously or more commonly in the palliative setting, subcutanenously. Subcutanenous administration is more comfortable. Artificial hydration is used in dehydrated patients who are not yet at the end stage to correct reversible conditions such as hypercalcaemia and electrolyte imbalances, which cause symptoms such as weakness, confusion and nausea. The point to make is that there is a difference between hydration in the end stage and hydration which is a part of good medicine in palliative care for patients who are not imminently dying. The question must always be asked is this crisis reversible, what is the cause, and should we actively treat this crisis?

Ethical Issues

Within the philosophy of palliative care the patient and family are seen as the unit of care. Furthermore, both patient and family are involved in making decisions about treatment, with emphasis being on informed consent and respect for patient choice. The reduction of suffering for patients *and* families is paramount. Use of artificial hydration in the end stage phase sometimes becomes an ethical issue in the palliative care setting when patient and family needs conflict. One of the most basic human needs and instincts is to care for our own in nourishing and nurturing them by giving food and drink. The mother-child relationship is the purest image of this. In fact, food and drink are intertwined with expressions of love and affection throughout our lives. Letting go of that fundamental means of showing love and care is difficult, and seems unnatural at first. Indeed in the Christian tradition water is a symbol of life. The point at which families have to accept that fluids are no longer helpful is that point at which they truly realise that life is coming to an end. However, with good communication between health care professionals and the family, these fears can be addressed and the need to care and nurture can be redirected. Generally, families can understand that at this stage the body is "shutting down." Cecily Saunders and her colleagues report that only two or three times a year per 1000 admissions to St. Christopher's Hospice, London, do circumstances arise where families are unable to accept that the dying person does not require artificial hydration until death.

A second set of circumstances involves requests by families to maintain artificial hydration in the hope that the patient may live a bit longer, whilst family are waiting for a close family member to arrive from some distance away. The family member expresses a need to see the patient and to say good-bye, but the patient has a basic need to die at the natural time, without undue discomfort and not to have a prolonged death. How can these conflicting needs be resolved?

The Principle of Due Proportion in Treatment

The Catholic tradition has a down-to-earth store of wisdom in the area of health care ethics. As committed Catholics we uphold the belief that life is a gift from God and our responsibility is to respect the dignity of human persons. Physical life is a basic value and it is the fundamental condition to achieve all other values. However, the Catholic tradition does not consider that the physical life of the embodied person is an absolute value that must be sustained at all costs. For that reason there are reasonable limits to keeping someone alive using life sustaining medical procedures. The Catholic tradition prudently directs committed Catholics to the principle of due proportion in treatment. (Charter for Health Care Workers: 1995). When there are "proportionate reasons", a patient in conscience may refuse treatment that would be judged disproportionately burdensome in the circumstances. In other words if the treatment does not alleviate distress or bring about real benefits to the patient then it is not obligatory.
In a situation where death is inevita-

"there are reasonable limits to keeping someone alive using life sustaining medical procedures"

ble and imminent, the duty of care to the patient involves avoiding procedures that are disproportionate to the good sought. If artificial hydration prolongs death, and is of no real benefit to the patient, then it is considered inappropriate and not part of the duty to care. On the other hand, if a family member has a particularly close bond with the dying patient, or strong need to see the pa-

tient, this is morally significant. The family, assisted by the health care professionals, must make a prudent judgement in the circumstances as to whether the discomfort which may be incurred by the patient, is proportionate to the good sought for the family member. In the situation where the family remain distressed in spite of all efforts by staff to explain the possible complications of artificial hydration at this stage, and provided that the patient has not expressed a contrary opinion, nor finds it too burdensome, then hydration may be justified. In these cases some of these distressing symptoms such as the "death rattle" may be palliated with appropriate medication.

In summary, good ethics take into account the reality of situations and are not simply a matter of applying abstract principles. In the case of artificial hydration in the terminally ill patient at the end stage of the disease ethical considerations are based on a thorough knowledge of the physiological processes at work. At the same time ethical considerations must take into account the patient and family as a whole including psychological, spiritual and social needs. Health care ethicists must dialogue in detail with multidisciplinary professionals who work in the area. It is clear that the philosophy of palliative care is based on respect for the individual's dignity and worth. This is the linch pin of ethics which is about doing the right thing by ourselves and others. There is no doubt that professionals are faced with ethical dilemmas in this field of work. These seem to particularly involve conflict between patient and family needs, and in situations where all efforts do not resolve physical, emotional or spiritual distress in patients and families.

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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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Director/Editor: *Rev. Norman Ford SDB STL PhD, Adjunct Professor, Australian Catholic University*

Research Officers: *Deirdre Fetherstonhaugh* DipAppSc PGCert BA MA
Tracey Phelan BSc BA(Hons)
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Administrative Assistant/Layout/Sub-editor: *Margaret Casey* BTheol