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Predictive Testing for Huntington's Disease in Young Children Part 1

Huntington's disease (HD) is an inherited disorder. Sufferers usually develop symptoms in midlife between the ages of 30 and 50 years.[1] HD causes neurodegeneration resulting in the progressive development of physical, cognitive and emotional symptoms. The impact on sufferers worsens over time with the final stage of the disease resulting in the need for professional assistance in a long-term care facility. More rarely HD develops in children and young adults, with less than 5% of HD sufferers being affected by Juvenile HD.[2] This article considers the ethical aspects of such testing.

Symptoms and Treatment

HD can present itself in a range of symptoms; however each individual is affected differently by the disease.[3] The symptoms include involuntary 'jerky' movements (chorea), abnormal gait, slurred speech and swallowing difficulties. The effects on cognition involve short term memory loss with HD eventually leading to the development of dementia. HD can also cause personality changes resulting in impulsivity and disinhibition, depression, mood swings and aggression. Juvenile HD has slightly different symptoms from the adult-onset HD. Approximately half of Juvenile HD sufferers experience epilepsy compared to two percent of adult HD patients.[4] Children affected by this disease have slow rigid movements, learning difficulties and some have severe behavioural problems.[5] Earlier onset of HD is associated with more rapid disease development. The symptoms of HD can be treated with medication but currently there is no cure for HD. Individuals affected by HD survive an average 17-20 years after the onset of symptoms.[6] HD has a dominant inheritance pattern which means that only one copy of the gene inherited from one parent would cause the disease.[7] Therefore a child of an individual carrying the HD gene has a 50% chance of inheriting HD and subsequently developing the disease. The *HD* gene is located on chromosome number 4 and contains a series of genetic codes that are repeated. Normally there are about 20 of the repeats but in the disease causing gene there are 40 or more repeats.[8]

Predictive Genetic Tests

In the case of HD, predictive genetic tests can be carried out for an asymptomatic individual who is at risk of inheriting the disease.[9] Undertaking genetic testing for HD is not an easy decision to make. These are many complex issues an individual would have to consider. Receiving a positive test result would have a strong impact on an individual's major life decisions including career, relationship and reproductive decisions. Some people may choose to end a relationship upon receiving a positive test result. Some individuals may already have children when they find out that they are at risk. The results of the test may also affect sibling relationships.

International guidelines on predictive genetic testing of HD recommend that testing should be available 'only to those who have reached the age of majority (according to the laws of the respective country).'[10] The Human Genetics Society of Australasia (HGSA) recommends that children should only have predictive testing when the test results will be 'used to help with their health management in the immediate future.' [11] As HD is typically an adult onset disease and doesn't affect a child's immediate health, predictive testing should not normally be carried out on children. There are several issues regarding predictive ge-

IN THIS ISSUE

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netic testing in children that are outlined in the HGSA policy on predictive testing in children that will be further discussed below.[12]

Autonomy

It can be argued that predictive testing in children for adult onset conditions results in breaching the child's future autonomy. It removes the right of the future adult to decide against predictive genetic testing. Adorno argues that telling children of their genetic status breaches the right 'not to know' and that there needs to be respect for the future adult.[13] Others argue that it does not breach a child's future autonomy because parents are already responsible for making decisions for the long term benefit of the child.[14] It is argued that bringing a child up with the full knowledge about their genetic risk creates a situation in which they are still able to lead autonomous lives and make decisions based on 'a realistic picture of herself and her relationship to the world.'[15] Malpas also argues that a child will not be limited in decisions about their future but will make different decisions.[16] This is opposed to the uncertainty of not knowing one's genetic status. These decisions need to take into consideration whether or not they are found to carry the gene mutation.

From what has been learnt from disclosure about biological and adoptive origins many believe that the earlier a child is told the less severe the impact on the child's sense of self will be; as they grow up they will be able to integrate this knowledge into their self-concept. [17] If this argument is applied to genetic testing then it follows that parents should make their child or children aware of the risk of inheriting HD from a young age. The HGSA recommends that 'Parents should be encouraged to make their child aware, at an appropriate age, of the genetic condition in the family and the implications, and for the child to be reared with this knowledge.'[18] It is argued that 'Being able to discuss this information within the family over a number of years at different stages of maturity will ultimately enable the child to make a better informed choice about predictive genetic testing as an adult.'[19] Malpas goes further to argue that if a child is to be told that they are at risk for a genetic disorder, it follows that they may be able to undertake genetic testing.[20] It is held that by simply telling the child of the risk their ability to make an informed autonomous decision about predictive testing later in life could be facilitated.[21] Malpas also believes that it is unfair for parents to withhold information about a child's genetic status or risk of an inherited disease; some may use this as a way of exerting control over their children.[22]

Potential Harms

It is a great concern that children may suffer negative effects after finding out that they have inherited HD. The child may suffer from reduced self-esteem or anxiety about their future. If a child has witnessed a parent of other relative suffering from HD they may become very anxious and frightened because they do not have the level of comprehension required to understand and cope with the thought of having the disease. There are also concerns that a positive test result will affect the way a child is treated within the family. The test results may harm the parent-child relationship and parents may have lowered expectations of the child compared to other siblings who haven't inherited the disease.[23] The HGSA notes that the child may suffer from 'stigmatisation in family and community and less opportunities for education, marriage and reproduction'.[24] Additionally parents may feel guilty for passing on an illness to their child.[25] The test results may also harm sibling relationships if one or more receive positive test results while others have negative test results.[26] Siblings who do not carry the HD gene may suffer from survivor guilt, where they feel guilty for not having the HD gene when a sibling has unfortunately inherited HD. Another issue that needs to be considered is the loss of privacy of a child's genetic information. Individuals who have been tested may resent the implications of their test for matters such as obtaining insurance and /or employment.

Potential Benefits

In addition to the benefit of a child growing up with a clearer picture of who they are and being given the knowledge to make informed decisions about their future there are other benefits to disclosing a child's likely HD status. Studies examining disclosure of serious illness to minors has found that giving children information about the disease is preferable to non-disclosure.[27] Children may be able to sense that other family members are upset and anxious about something and explaining HD to children may in fact allay their fears. Giving children information that is at the right level for their age and level of maturity and in a supportive family setting may prevent misunderstandings and groundless fears that can result from a child using their imagination to fill in gaps in knowledge. While there are serious concerns that disclosure of a positive HD test can impact negatively on family dynamics, it can be argued that a positive test result can bring families closer together with increased communication about the disease within the family, decreased parent and child anxiety and decreased uncertainty about the child's future.[28] Telling children of their risk of HD would prevent them feeling resentful towards parents who haven't told them of their risk of inheriting HD. HD often develops earlier and earlier in individuals as it is passed on through generations, particularly if it is passed on by fathers.[29] An individual who is in their twenties and is developing symptoms of HD may have appreciated being told that they would develop HD from a young age.

Some children will witness a family member suffering from HD and may begin to ask questions about the ill-

ness. In this case it is important that parents do not withhold information as this would be harmful to the child who will sense that there is something wrong. When children begin to ask questions about the disease it is important to give them clear factual information about HD. As for children who are unaware of the risk, it is important to leave it to parents' discretion to decide whether to tell their children that they are at risk. Parents can inform them about HD in accordance with their need to know and their present capacity to cope with this knowledge of risk concerning themselves and with the knowledge of family support. This decision must be made with a full understanding of the range of issues involved and also be made with the help of a genetic counsellor. However, one might ask is it worth telling the child that they are at risk and burdening them with this knowledge when they may not have inherited the disease? It may be better to find out firstly whether they do have the disease and then take action if it is in fact required i.e. the test result is positive. The genetic counsellor must act as an advocate for the child and determine whether the family situation is one in which the child will receive love and support regardless of their genetic status. It is also important that parents are able to get guidance from a genetic counsellor about the ways that they should explain HD to their children. This would make it more likely that children will be informed in a sensitive and appropriate manner. Parental discretion and the good of the child are the key factors.

ENDNOTES

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Predictive Testing for Huntington's Disease in Adolescents : Part 2

Predictive genetic testing Part 2 will examine the issues and ethical aspects that must be considered when adolescents below the age of majority make a request to undergo predictive genetic testing for Huntington's disease.

Given the serious nature of predictive genetic testing for adult onset diseases international guidelines have been developed outlining recommendations on how professionals should manage the multitude of issues they face. These guidelines state that genetic testing should only be carried out on children and adolescents if there is a medical benefit i.e. the illness can be treated or can be prevented.[1] This is the case of familial adenomatous polyposis (FAP). This is an inherited disorder which results in hundreds and thousands of polyps developing in the large intestine generally by the late-teens.[2] It is almost certain that some polyps will become cancerous. People with FAP are at risk

of developing bowel cancer much earlier than the general population if no intervention is undertaken. That is why genetic testing is carried out in minors at risk of inheriting this disorder. If the mutation is detected then regular screening can be carried and surgery can be done to remove the affected section of the intestine to prevent the development of cancer. However, for illnesses such as Huntington's disease (HD) where there is no medical treatment, testing adolescents would have no medical or physical benefit. International guidelines advise that only those who have reached the age of majority, when they are considered to be adults, should undergo genetic testing for HD.[3] Australasian guidelines also recommend that predictive genetic testing should only be available to those who have achieved the age of majority.[4] But some argue that an exception should be made for adolescents who request to undertake a genetic test if they demonstrate sufficient maturity.

Reasons for the Genetic Testing of Adolescents

Adolescents who are aware that they may have inherited HD may wish to undergo a predictive genetic testing for HD. There are multiple arguments for allowing adolescents to undergo predictive genetic testing. The adolescent may be anxious to know their genetic status in order to make plans for their future.[5] These plans may include decisions about their career, relationships, future reproductive decisions and financial plans. It is also argued that if an adolescent were allowed to undergo a predictive genetic test, finding out if they have inherited HD would allow them to prepare psychologically for the illness.[6]

A major argument against predictive genetic testing of minors is that it breaches the autonomy of the future adult. However other authors argue that allowing a mature adolescent to undergo testing at their own request actually promotes the development of their autonomy.[7] Adolescents would feel empowered by being given the responsibility for making serious decisions about their personal well being and health. It is also argued that there may be a reduction in anxiety even when a positive result is obtained as the trauma caused by the uncertainty of not knowing one's genetic status is removed.[8] In one study adults that chose to undergo testing reported that the burden of not knowing was greater than that of knowing their genetic status.[9] While many argue against the predictive genetic testing of adolescents because of the psychological harms that can be caused, some authors point to the harms that could be inflicted by not allowing adolescents who so wish to undergo genetic tests.[10] Bloch et al. write "the decision to postpone testing can never be taken lightly.[11] The stress of undergoing testing, receiving a result, and adjusting to the new risk status must be weighed against the stress and uncertainty of living at risk for HD, the blow to the candidate's self-respect by being denied testing and the possible sense of humiliation and helplessness by having one's autonomy undermined."[12] Adolescents may have personal experience of seeing a parent or another relative affected by HD and this may influence them to want to find out their own genetic status.

Arguments against Genetic Testing of Adolescents

Many of the arguments against predictive genetic testing for HD in young children can also apply to adolescents. For example, the concerns of self-esteem, anxiety, depression, family relationships, privacy and insurance (discussed in Part 1 of this article), are critical issues that need to be taken into consideration. One of the major concerns with testing adolescents is the potential to cause psychological harm. A study into the effects of the psychological impact of predictive testing for HD on adults has shown that there have been few adverse outcomes.[13] However, it has been argued that these studies haven't examined the long term effects.[14] Some authors have made the point that adverse outcomes may have been underestimated because those who are having difficulties adjusting to the knowledge that they have HD may not present for follow up studies.[15] It was found that in the long term, levels of hopelessness were higher in those adults who found out they had the gene for HD.[16] These findings illustrate the gravity of the decision of whether to test adolescents for HD. While it can be argued that withholding a predictive genetic test can be harmful to an adolescent it has also been argued that this harm is reversible as the adolescent will be able to undergo testing when they have reached the age of majority.[17] It is an additional concern that while adolescents may themselves request to undergo a genetic test, they may still be vulnerable to coercion by their family or friends.[18]

Richards examines the issue of brain development and points to evidence that the brain is still developing in the late teens.[19] This means that adolescents are 'disadvantaged in their decision making capabilities by incomplete brain development and associated underdevelopment of executive functions.'[20] Richards outlines the circumstances of three eighteen year olds who requested genetic testing for HD to 'highlight the concerns about the maturity of judgement of these individuals in this context.'[21] Two of the three case studies will be outlined. The first case study is about 'Alex'. Alex's parents had been separated for some time and Alex's father with whom he had little contact, died from complications of alcoholism. It was found post-mortem that Alex's father carried the gene for HD. Richards explains that when Alex was asked why he wanted to undergo testing he replied "Because I am 18 now and I can have the test." Alex did not demonstrate an understanding of the serious implications of genetic testing including the emotional implications of a positive test result or the implications for his future. Alex and his girlfriend whispered and gig-

gled during a video documentary about HD and didn't have any questions after watching the video. Alex decided to postpone testing after it was explained that undertaking the test may jeopardize his application for a job in the public service which required extensive training.

The second case study outlined the situation of Jasmine whose mother had been affected with HD when Jasmine was seven years old. Jasmine requested testing for HD at eighteen years of age but was unable to give any clear reasons for wanting the test beyond that she wanted to know her HD status. Jasmine did not demonstrate an understanding of how a test result would affect her plans or affect her emotionally. Jasmine also didn't understand the importance of nominating a support person but in the end nominated her mother's sister who had previously tested negative for the HD gene. Her aunty was concerned about Jasmine's immaturity and lack of understanding of HD. Additionally Jasmine's aunty was planning to travel abroad for a long period off time. Since her aunty was the only support person Jasmine could nominate it was decided that Jasmine's test would be postponed. Jasmine returned four years later to undergo testing and stated that she hadn't been mature enough at eighteen to make the decision to undergo testing and is now postponing testing while examining her insurance options.

These two cases are enlightening and suggest that even at the age of majority young people may not have developed the maturity to undertake a predictive genetic test for HD. The cases also suggest that if adolescents were allowed to be tested it is of vital importance that they are thoroughly assessed. However, Richards argues that the current methods used to assess competence are inadequate and that undertaking studies into the effect of testing on adolescents would 'breach the principle of non-maleficence' towards them.[22]

The most important thing to take into consideration when an adolescent is undergoing genetic counselling prior to undertaking a predictive genetic test is whether that individual is mature enough to understand the implications of their test results. Disallowing predictive genetic testing for HD in adolescents in general is a protective measure that would prevent the occurrence of serious psychological damage. However, requests for genetic testing by adolescents should never be ignored. Adolescents should be heard and respected and it may be beneficial for them to be given the opportunity to undertake counselling and assessments of maturity to enable them to serenely accept that it may not be in their best interests to pursue the avenue of predictive genetic testing for HD before they turn eighteen.

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Barriers to Rehabilitation

In Victoria, a complex maze of issues govern the accessibility of appropriate support for people with a severe disability or serious illness, be it financial assistance, or a range of rehabilitative services. This article is a continuation from the previous article printed in the last issue of the Bulletin - Crisis: Young People Living in Aged Care Homes.

Following catastrophic injury or illness the need for rehabilitation may affect all areas of a person's life. The Honourable AO Woodhouse (1974) captures the encompassing scope of rehabilitative services by referring to the fields of 'medical, vocational, educational and social' rehabilitation.[1] Yet across Australia, the way in which an illness or disability is acquired, has tremendous influence regarding the availability and duration of rehabilitative services or long term care support.

A person who sustains a head injury in Victoria may have vastly different access to material and financial support, and *subsequently health care and rehabilitative support*, depending on whether the injury was acquired from a registered Victorian (moving) motor vehicle, a work accident, a criminal act of vicious assault, medical error, or an unintentional fall without the involvement of a liable third party. *The pivotal issue here seems to be that differences in the ways injured people are rehabilitated can arise from factors such as whether they are recipients of financial compensation, or whether their injury or illness is non compensable.* The National Health Priority Areas Report (1997) states:

> '…coordination of various aspects of rehabilitation is less often managed by rehabilitation specialists…In the absence of a coordinated and clearly identified rehabilitation program for a particular client, a range of services are generally brought into play to provide some degree of rehabilitation….Clients outside the target group for CRS…. are faced with poor links between treatment and rehabilitation services and are likely not to receive timely or adequate rehabilitation if their injuries are due to a non compensable cause….'[2]

Whilst a more recent statement on the accessibility of rehabilitation in general could not be located, the Australian Government Department of Health and Ageing (2006) comments that for 'people recovering from heart attacks, cardiac procedures or stroke…there is a reported deficit of rehabilitation programs and services…'[3] Recently, the question of inconsistency in the rehabilitative care offered has been raised elsewhere. The Australasian Faculty of Occupational Medicine The Royal Australasian College of Physicians Health Policy Unit (2001), summarises: 'While this is important, it does not explain the difference between outcomes for patients with compensable and non compensable injuries, since they presumably receive the same type of treatment from GP's and allied health professionals. But do they ?...'[4]

It is more than reasonable that a system exists through which rehabilitative medicine is prioritised. But it makes little sense for compensation, and the rehabilitation that can be purchased from this, to be significantly influenced by arbitrary secondary factors such as how the injury or illness was acquired.[5] The high variability in the award of damages for compensable injury or illness is concerning.[6] The Commonwealth of Australia (2002) highlights that the separate statutes covering different causes of injury, and different laws for 'compensation for personal injury and death' in Australian states and territories contribute to this problem.[7] Uncertain outcomes for injured and ill people in respect of claims for financial assistance has un-stated, but obvious ramifications regarding their disempowerment resulting from imparities in purchasing power. More often than not this limits not only the injured persons' purchasing power, but also their progress. This point is summarised most succinctly by the Commonwealth of Australia (2002): 'There is also no principled reason, for example, why a person should receive less damages for an injury sustained in a motor accident than for one suffered on holiday while at the beach…'[8]

Impact on people's lives

One of the most compelling reasons to take this problem seriously is the fact that many people with severe disabilities or serious illness have little choice over the type of accommodation in which they reside. *Imagine this scenario* - A healthy young woman of just 16 years, has a well developed personal interest in pursuing a career in the field of psychology. In the midst of a promising future she endures a horrific assault. She survives strangulation and is repeatedly bashed, and is left unconscious. It is a nightmare for her family, who struggle to reason that their daughter and sister now has a serious brain injury, with total body paralysis and post traumatic amnesia. After 7 months some movement is gained in her little finger.

At this time it is impossible for her parents to arrange for permanent private rehabilitation, because it is unaffordable. The defendant had limited financial assets and did not have third party insurance, so an award for damages through civil litigation was not possible. Compensation

for the primary victim of $7,500 for pain and suffering and up to $60,000 for the payment of bills, was awarded by the Victims of Crime Tribunal. Secondary compensation was awarded to her parents. Adding to their overall sense of despair, her medical specialists verbalise their belief in her poor prognosis. She was discharged from hospital to a nursing home, where she was a recipient of the Acquired Brain Injury Slow To Recover (ABI STR) Program funding, which is for people who acquire a (non compensable) brain injury.

This is not a work of fiction. The personal journey of this young lady has been marked by courage and determination. But the question needs to be asked: whether her pathway and access to rehabilitation should be any different from someone with a comparative brain injury, but for whom the cause was a car accident or work accident? Today, she is again highly articulate and perceptive; she communicates with ease through computer aided technology; and now lives at home with her family, still with the support of ABI STR funding.[9]

Or consider a lady who has Multiple Sclerosis, and who at under 50 years of age, resides in a nursing home. She is unable to get into the community as often as she would like because of her physical limitations. She now quietly discusses that she wishes more of the community could come to her. In spite of her grace and fortitude, there has been the enduring trauma of the systemic depletion of independence over a long period of time. Some stages of physical deterioration have been accelerated and without warning, making the psychological adjustment to changing circumstances an uneasy process. On top of this, imagine permanent separation from most of your material possessions, because they no longer fit into one small room in a nursing home. Her need for appropriate accommodation which focuses on proactive rehabilitation, and access to people with whom she can develop meaningful personal relationships is no less important.[10]

A whole of community issue

It is a sobering thought, but no one is immune from the possibility of having the course of their life drastically altered through injury, accident, illness or trauma. In Australia there are a variety of provisions designed to support people who become incapacitated from earning income. Depending on the circumstances of injury or illness this might include civil law or statutory compensation, a range of insurance products, Medicare, private health or life insurance products or the Australian social security system. In-spite of this, many people who experience the need for significant medical and rehabilitative intervention find themselves in financially devastating circumstances. In Australia there is not a universal system that allocates resources to people based purely on assessed need. The Insurance Australia Group confirm that 'people who suffer fundamental, life changing injuries face futures that differ, depending on where and how they were injured.'[11]

What we as a society do with this information is revealing. Is our responsiveness to the most disadvantaged of our citizens a true reflection of the values we as a society have adopted? Kendrick (2002) reminds us:

> 'It is one thing to be seen to embrace a value, and another to sacrifice oneself for its realization, and to bear the cost involved. When values get too tough to stay firmly resolved to, people and groups often become quite expedient, and choose the path of least resistance. Honourable people, whose characters we admire, stand in contrast, because they tend not only to espouse values, but organise their lives to uphold them.'[12]

Should our community be more proactive and step in the gap, so to speak and support an approach to public health care that will reliably provide standards of rehabilitation without significant variation between compensable and non compensable cases? In acknowledgment that this issue is unresolved, the purpose of this article is to encourage the Government and the community as a whole to consider the more egalitarian benefits of a national, publicly funded no fault social insurance scheme. The intention of such a scheme would be to accommodate those people who are catastrophically injured or seriously ill, and who have been excluded from either compensation or appropriate insurance coverage. The Honourable Mr Justice AO Wood, in his 1974 Report of the National Committee of Inquiry anticipated that such a scheme would cover injury, congenital disabilities and sickness.[13] The Honourable Mr Justice AO Wood wrote:

> 'The principle of community responsibility carries with it the natural corollary of comprehensive entitlement. Once society as a whole has accepted the need to support those of its members who are burdened by injury or sickness, they could not, in fairness, be assisted or ignored, or supported by differing levels of compensation, depending merely upon the fortuitous cause of the incapacity.'[14]

Whilst it is beyond the scope of this article to define a specific model for a no fault social insurance scheme for Victorians, it is not envisaged that such a scheme should replace either of the (Victorian) statutory compensation schemes of Work Cover or TAC. Clearly where people can afford to arrange for their own future income protection through insurance this should remain a personal responsibility.[15]

Snapshot - rehabilitation barriers

In understanding why such a scheme is needed, the complexity of the underlying causes that contribute to the un-

equal distribution of health care services needs to be considered. A snapshot of these issues can only be presented here.

On the topic of civil law, Luntz (2006) highlights that in 1995 in Australia only a few of the people who suffered a personal injury proceeded to litigate.[16] Many of those who did succeed 'had their damages reduced for contributory negligence.'[17] Additionally, the amount of compensation awarded to plaintiffs is often reduced by diverse factors during negotiations in litigation. Luntz (2006) suggests that contributory negligence is often used as such a '*bargaining factor*'.[18]

It is widely reported that the success of civil law compensation relies heavily on the establishment of *proof of fault* at common law. Consider the injustice of such a system in the following fictitious example. Two new born babies of different families have intense life long care needs associated with disability, acquired through hypoxia from birth trauma. In case one, the birth trauma is compensable, because an obstetrician was found to be negligent in some way. The parents are awarded compensation and have access to financial support to assist in the infant's care needs, and throughout the child's life course. In case two, a similar level of birth trauma is experienced. However a close review established that the actions taken by the obstetrician were found to be reasonable, according to the standards and expectations of the profession. A detailed investigation was undertaken to see whether another course of action might have led to a different outcome, but ultimately the obstetrician was not found to be negligent, as such. The outcome of birth trauma is the same for both parents, both babies have the same level of hypoxic brain injury, and nil abnormalities were identified prior to the birth. But only the parents in case one have access to financial support through compensation.

Despite the combined coverage of the Victorian statutory compensation schemes of the Transport Accident Commission (TAC) and Work Cover, there is still a significant proportion of injury victims who are ineligible for any form of compensation, and who may also be precluded from insurance. In support of this the *Australia's health 2006* publication reveals that falls alone caused 36% 'of all hospitalised injury separations', compared to 14% caused by transportation.[19] The *Injury deaths, Australia 2003-04* report states: 'the most common cause of injury death was Unintentional falls, which accounted for 30% of all community injury deaths' in that period.'[20]

The Investment and Financial Services Association Ltd (IFSA) advises that approximately 6.3 million Australians have 'individual life, disability and trauma' insurance policies.[21] Whilst the majority of people (93%) can purchase insurance policies in the standard manner,[22] the reality is that for people with long term illness and disabilities, policy exclusions may mean that the desired support is actually unavailable.[23] IFSA confirm that up to 2% of applicants are refused any cover due to serious health impairments. Another 5% are affected by the underwriters' assessment that they are high risk clients, and therefore face either higher premiums or policy exclusions.'[24]

Conclusion

In undertaking research for this article, local cases surfaced, where a worrying variety of barriers prevented access to rehabilitative support. A literature review confirmed that this problem is in fact magnified, by the presence of other unique cases, with albeit similar outcomes. When injury or illness is not compensable, and where suitable private life insurance products are not purchased beforehand, the prohibitive cost of private rehabilitation, and the limits to what is currently provided through the public sector can have a devastating impact on potential recovery.

ENDNOTES

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Kate Jones ✠

Stem Cells, Altered Nuclear Transfer & Ethics

Once therapies using embryonic stem cells enter clinical practice, pressure will increase to find pluripotent stem cells for therapeutic purposes that are not derived from human embryos. This article explores several likely sources of such pluripotent cells.[1]

Use of Pluripotent Human Embryonic Stem Cells in Australia

The Australian Parliament accepted the Lockhart Review Recommendations and passed the *Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Act 2006*. This was granted Royal Assent on 12 December 2006, effectively permitting human embryos to be created for the purpose of research, subject to each project's licence approval and conditions.

Human embryonic stem (hES) cells are eagerly sought by researchers for both scientific and therapeutic purposes. They are called hES cells because they are derived from a human embryo, i.e., the inner cell mass (ICM) of a six to seven day old human blastocyst. They are said to be pluripotent because, after transplantation, their cell progeny can virtually contribute to any cell type of the body. Researchers would like to induce hES cells to develop along specific pathways to form blood, cardiac or neuronal cells for therapeutic purposes.

Respect due to human embryos

Regrettably hES cell research involves the destruction of human embryos. There are credible scientific and philosophical reasons for holding that the new cell resulting from fertilisation, the zygote, is already constituted with the biological identity of a new human individual, i.e. a human being. Pope John Paul II in his 1995 Encyclical Letter *Evangelium Vitae* rightly says:

> What is at stake is so important that, from the standpoint of moral obligation, the mere probability that a person is involved would suffice to justify an absolutely clear prohibition of any intervention aimed at killing a human embryo…*'The human being is to be respected and treated as a person from conception.'*[2]

The challenge to find ethical alternatives

The prospects of cell therapies derived from hES cells entering clinical practice is real. Catholic healthcare facilities could not ethically have recourse to any therapies that rely on the use of hES cells since this would involve collusion with the destruction of the human embryos. It is imperative that Catholic healthcare facilities find alternative cell therapies by seeking to obtain pluripotent stem cells from non-embryonic sources.[3] This may need to be done in collaboration with overseas firms.

Adult stem cells

Adult stem cells are not derived from embryos and do not raise the ethical problems of hESs. They can be obtained from blood formation in bone marrow (hematopoiesis) and other parts of the human body. Mary Horowitz reports "thousands of patients have received hematopoietic cell transplantations (HCTs) to treat life threatening malignant and non-malignant diseases. Current estimates of annual numbers of HCTs are 45,000-50,000 worldwide. Reasons for widespread use include proven and potential efficacy in many diseases …"[4] But, proponents of hES cell research claim adult stem cells lack the required versatility of pluripotent hES cells.

However, some cord blood (CB) cells are pluripotent. These could be stored in CB banks and be used to make a sufficiently close match to the tissue of patients in need of a transplant to repair a variety of damaged tissues. Since pluripotent CB stem cells are not easy to isolate, the ethical need to find other non-embryonic derived pluripotent SCs remains. This in turn has its own scientific and ethical problems which have to be solved and this requires an understanding of what is, and is not, a human embryo.

Recently researchers have 'isolated human amniotic fluid-derived stem cells (AFS) that express embryonic … stem cell markers… Clonal human lines verified by retro-

viral marking were induced to differentiate into cell types representing each embryonic germ layer… Examples of differentiated cells derived from human AFS cells displaying specialized functions include neuronal lineage cells … hepatic lineage cells producing urea, and osteogenic lineage cells forming tissue-engineered bone.'[5] This good news is exciting because effectively pluripotent stem cells can be derived in this way from amniotic fluid cells without the need of creating cloned human embryos nor the use of any eggs.

Definition of the human embryo

The following suggested definition of the human embryo may be helpful:

> 'a totipotent single-cell, group of contiguous cells or multicellular organism, in virtue of whose genome, it has the inherent actual potential to continue organised species-specific human development, given a suitable environment.'[6]

Once typical human development begins, an embryo is present as long as development is not irreversibly arrested.

Nicanor Austriaco, a Dominican priest, offers a similar definition:

'Philosophically, an organism can be defined as a complete living substance that has its own internal principle of motion and change directed towards its natural perfection; and scientifically, as a discrete living unity of matter that follows a self-driven, robust developmental pathway that manifests its species-specific self-organization.'[7]

Pluripotent ES cells are not totipotent, because of themselves without first being modified, they cannot form a whole offspring, a complete, integrated, living being from the embryo stage onwards.[8]

Pluripotent stem cells from altered nuclear transfer: -- an ethical option?

Dr William Hurlbut, a biologist at Stanford University and a member of the USA President's Bioethics Commission, took up the challenge to find a way to generate human pluripotent stem cells that were equivalent to ES cells without creating or destroying human embryos. Successful fertilisation results in the formation of a new zygote or organism, i.e. 'a dynamic whole, an interactive web of interdependent processes that express emergent properties not apparent in the biochemical parts'[9]. In cases of failed fertilisation there is no intrinsic capacity to form a totipotent developing embryo. Likewise, a disorganised mass of cancerous cells found in tumours or the uncontrolled growth of cells in a teratoma are not embryos: they are not totipotent nor are they capable of becoming integrated self-regulating organisms.[10] Teratomas can form ES cells but not an integrated functional blastocyst. Hurlbut adds: 'Altered nuclear transfer [ANT] proposes the artificial construction of a cellular system… that lacks the essential elements for embryological development but contains a partial development potential capable of generating embryonic stem cells'.[11]

By inactivating the gene Cdx2 of a mouse somatic-cell nucleus, development begins in the enucleated mouse egg following ANT and activation, but ceases by the blastocyst stage due to the absence of the blastocyst's outer trophoblast cells. These cells are necessary for implantation to occur as well as for on-going the development and the formation of the placenta.[12] The deficiency of trophoblast formation is not merely a defect of a part but 'is more properly understood as an "insufficiency", not a defect in a being (like not having a limb) but an inadequacy at such a fundamental level that it precludes the coordinated coherent and active disposition for development that are the defining characteristics of an embryonic organism.'[13]

In the light of his view of an organism Hurlbut holds that the transfer of a Cdx2 muted somatic-cell nucleus into a human egg whose Cdx2 genes has likewise been inactivated would result in a

> 'cell system that would have no inherent principle of unity and coherent drive in the direction of the mature human form, and no claim on the moral status due to a developing human life', without creating or destroying a human embryo, but merely 'a non-embryonic entity.' [14]

Dr Maureen Condic, an eminent developmental biologist, lends her support to Hurlbut's proposal:

> 'The weight of the scientific evidence to date strongly indicates that formation of the trophoblast is required for subsequent development, and that this primary deficit preludes the formation of an integrated organism. Cells of the trophoblast and of the ICM communicate with each other, and this communication appears to be required for coordinated development of the embryo as a whole. When the trophoblast does not form, subsequent development follows a chaotic pattern suggesting that organismal development has not been 'disrupted' in the absence of the trophoblast, but rather that an organism never existed in the first place.' [15]

Scientist Douglas Melton thinks that the products of ANT are true embryos and suggests 'an alternative interpretation would be that embryos lacking Cdx2 develop normally until Cdx2 function is required, at which point they die'.[16] Nobody questions the humanity of living fetuses who have a lethal genetic or chromosomal abnormality,

e.g. trisomy 16, that causes death before, or soon after, birth.

Hurlbut replies that a Cdx2 muted pseudo embryo is not really an embryo because it is not totipotent from the very start of its existence since it would lack the intrinsic capacity to successfully undergo the first major cell differentiation into ICM and the outer trophoblast cells of the blastocyst. After all, a normal zygote is totipotent and a human embryo on account of its intrinsic potential to express its actual totipotency for organising a whole human being, albeit immature, in virtue of its human genome and the relevant sub-set of genes being switched-on. It is not necessary for human development to proceed beyond the fetal stage and much less to be born alive to qualify as a human being. Hurlbut's point is that a living entity that, from the start, is intrinsically incapable of developing to the blastocyst stage fails to achieve typical human development and only gives rise to a disorganised cell mass. Unless the developmental program is intrinsically capable of organising an integrated functional blastocyst, it is hard to hold a human embryo with the requisite totipotency is present at all.

Hurlbut's concept has received endorsement from the recently published results of a study in mice by Alexander Meissner and Rudolf Jaenisch:

> 'The results reported in this paper provide proof of principle that inhibition of genes important for trophoblast function can prevent placentation without interfering with ES potency… Cdx2 deficient blastocysts are able to form an ICM and generate ES cells when explanted in tissue culture.'[17]

Austriaco rightly agrees this proposal is ethical, subject to conditions. He requires proof from animal trials that the nucleus prior to transfer is pluripotent and not an embryo. He also requires that after insertion into a receptive female mouse 'the reconstituted cell of ANT-Cdx2 must not develop along the trajectory of a mature organism'.[18]

Altered nuclear transfer – oocyte-assisted reprogramming

Due to the early ethical problems of Hurlbut's ANT proposal, a group of US scientists, philosophers and ethicists discussed another form of ANT that would unambiguously result in the formation of a pluripotent stem cell. Instead of inactivating the gene Cdx2 in a somatic cell nucleus, it was proposed to modify key genes of the somatic cell nucleus so that after its transfer to an enucleated egg only a pluripotent stem cell could be formed – not a totipotent cell or embryo. This would be achieved through genes called Nanog and Oct3/4 whose transcription factors are responsible for setting in place and maintaining cells in the pluripotent state. Nanog is not found in oocytes nor in the single-cell embryo, but it is expressed in the cells of the ICM beginning from the morula stage.

In the Dolly cloning procedure, the egg's cytoplasm epigenetically reprograms a somatic cell nucleus back to the totipotent state by varying the expression of its gene activity. In this new proposal, prior to transfer to an enucleated egg whose Cdx2 is also inactivated,[19] the somatic nucleus would be modified by manipulating it to acquire high levels of expression of the genes Nanog and Oct3/4. This causes the cytoplasm's epigenetic reprogramming to form a pluripotent cell which could be grown and multiplied in culture to produce a pluripotent stem cell line. No embryos would be formed and none would be destroyed. This procedure has been called altered nuclear transfer – oocyte assisted reprogramming (ANT –OAR). The above mentioned group has published its proposal in full with a list of 35 signatories, including Hurlbut, and concludes that ANT-OAR

> 'would achieve its objective, not by a gene deletion that precludes embryonic organization in the cell produced, but rather by a positive transformation that generates, ab initio, a cell with the distinctive molecular characteristics and developmental behavior of a pluripotent cell, not a totipotent embryo. This should allow us to produce a pluripotent stem cell line with controlled genetic characteristics.' [20]

Ethics

Research should begin with animal cells and not to proceed to human cells unless it is morally certain a human embryo would not be created. Again I agree with Austriaco's prudent caution, and would require his same guarantees for Cdx2 deficient cells, i.e. proof of pluripotency, inability to develop into an embryo once implanted and proof of a capacity to produce a pluripotent stem cell line.[21] Additionally, the source of human eggs would need to be beyond moral reproach.

Direct reprogramming adult cells into pluripotent stem cells

In our previous article, we described the success of Japanese researchers Kazutoshi Takahashi and Shinya Yamanaka in directly reprogramming mouse pluripotent adult cells into pluripotent stem cells.[22] If trials with human cells verify this method, an ethical way would be at hand for using pluripotent stem cells for medical research and therapies without the need of using human eggs, nor the creation and destruction of embryos. Time will tell if this proves to be safe and effective as well as being ethical.

ENDNOTES

[1] This article draws on and develops some issues discussed in 'Human pluripotent stem cell research and ethics', *Monash Bioethics Review*, 25/1 (2006) 31-41. . Most of this article was

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STOP PRESS: Human Cloning Bill in Victorian Parliament

On March 13 Victoria's Minister for Health, the Hon. Bronwyn Pike MLA introduced a Bill to allow therapeutic cloning in Victoria. It is proposed that this bill will mirror the Commonwealth's *Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Act 2006* passed just before Christmas. If this Bill is passed, Victoria would be the first State to permit somatic cell nuclear transfer (therapeutic cloning) and thereby open the way for the destruction of cloned human embryos for therapeutic purposes and medical research. The reason for introducing this Bill is to amend the current legal prohibition in Victoria against cloning human embryos. Our Centre hopes that the Parliament rejects this Bill as it permits licenses to be given to researchers to destroy human embryos. We see no justification for this in the light of the various ethical alternatives outlined in my above article

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