

# Chisholm Health Ethics Bulletin

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## How Private is Our Privacy in Health Care?

*People seeking medical care expect that health professionals will respect their dignity and that all aspects of their care will remain private. Yet the reality is that their privacy is frequently violated. The legal and ethical challenges related to preserving privacy in health care will be discussed in a two part series. Part one examines personal and informational privacy in health. Part two, next bulletin, will examine how privacy is secured.*

**T**he Victorian Public Hospital Patient Charter states that 'health services will be provided in surroundings which allow privacy, including privacy to undress and only be seen by the doctor, nurse or other health care staff providing care'.<sup>1</sup> Breaches of privacy may be unintentional. It may not mean that the individual will litigate, but it will leave a legacy of insecurity and mistrust. In addition, other information about patients may be exposed to numerous individuals without their knowledge or consent. Again this may be unintentional yet have serious repercussions for that individual. But what is privacy and do we have a right to claim it.

### Do We Have a Right to Privacy?

There are varying opinions about the philosophical and ethical assumptions about a right to privacy. Placing privacy in the context of a moral principle aligned with respect for autonomy as argued by Beauchamp and Childress, 'includes the right to decide in so far as possible what will happen to one's person - to one's body, to information about one's life, to one's secrets, etc.'<sup>2</sup> They extend this right to those who have never been autonomous in that they have rights not to be 'needlessly viewed or touched by others'.<sup>3</sup> However, if I go out in public I don't have the right not to be seen. Anyone can look at me and I at them, in certain social situations. People have developed tolerance for this because humans are social beings, which implies some degree of interaction with others, though there are limits to this tolerance from a social, cultural, legal, ethical and individual point of view.

There appears to be no explicit right to privacy generally conferred by federal or state laws. We have legislation covering aspects of privacy but none that categorically gives an individual the right to be left alone. This was made apparent when the High Court found that a tort of Privacy was not recognised in Australian Law.<sup>4</sup> However, a Queensland judge recently paved the way to allow individuals to recover civil damages for mental, psychological or emotional harm, where 'a willed act of another intrudes on their

privacy or seclusion in a manner which would be considered highly offensive to a reasonable person'.<sup>5</sup>

It's suggested that Australia's lack of a constitutional or statutory Bill of Rights means that any attempt to develop privacy laws as an aspect of human rights is thwarted. In addition, there have been few cases in court to test privacy laws.<sup>6</sup> The Victoria Law Foundation defines privacy as the right to be left alone, and includes stopping or setting limits on intrusions into one's body, place of residence, personal mail, telephone calls or other private communications and personal information.<sup>7</sup> Whilst Australia lacks a Bill of Rights to enforce assumed privacy rights there is a universally declared agreement in principle. Article 12 of The Universal Declaration of Human Rights states: 'No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks'.<sup>8</sup>

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## Legal Protection of Privacy

Some examples of Commonwealth and State Laws which protect aspects of privacy in Victoria include:

- Information Privacy Act 2000 (Vic)
- Health Records Act 2001 (Vic)
- Privacy Act 1988 (Cth)
- Surveillance Devices Act 1999 (Vic)
- Telecommunications Act (Cth) 1997
- The Crimes Act (as amended) 1914 (Cth)
- National Health Act 1953 (Cth)
- Health Services Act 1988 (Vic)

### Information Privacy

Personal information is information about an individual whose identity is clear or can reasonably be worked out from that information, eg., name, address, age, financial status and eligibility for concessions or benefits, and family information. Privacy laws cover documents, photographs, electronic material and digital databases. Sensitive information refers to a person's racial or ethnic origin, philosophical or religious beliefs or affiliations, political opinions, membership of political associations, professional or trade association or union, sexual preferences or practices, or criminal record. The Commonwealth Privacy Act recognises health information as sensitive information but Victoria's Information Privacy Act doesn't, because health information is protected by the Health Records Act. A general exemption to privacy of personal information is allowed with employee records, which are not covered by the Privacy Act.<sup>9</sup>

### Preserving Privacy in Health Care is a Challenge

Health care professionals have certain privileges in relation to privacy due to the nature of their work, but are not above the law if they abuse them to the detriment of their patients. Australian case law permits breaches of confidentiality only in situations where there is a clear risk of harm to an identifiable person, though there is not a duty to warn.<sup>10</sup> The Privacy Act does allow for disclosure if it is in the public interest, eg. serious threats to life, health or safety. This concept can be interpreted in terms of community versus individual benefit where it is suggested that doctors not only seek to restore a patient's health but must do so in a manner that preserves and promotes the common good.<sup>11</sup> Examples of this may be informing authorities about a person's medical condition that may impair their ability to drive safely. Another is reporting suspected child abuse under mandatory reporting laws. In general the common good protects confidentiality: cases are rare when disclosure is required. When the common good requires disclosure in particular circumstances, public trust in medical confidentiality is not eroded.

Breaches of privacy would appear to attract equal consid-

eration in law, but are more difficult to prove and defend. Privacy can be breached merely by unauthorised access to client information. Unless this information is disclosed in some way, technically the rights of confidentiality may remain inviolate. The Crimes Act does cover offences relating to unauthorised access. Can one's privacy be breached if one does not know one's information has been accessed without consent? In reality, this practice may be pervasive but we don't know about it. Whilst much of this relates to written information, can similar questions be asked about personal and bodily privacy? People trust health professionals to treat their bodies with dignity and respect in life and death.

### Ethical Issues and Privacy

It would be possible to be very respectful yet at the same time violate a patient's privacy. How much information is really relevant? How much looking and touching is unnecessary? How many people not involved in a patient's care, have access to their health information or invade their privacy by intruding during discussions or examinations. Perhaps someone inadvertently witnesses or overhears a patient's private examination or discussion with a health practitioner because they are being treated in the near vicinity. Has the practitioner been negligent in not protecting privacy? Has the patient suffered damage by another's inadvertent intrusion even if that person just happened to be passing by and looked. Should this be the expected standard and can it be condoned, even though, technically, someone's privacy has been breached.

Who has access to an individual's health record is not always accurately conveyed to that particular individual. Sharing of information between treating practitioners has also come under scrutiny following a survey which identified that implied consent for 'routine' uses of health information should not be assumed.<sup>12</sup> Privacy laws now allow an individual to access their own health information held by private and public health providers. How this information is regulated is currently being drafted in the form of a National Health Privacy Code. The draft code generally aims to safeguard the health privacy and dignity of all individuals in a consistent way nationally, taking account of technological change.<sup>13</sup>

Reality TV shows which give us a voyeur type view into aspects of life, including medical care, are considered entertainment. Viewers are exposed to real medical dramas with sick and injured people, not actors. Does having an audience, albeit a hidden one, then affect the therapeutic relationship for that person in some way? Do the health professionals change the way they practise for the camera? Does editing of the material give a biased perspective? The potential for these images to be used for litigious purposes has been considered in America, where filming an emergent medical situation may take place before consent can be obtained. If consent is then denied, the filming may technically be considered as an invasion of pri-

## Threats to Privacy

Over the years there has been an insidious march into territory that was once considered private. The country supports a welfare state, and in doing so, requires both givers and recipients to disclose personal information. Tax File Numbers are a form of national identity for financial purposes, yet Australia rejected the idea of an identity card many years ago. Some suggest that health data about individuals should be traceable throughout all jurisdictions nationally, and a system is being considered for a HealthCare card to carry data about us from birth till death.<sup>15</sup>

Everyday our privacy is intruded upon: video-camera surveillance as we enact our daily commercial chores, some whilst we engage in work activities. Picture enabled mobile phones are popular and issues regarding their potential to violate privacy have been discussed in the media.<sup>16</sup> There are also calls to restrict solicitation over the phone by direct marketers.<sup>17</sup> Personal frustration with such cold calls has prompted me to demand, 'Where did you get my number?' 'From a database,' is the usual reply. 'Where did you get the database?' 'We bought it!' Transaction details are used to create such databases.<sup>18</sup> Some calls, representing Australian Companies, are from overseas phone numbers, eg. India.

Is a person's health data safe from commercial exploitation? Traditionally, health data has been used for research and auditing purposes. The various privacy laws have impacted on how data can be accessed and in what circumstances. For example, ethical research conduct mandates that human participants give a valid consent. Yet at present a person's consent is not required for use of their de-identified health data and it is irrelevant if they state that they do not wish their health data to be used for research purposes. In this respect a person has no rights to decline since their information becomes part of a large data and statistics pool - one that can be bought and sold for commercial and research purposes. Use of their data may confer a social good if used to further knowledge, but it does take away the right of that individual to choose.

## The End of Privacy as We Know It

We may wish to preserve our bodily privacy out of modesty, and our personal health information for fear of it being used to discriminate against us, yet it appears we are tolerant about the prospect of our physiology and/or behaviour being used in ever more innovative ways to prove we are who we purport to be - for security purposes to protect our notion of privacy. Since the September 11 terrorist attack, people in the Western World may be forgiven for having a heightened sense of vulnerability. It is surprising, therefore, that the USA Patriot Act of 2001<sup>19</sup>, rushed through soon after the attacks, is now causing

some concern due to the inordinate and unregulated nature of surveillance and detection activity that it legitimises. Some suggest that aspects of the Act violates civil liberties.<sup>20</sup> Strict privacy laws, not only in health care, but generally, have expanded the security market. Hence the boom in the Biometric industry, which is the topic of Part Two in this series about Privacy.

## ENDNOTES

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Anne Moates



## Safer Advances in ART?

*Recently, Assisted Reproductive Technology (ART) has come under scrutiny both here and overseas. An article in the previous issue of this Bulletin looked at concerns with established techniques; this concluding article examines the safety of novel advances in ART.*

**D**emocratic societies allow individuals to decide between genuinely competing values and determine in the light of these values how they ought to proceed. This central plank of liberal societies may seem well and good, except that in the case of starting a family, there is the child, whose interests need to be taken into account. Nowadays, other parties, such as the embryologist and clinician, and social issues, such as state funding of health resources, are inextricably involved in the whole equation. The interests of the developing child still remain paramount, but, the fact that fertilisation is now achieved ex vivo raises a host of other concerns. And this is by no means an isolated or minor issue. It is estimated that approximately one in six couples now experience problems with fertility at some point in their reproductive lives,<sup>1</sup> with Assisted Reproductive Technology (ART) now being a central part of treatment for the estimated 10% of infertile people of reproductive age.

The rapid pace of scientific advances within the field of ART, therefore, may at first seem to be all good news for infertile couples. On closer inspection, however, it becomes apparent that revolutionary techniques such as intracytoplasmic sperm injection (ICSI), preimplantation genetic diagnosis (PGD) and cytoplasmic transfer are being utilised, and some such as ICSI widely so, before comprehensive clinical trials have determined their efficacy and long-term safety for the offspring involved.<sup>2</sup>

### ICSI Concerns

ICSI involves the micromanipulation of sperm and eggs in the laboratory. Basically, while the egg is held by suction, a single sperm is inserted into it using a fine glass needle. Although ICSI was originally developed to overcome infertility attributable to the male (such as immotile sperm), it is now extensively used for many other types of infertility, with some ART laboratories routinely using the technique in up to 80% of all cases.<sup>3</sup> It seems evident, then, that the procedure has become somewhat trendy in many IVF clinics. The major concern with

such a technique is that it bypasses the great majority of natural selection checkpoints encountered by the sperm during normal fertilisation. There is also a real risk of damaging chromosomes and other cellular structures as a result of inserting a glass needle into the egg at such a critical stage. ICSI also introduces sperm and artificial elements that would not normally enter the egg, such as the outer-sperm membrane and synthetic media components. Furthermore, it has been shown that the ICSI procedure invariably causes essential events that occur after sperm entry (such as replication of paternal DNA) to be delayed. With the growing prevalence of ICSI, such differences bear closer inspection and warrant longer-term studies in order to assess whether the technique has any detrimental impact on the developing ICSI-conceived child.

### Extended Embryo Culture

Another recent innovation in many ART centres has been the transfer of embryos into the uterus at a later time---usually 5 days after fertilisation as opposed to the conventional transfer after three days in culture. Theoretically, this should allow the embryologist to transfer the 'best' possible embryo(s), resulting in a higher pregnancy rate. The problems with this approach are manifold. Firstly, although indicators for embryonic health do exist, they are only based on the superficial appearance of the embryo and have not been shown to be definitive or strongly diagnostic. Furthermore, there is no molecular basis supporting this observation.<sup>4</sup> Thus embryos that may well be viable and have developmental potential may be discarded as 'suboptimal', while the 'best' embryos may not in fact be so. The most telling point, however, is the fact that this theoretical advantage has not been translated into practice. Parallel experiments have so far shown no advantage of extended culture over 3 day culture.<sup>5</sup>

Experiments in animal models point to other grave concerns with extended embryo culture. For instance, mouse embryos, similar to ours in many ways, have been

shown to be very sensitive to small changes in the composition of the liquid media they are cultured in. Wholesale changes in gene expression have been documented and epigenetic states may well be effected.<sup>6</sup> Epigenetic modifications occur to the DNA in order to ensure the correct level of gene expression within an individual's cells at any one particular time. It is poorly understood but is known to occur on a massive scale (globally) during very early embryonic development and is essential for normal mammalian development. Aberrant epigenesis can lead to profound consequences later in development as the examples of Angelman and Beckwith-Wiedemann Syndromes show.<sup>7</sup> Whether culture conditions used in ART centres affect gene expression and human embryo metabolism, although plausible, is not yet known.

## PGD and Broad Screening

Preimplantation genetic diagnosis (PGD) was originally developed to limit the transmission of serious heritable conditions in fertile couples, with the so-called 'affected' embryos discarded, and those without the condition transferred to the uterus. This method is now being used more as a screening tool, with many wider applications, such as sex selection, that are not considered life threatening or clinically serious.<sup>8</sup> Fertile couples are now using IVF or ICSI in combination with PGD to ensure the embryo has a particular genetic make-up. Typically, one or two cells from the 8-cell embryo is removed for testing, constituting a significant proportion of the whole embryo (up to 25%) at a very early stage of development. This is a cause for concern because, although it appears safe, we really do not know the full effect on children born after the procedure.

In addition, many are concerned about the accuracy and integrity of sensitive genetic probes. Currently, there is no system in place to ensure the quality of these genetic test results. Dr Hudson, director of the Genetics and Public Policy Center at Johns Hopkins University, highlights the issue when she points out that results of these tests were often the only clinical information on which parents or would-be parents made important decisions, such as attempting a pregnancy in the first place. 'These are profoundly important decisions, and there is a need to ensure that any genetic testing be accurate and reliable.'<sup>9</sup>

## Cytoplasmic Injections

In the quest to produce a badly wanted child, embryologists and clinicians are sometimes willing to employ techniques, the consequences of which are poorly understood.<sup>10</sup> Scientific endeavour is usually a good thing, but the technique of cytoplasmic transfer well illustrates how technical prowess developed in science can outpace ethical concerns. Using a mouse model, scientists found that suboptimal eggs could have better fertility outcomes if injected with cytoplasm from a healthy egg. Such cytoplasmic transfers have now been performed in the clinic with

a resulting live birth.<sup>11</sup> The safety issues have not adequately been addressed and the long-term consequences on children born using this process are unknown. Concerns have been raised because several serious metabolic disorders have been traced back to components of the cell's cytoplasm (the mitochondria) which are transferred in this process. The resulting embryo contains genetic material from three people; the mother, father and the cytoplasmic donor. This practice has been outlawed in Australia through The Prohibition of Human Cloning Bill, 2002, but is still permitted in the US and many other countries where ART is performed routinely.

An even more experimental technique, recently attempted in China with the assistance of US expertise, involved nuclear transfer, a procedure used in cloning.<sup>12</sup> Shortly after in vitro fertilisation, the nucleus from a newly formed embryo was removed and inserted into a younger woman's egg (with its own nucleus removed), the idea being that this egg's cytoplasm would 'rejuvenate' the nucleus of the infertile couple's embryo, improving the chance of pregnancy. The resulting embryo, as with cytoplasmic transfer, contains genetic material from three people. Furthermore, it is a highly experimental technique and the effects on the human embryo and its development are totally unknown. The fetuses created in this way did not survive to term, and the practice has now been banned in China.<sup>13</sup>

## Time for Reevaluation

Apart from these emerging trends, highly publicised incidents of irresponsible, illegal and immoral behaviour by reproductive technologists have been documented recently. 'Alarming incidents where clinicians have used their own semen for patient insemination, unauthorised use of human eggs, theft of eggs, enormous sums of money being paid for egg donation and extraordinary multiple gestations (of seven and eight fetuses) have all occurred within the US.'<sup>14</sup>

Although such incidents may be isolated, and hopefully never occur in Australia, evidence is gathering that the various ART techniques may bring attendant risks not previously acknowledged. Compounding the problem is that much of the research into assisted reproduction has concentrated more on the needs and dilemmas of the parents.<sup>15</sup> Very few studies have been performed to gauge the real long-term risk of ART techniques on those conceived through these clinics. Set against this is the fact that the pace of advances in the treatment of infertility has been extremely rapid.<sup>16</sup>

Lord Winston, a prominent British fertility expert, goes further. He believes clinicians introducing new ART techniques, such as the examples given above, without adequate research into their safety are effectively experimenting on infertile couples and their babies. When asked for clarification on whether IVF patients were 'treated as guinea pigs for new techniques', Lord Winston replied, 'That's exactly what I'm saying. While the early

reports of IVF were wholly reassuring in terms of abnormality rates, a lot of data out there in the public arena suggest that some procedures under some circumstances might be quite dangerous. The problem is that we are now doing things in the laboratory that are not being tested in a way they should be.<sup>17</sup> The recent case in China reinforces such a view clearly.

The high prevalence of various ART procedures has also detracted from alternative treatments for infertility such as tubal surgery. 'I think it's rather sad that tubal surgery has been written off. It's a phenomenally successful treatment.....in select cases it is more successful than IVF and it has the big advantage in that it cures infertility.'<sup>18</sup>

In order to accurately determine the full effects of these technologies and minimise harm, there really ought to be increased monitoring of children born after ART treatment. Perhaps it is time to thoroughly reassess the safety of both novel and established techniques in this field. 'We do not have an effective system for monitoring the health, development, and outcomes of these children,'<sup>19</sup> said Dr Hudson. Large, prospective studies should be able to identify problems and clear up much of the uncertainty.

Children born after ART will have a very different view of the justification for exposing them to excessive risks, especially if they realise safety considerations were not paramount for those responsible for helping their parents conceive. The success of ART procedures should not be so reliant on the rate of live offspring per transfer but rather judged on the health of the developing child and later stages through to adulthood.<sup>20</sup> The various health problems and subsequent costs are a tragedy, not only for the child, but the whole family and challenge the responsible practice of medicine.<sup>21</sup> After all, it is the children that matter most!

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Michael Herbert



## ADVANCE NOTICE:

### April 30, 2004 Primary School Children, Health & Ethics

A Conference for Teachers and professional carers of primary school aged children concerning the ethical challenges facing them in relation to children's health and mental well-being.

Registration forms at the Centre. See P12 for contact details.

# Special Need Children in Mainstream Schools

*All children have the right to receive an education, even children, who historically have missed out on educational opportunities due to chronic disabling conditions. There is growing community acceptance of children with disability and chronic medical conditions attending mainstream schools. The potential legal liability issues inherent in supporting inclusive education philosophy will be examined.*

## Defining Disability

Advocates of inclusion argue that it is discriminatory to exclude children with certain disabling conditions from mainstream schools, and indeed these schools should have inclusive curricula already in place. Whilst many schools have set up processes that allow for integration, the ideals of inclusion remain frustrated. We are an increasingly litigious society and there is potential for this to affect participation and inclusion of children with particular needs. Legislation prevents discriminating against the less abled in our society. But what is a disability? The Commonwealth Disability Discrimination Act 1992 defines disability, in relation to a person, as:

- "(a) total or partial loss of the person's bodily or mental functions; or
  - (b) total or partial loss of a part of the body; or
  - (c) the presence in the body of organisms causing disease or illness; or
  - (d) the presence in the body of organisms capable of causing disease or illness; or
  - (e) the malfunction, malformation or disfigurement of a part of the person's body; or
  - (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
  - (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour; and includes a disability that:
  - (h) presently exists; or
  - (i) previously existed but no longer exists; or
  - (j) may exist in the future; or
- is imputed to a person".<sup>1</sup>

## Children's Legislative and Human Right to be Educated

The Education Act 1958 (Vic) states that a person is required to attend school from the age of six until reaching the age of 15. Exceptions may arise where a child is ill or incapacitated, or can be educated at home, subject to certain conditions.<sup>2</sup> Due to technical advances and improved medical treatments, children with various chronic and/or disabling conditions are able and encouraged to pursue a 'normal' education within 'mainstream' rather than 'special' schools. It is also their legislative right to equal access to educational opportunities. Chronic illness potentially dis-

turbs the child's pursuit of education and presents physical and social challenges.<sup>3</sup>

Ascribing the adjective 'chronic' to illness or medical conditions can be imputed to apply in various instances, but should not imply that the child is 'chronically' not well. Rises in the incidence of asthma, diabetes, cystic fibrosis, and leukaemia and improved mobile technology has enabled many students with complex health needs such as catheterisation, tube feeding, and ventilation, to attend school when they might previously have been unable to do so.<sup>4</sup> The United Nations Convention on the Rights of the Child, which Australia signed and ratified in the early 1990's, urges that all children have access to a free quality basic education and should be allowed to realise their full potential.<sup>5</sup> However, the situation is that some children, especially those who are medically fragile and/or technology dependent, are denied these basic rights.<sup>6</sup>

Many chronic illnesses are invisible, and disclosure about them brings unwanted attention, eg. children with diabetes do not consider themselves disabled or health impaired yet they may suffer adverse effects due to the nature of their condition or its medical treatment. It is suggested that students with chronic health conditions are at the intersection of the health and education systems, which traditionally operates in separate realms with different policies and philosophies. Children receive service when their needs fit in with a school's established program. When children are acutely ill, their academic performance is not perceived as a priority, but when these same children are well, health is not perceived as a factor in their education.<sup>7</sup>

## Duty of Care and Children with Special Needs

With the rise in the number of students who may need routine medical attention at school, there is the expectation that these needs will be met by the educational sector. However, the position is precarious in regard to the boundaries of responsibility. This is where the concept of duty of care is evoked.<sup>8</sup> Does the teacher have a duty of care for ensuring that the routine medical needs of students aren't compromised, and either way, is there an assumed moral or legal obligation implied? Traditionally, children with particular needs were catered for in 'special' schools, or stayed at home, or were 'institutionalised' for some or all of their life. Times have changed and in 1998, about 92% of children with a disability were enrolled in

mainstream schools.<sup>9</sup>

Civil torts about bullying in school have succeeded in the court system recently in regard to negligence claims. Should something go awry with chronically ill or medically fragile students whilst at school, could civil actions be taken against that school? Certainly, a teacher may be liable for negligence where a pupil is injured in an accident while under supervision or control of a teacher.<sup>10</sup> But what constitutes an accident? Most of us automatically consider the obvious - falling off playground equipment, tripping over in the normal course of play. Yet the word has greater connotations - undesirable or unfortunate happening; casualty; mishap: anything that happens unexpectedly, without design, or by chance.<sup>11</sup> There has been comment about the potential legal liability concerns in Catholic schools.<sup>12</sup>

### **The Needs of Medically Fragile/ Technology Dependent Children**

Roberta Rehm's study of one school district in America identified the ambiguous role of the teacher as both educator and care provider, though most lacked formal training or particular experience with providing health care. Teachers were expected to provide or supervise care such as tube feeding, or managing seizures. Whilst there was provision for school nurses to attend emergencies they were not allocated to attend to routine care. Do Not Resuscitate (DNR) orders, which the school board agreed to honour, and the ethical dilemma educators faced in being expected to allow a child to die was discussed. Some teachers sought training for cardio-pulmonary resuscitation (CPR), but others studiously avoided it with the rationale being that because they lacked CPR certification, they were not obligated to attempt resuscitation. Future liability issues were identified as a concern in regard quality of care standards and issues of responsibility for care rendered by non-health care personnel in school settings - skills not normally taught to teachers in their own pre-service education.<sup>13</sup>

Policy about the legal implications inherent in meeting the medical needs of children with chronic illness or disability in mainstream schools is not easily accessed. Medically dependent children's special needs can be met in 'special' schools, however, funding cuts have closed some of these schools or restricted enrolments, with the prospect of children with functional and intellectual disabilities being forced into an education system ill-equipped to meet their needs. If School Principals are responsible for the general welfare of any child in their care, are they also ultimately responsible if injury or misadventure occurs in relation to health care given to children by non-health-professional staff. Concern about ambiguity in regards to who has responsibility for these students both in terms of coordinating support and providing medical care within mainstream schools was a finding by UK researchers. Their study identified that teachers didn't always believe students who

said they were experiencing symptoms. Some students reported they were unnecessarily excluded or inappropriately forced to take part in some activities.<sup>14</sup>

Other research found that school staff's awareness of pupils' needs and willingness to believe that a child was well was related to the visibility of the condition, for example, whether they used a wheelchair or had an obvious disability. This research also suggests that teachers and parents have concerns about medical care provision in school, particularly teacher's involvement, equipment availability, and the appropriateness of school buildings following medical emergencies. Reluctance to get involved in medical care stemmed from a lack of expertise in medical matters, concerns about being held to account should anything go wrong, and lack of support. Storage space for medications and equipment and private, hygienic rooms to facilitate therapy were lacking. Responsibility for the purchase, maintenance and insurance of equipment and the disposal of clinical waste was another concern.<sup>15</sup>

### **Meeting the Needs of all Victorian Children in Schools**

The Victorian Education Act 1958 states that, 'A parent of a student with a disability is not required to contribute to the cost of the provision of additional support for the education in a state school of that student'.<sup>16</sup> The Victorian Department of Education and Training suggests that children with chronic medical conditions or allergies have a management plan completed by their doctor, attached to their records.<sup>17</sup> Information about who has the duty of care and the potential legal liability for meeting the medical or physical needs of children who have a disabling condition in the event of medical misadventure is lacking. Or in other words, what legal ramifications might ensue should a child receive incorrect, and potentially damaging health care, from someone without a recognised health profession credential. Might it be foreseeable that this eventuality is not merely probable but predictable, and therefore potentially negligent.

### **Integrate or Include**

The Senate Employment, Workplace Relations and Education References Committee "Education of students with disabilities" report, comments that dealing with the needs of students with disabilities contribute to increased stress among teachers, but acknowledge that anti-discrimination legislation supports the rights of students with disabilities to access education.<sup>18</sup> The Australian Education Union make implicit the understanding that a teacher's primary responsibility is education and that non-disabled students also have rights.<sup>19</sup> There are misconceptions about how well children with special needs are integrated or included into the education system. In addition it is wrongly assumed that inclusion and integration are interchangeable terms.

Integration involves educating special need children with their peers to the fullest extent possible, whereas inclusion implies that every child, regardless of ability, is enabled to participate in every activity. That is, if a child with a disability cannot participate in some activities, then these activities are modified for the entire group so that no child is excluded.<sup>20</sup> However, might this also create opportunities for children to stigmatise and victimise their differently abled peers due to inadvertently pushing an agenda which encourages positive discrimination because of these different abilities. It seems that while an educational policy may favour inclusion the organisation may lack the infrastructure to facilitate its implementation and deal with potential legal ramifications.

## Should We be More Concerned About Legal Liability Issues?

What remains unclear is who is ultimately responsible for meeting the medical needs of medically dependent children in schools. Given that our society is concerned about the welfare of children, shouldn't care planning of children whilst at school be made transparent. Anecdotes about children being denied access to, or diverted away from, mainstream schooling, because of supposedly undesirable physical or particular medical needs are commonplace. Increased legal liability insurance costs have led to restricted choice in regards recreational pursuits. Can we expect the same to impact negatively on children with particular needs reaching their potential in the educational setting?

Society is constantly bombarded with the potential of technology not only to enhance someone's ability to lead a normal life, but also how science may eventually eradicate the burden of having to provide for certain members of our community by interfering with their right to exist in the first place. These double standards do little to advance the human rights of all regardless of ability. If authorities fund practice which may filter out certain members of our society through, for example, predictive genetic testing, it seems paradoxical to pursue an inclusion philosophy. The legal liability dilemma will not go away, and insuring against it may mean that the medical needs of children at school should be serviced by appropriately prepared health care practitioners.

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Anne Moates



# Risks and Ethics From Conception to Birth

*We live with risks we confront every day. This article examines how to manage ethically the known risks we encounter from conception to birth*

**R**isks that are known from epidemiological studies of disease or derived from statistical data enable objective assessments of risks in clinical practice. While the prevalence of major abnormalities at birth is about 2%, it varies from place to place, depending on factors like culture, ethnicity and the reliability of accurate recognition and reporting. The rate rises to 5% if minor abnormalities are included.<sup>1</sup> Objective risks may be perceived by some to be worse than they really are. In other words, the subjective assessment of risk of a disease may be much higher than is objectively warranted.

## Inheritable Diseases and Responsible Parenthood

Known carriers of a gene for major disease passed on by recessive inheritance (eg, cystic fibrosis, CF) need to consider the implications of entering relationships with partners who may be carriers of the same gene. If their partners are non-carriers, none of their children would be affected but there would be a 50% risk of them being carriers, whereas if both partners are carriers, there is a 25% risk of their children being affected. Prospective parents should not turn a blind eye to a known risk of a disability for their children. Without wishing to offend people with disabilities it would be better for carriers of the CF gene to choose partners who do not have this gene to ensure their children will not be affected by CF.<sup>2</sup>

People who are carriers of a gene for a serious disease passed on by dominant inheritance (eg, Huntington's disease) need to consider whether to choose to assume the responsibility of having children with a 1 in 2 risk being affected by the disease. Referring to the child, it is not a question of it's being better to be or not to be. Every child with a disability is of inestimable value. Nor is it a question of telling a person with a disability that they should not have been born -- this would be offensive. However, morally responsible family planning implies that a couple ought not risk conceiving a child with a dominant disease unless they are prepared to raise their child with loving care. Such couples need to be informed of the 1 in 2 risk of their child being affected, the usual age of its onset and how much suffering their child would likely have to endure. To choose to have a child with a 1 in 2 risk of having to endure much suffering for most of their life implies assuming an awesome responsibility.<sup>3</sup>

## Prenatal Screening and Diagnosis

The risk of a live-born child with Down syndrome increases with maternal age, ranging from one in 1560 at 20 years of age, to one in 1350 at 25 years, to one in 890 at 30 years, to one in 355 at 35 years, to one in 97 at 40 years and to one in 23 at 45 years.<sup>4</sup>

### Pregnant women's anxieties

Judith Searle has researched why pregnant women overestimate the risk of their children having Down syndrome and fear the worst outcome. She found that of 367 participants in a survey 242 (66%) reported that they felt anxious sometimes, or a lot, about having an abnormal baby. She also found that while these women hoped that confirmation of fetal normality would result from prenatal screening tests, they feared abnormalities would be revealed. Society's attitudes towards abnormality and disability, along with the desire to avoid burdens and sufferings for their child and themselves, were potent considerations in women's perception of risk. The role of the media in focussing on negative outcomes has also influenced pregnant women's perceptions of pregnancy's risks. The reasons for pregnant women's perception of risk of having an abnormal child were based on a socio-cultural, rather than a medical, definition of risk and this creates anxiety. This anxiety, however, can be reduced by prenatal screening tests which are sought for reassurance and perceived certainties amid fears and uncertainty. Hence, there has been a rise in the number of women seeking prenatal screening for Down syndrome.<sup>5</sup>

When providers of prenatal screening inform pregnant women of the true epidemiological risks of anomalies, disproportionate fears may be generated. Pregnant women usually have a non-invasive ultrasound screen at 10-13 or 16-20 weeks gestation, and if they are deemed to be at an elevated risk, they may choose to have an invasive diagnostic test soon after, such as chorionic villus sampling (CVS) or amniocentesis. These tests provide a definitive diagnosis. About 95% of pregnant women who have a diagnostic test are reassured to learn that their unborn children do not have Down syndrome.<sup>6</sup>

### Risk of miscarriage

Depending on the expertise of the operator for CVS or amniocentesis there is an increased risk of miscarriage ranging from 0.5% to 1.0% or to 2.0% respectively over the normal background rate for the pregnant woman's age. Pregnant women have a moral responsibility to

evaluate these increased risks. At the same time the assessment of these risks necessarily involves both objective and subjective elements, especially for the mother who may be enduring great stress and anxiety over the health of her fetus who, incidentally, also benefits from the allaying of maternal fears.

The responsible taking of risks is an inevitable part of parents' lives. Doctors performing prenatal tests also have a personal ethical responsibility to evaluate risks. A reasonable evaluation may go either way. It is necessary for genetic counsellors and doctors to respect the conscientious evaluation of pregnant women as well as their own consciences. What is required for ethical conduct is that the risks involved in prenatal tests must not be disproportionate to the benefits reasonably expected.<sup>7</sup> It is to be noted a pregnant woman may believe a 12% risk of miscarriage following amniocentesis is justified, whereas the same risk for her child after birth following a medical procedure would not be held to be warranted.

## Fetal Surgery

*Fetal urethral obstruction* impedes the development of the fetal kidneys and the passing of urine into the amniotic sac and thereby may seriously harm the kidneys. A build-up of fluid inside the fetal body is created instead of in the amniotic sac. The swallowing of amniotic fluid is necessary for fetal lung development. For some fetuses, the result is fatal without treatment. The benefits of probable correction would have to be weighed against the trauma of surgery for the mother, risks of perinatal death, severe disability from renal failure and the emotional stress of costly and likely burdensome treatment of chronic renal failure after birth.<sup>8</sup>

*Congenital diaphragmatic hernia* is the absence of a membrane which lets internal organs rise up and constrict lung development. It is difficult to predict the outcome of fetal surgery to correct it. Liveborn babies have been treated by surgical intervention to remove protruding viscera from the chest region to their proper place in the abdomen and the hernia in the diaphragm is repaired. This gives the lungs a chance to develop normally, but still many babies die after treatment due to underdeveloped lungs.<sup>9</sup> Despite good postnatal care, up to 60% of newborns with this defect die. Repair before birth seems to make physiological sense and is technically possible since the fetal lungs can grow after repair.

The risks of surgical intervention should be outweighed by the risks of non-intervention. One needs to consider the risks of surgery to both fetus and mother which may include perforation of the uterine wall, loss of blood, inadvertent injury to adjacent organs, the trauma of a misguided catheter or placental abruption. Infection could induce premature labour and delivery which would be detrimental to both mother and child. The medico-ethical dilemma is magnified when we recall that diaphragmatic

hernia in conjunction with excess amniotic fluid is 90% fatal without successful treatment.<sup>10</sup> Expert diagnosis is crucial to determine which fetus will die without surgery and which fetus will have a better chance of survival with it. In a case of confirmed congenital diaphragmatic hernia it would be a matter of judging whether no intervention would mean a high risk of loss of life after birth or whether correction would allow the lungs to grow enough to support life at birth. Surgeons at times need the wisdom of Solomon to determine whether the odds warrant intervention or not.

The risks of surgery for a fetal malformation should be weighed against the probability of its correction and objective improvement. The possible benefit to be derived from the surgery would depend on the severity of the malformation, its likely degree of correction, the prospects for survival without severe disabilities and the need of ongoing treatment. At present fetal surgery should normally be regarded as an extra-ordinary means of medical treatment to preserve life and improve the quality of life. It needs to be justified in the sense that the normal presumption favours postnatal treatment.<sup>11</sup>

## Newborn Babies

Survival rates of preterm newborns in a hospital with a NICU over the three years 1994-1996 are given in Table 1 by gestational age.<sup>12</sup>

Gestational age (weeks)	Live births	Survivors (percentage)
23	31	35.5
24	36	65.6
25	46	73.9
26	64	85.9
28	75	96.0
32	262	98.1

Table 1. Survival rates by gestational age modified and calculated from data in the Royal Women's Hospital in Melbourne, *Medical Journal of Australia* 7 June 1999.

## Survivors with Disabilities

Severe disability rates of survivors at 30 months in a major study in the UK and Ireland for newborns at 23, 24 and 25 weeks were 30.8%, 24% and 21.5% respectively; the rate of other disabilities in the same group of survivors was 23%, 28% and 23.7% respectively. Severe disability was defined as unable to walk without assistance, unable to sit, to use hands to feed self, no head control, blind, hearing impaired even with hearing aid, and not communicating by speech. Other disabilities included abnormal gait, unstable sitting, difficulty in using both hands, vision needing correction and speech defects.<sup>13</sup> Doctors have the

difficult task to determine when the benefits of treatment outweigh expected burdens and risks of harm. Neonatologists are qualified to make these assessments.

Once it is determined that the baby's condition is not fatal, the likely benefits, burdens and risks of treatment options and their short- and long-term outcomes, including quality of life, should be discussed with the parents before obtaining their informed consent. A therapy may be tried if it offers a reasonable hope of curing a serious disability, even if death might result, provided no other alternative is at hand and the risks are not disproportionate to the expected benefits.

Doctors should not act against their own judgement to comply with parents' wishes by aggressively treating newborns to save their lives when the outcome would be a probable prolonging of a distressing dying process. But in cases where reasonable doubts persist the parents, as their child's natural trustees, may assume more responsibility in making the decision between the various treatment options, bearing in mind the likely benefits, risks, short- and long-term prospects for the child, including the burdens of physical and psychological suffering and the capacity of the family to cope. The risk of a burdensome existence should not be lightly dismissed when making these decisions. In such grey zones subjective factors play a role in decision making. Parents may then have no less expertise than doctors in making the right decision and doctors should normally defer to the judgement of the parents in such cases.<sup>14</sup>

It could be that the reasonable and morally permissible option, on the balance of probable benefits over burdens, is equally poised between treatment and non-treatment, provided normal medical and nursing care continue. The benefits of paediatric surgery could also be off-set by some fatal risk caused by it. If a newborn baby with a severe cerebral haemorrhage had a prognosis of 20% survival with respirator treatment in NICU and a 75% risk of a serious disability after survival, I do not think continued therapy would be ethically necessary because

the harm would outweigh the benefit.

Doctors also have to learn what the objective risks of certain medical procedures are in certain circumstances and then evaluate whether it is ethical to take the risk in each case, bearing in mind the health condition of each fetus or newborn child as well as the family circumstances of the mother and her own subjectivity, including her wishes. The obstetrician delivering a newborn baby and the attending neonatologist need to consider all these factors after the delivery of a premature baby at 23 weeks gestation when they have the services of the staff of a well equipped third level neonatal intensive care unit available. This situation would be completely different where there is no care beyond what the mother and a midwife could provide.

#### ENDNOTES

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