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July 1997

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**FIRRAGE**

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**Feminist International Network of Resistance to Reproductive**

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**and Genetic Engineering**

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## Editorial

Dear Readers

Thanks to all of you who renewed your subscriptions in the last three months. For those of you who didn't send us a subscription, this is the *last* issue of the FINRRAGE (Australia) Newsletter you will receive. We are sorry about this but we can no longer support those who do not subscribe. As promised, here is the first issue for 1997 following the November, 1996 Newsletter, it is a double issue and we have plenty more planned.

This issue has articles ranging from infertility, prenatal genetic screening, Creutzfeldt-Jacob Disease (CJD) to euthanasia. Also, with the current debate surrounding euthanasia and the recent controversy over the Andrews Bill, we thought we would include the FINRRAGE (Australia) Submission for your interest. The November edition promises a report on the 1997 Family Planning Australia - Biological Sciences Meeting in Sydney, Australia.

FINRRAGE (Australia) continues to support the international campaign to stop anti-pregnancy vaccines. T-shirts are still available which display a woman stamping out the vaccine shown on a previous edition of the FINRRAGE (Australia) Newsletter.

If you would like to contribute to FINRRAGE (Australia) with either articles, conference reports, announcements and news and views nationally and internationally, write to the co-ordinators at the following address. Preference is for copy to be submitted in Word 5 or 6 on Macintosh disks (we can convert IBM too!!) but email is also fine.

We hope you enjoy this issue of FINRRAGE (Australia) Newsletter and continue to support us by renewing your subscription. We plan to have the next issue in November, and we look forward to your contributions and comments.

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## Is Infertility an Illness?

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### A Sociological View

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*Penelope Clarke*

There is an enormous stigma attached to infertility. Being unable to have one's own biological children for many people, particularly women, amounts to suffering from an illness. Klein (1989) reveals one woman's experience:

Our families - and particularly my in-laws - were shocked and, as they told me, disappointed not to have grandchildren. Since the day I told them they've treated me very condescendingly ..... with a mixture of pity and contempt: somewhere along the lines that I now was a sick person who could not be taken seriously.

Infertility has not always been regarded as a medical problem involving associated concepts such as 'illness' or 'disease'. Although infertility may be the result of diseases like pelvic inflammatory disease or endometriosis, infertility itself has not been regarded in a medical sense but more as a social issue. It is said that at least one third of the infertility problems are idiopathic in that there is no identifiable reason found to have caused the infertility (Klein, 1989). For centuries the childless couple was actually seen as the result of 'God's will' - albeit already fundamentally the woman's failing! It is well acknowledged that

... social and psychological factors are crucial in the aetiology (causation) of illness' (Turner, 1987, p.2).

In order to further examine the phenomena of infertility as an ill health experience several aspects need to be explored.

To facilitate this a framework developed by Willis (1993) will be used. According to Willis (1993) such a framework contains four different aspects: historical, cultural, structural and critical.

Firstly however it is important to establish what is meant by the terms 'illness' and 'infertility'. Whilst the term disease describes '... malfunctions of a physiological and biological character' illness refers to the '...

individual's subjective awareness of the disorder' and sickness '... designates appropriate social roles' (Turner, 1987, p.2). When analysing infertility as an ill health experience it will be important to consider it from the point of view of the person experiencing it. The medical definition of 'infertility' has varied but is now generally accepted to be '... the inability of a couple to conceive after 12 months intercourse without contraception' (Smith, 1992 p.70). This is a narrow definition only really applicable to heterosexual couples who are attempting to achieve pregnancy. Childlessness in a couple where children are desired is often referred to as 'involuntary infertility' as opposed to another term often associated with infertility that of 'voluntary infertility'. The issue of 'voluntary infertility', or the couple who are 'childless by choice' as it is also referred to, will not be discussed here although they also suffer from the same, if not more, social stigma as the 'involuntarily infertile' couple do.

#### Historical

In the study of an ill health experience examining the history of the experience '... can tell us about the shape that our current society takes' (Willis, 1993, p.42.) It can also help 'us make sense of new developments in the way our society is organised' (Willis, 1993, p.45).

Medicine has provided the basis for control of increasing areas of social life in many Western, and non-Western Societies, particularly since World War II. The spread of Western medicine and medical power has been closely linked to the globalisation of the ecosystem. The increasing influence of medical ideas is often referred to as 'medicalisation' of life, since it extends to problems with 'complex social causes, for which medical remedies appear highly inappropriate' (Conrad and Schneider 1980, p.16). Infertility has become

one of the problems involving complex social causes that medicine has attempted to remedy. In order to direct its intervention in cases of illness, medicine has established certain guidelines. These are that people:

- (1) are normally free of symptoms of ill health
- (2) become ill as a result of deviation from some biological norm
- (3) respond to perceived emotional or physical changes which make them aware something is wrong
- (4) will seek help from a doctor if symptoms persist
- (5) will be accurately diagnosed by a practitioner or assured that there is nothing wrong
- (6) will be proscribed an effective remedy and will get better and be cured (Dobraszczyk, 1989, p.3).

Infertility fits into this guide, except for perhaps the last point, and this further encouraged the concept of infertility as an illness - its success rate at 'curing' in that a live birth as an outcome of the treatment is debatable. These guidelines also are indicative of the way society at large regards illness which can lead to problems which will be discussed later.

Reproduction became viewed as

... an especially desirable event from the viewpoint of a woman's physiological, psychological and social functioning and that failure to become or remain pregnant is therefore pathological (de Lacey, 1992, p.74.)

Medicine thus came to view itself as the appropriate 'fixer' of childlessness, an opinion furthered by attitudes such as those expressed by infertility specialist, Patrick Steptoe, who stated in 1989:

It is a fact that there is a biological drive to reproduce. Women who deny this drive or in whom it is frustrated, show disturbances in other ways (Smith, 1992, p.72.)

This assumption is not new although many may see it as unusual that it persists today. In the nineteenth century the term 'hysteria' was used to describe the 'malfunctioning' womb. It was believed that the absence of normal sexual activity designed to bring about reproduction was the major cause for hysteria. Female independence of the mind was another way hysteria manifested itself. Treatments for this condition ranged from

the surgical in a hysterectomy

to liquefaction (hot water baths

of ten to twelve hour duration) (Scutt, 1988). Inherent to the understanding of this 'illness' was the concept that a woman could only lead a healthy life if she was sexually connected to a man with the ultimate aim of reproduction (Turner, 1987). Infertility became to the twentieth century medical profession what hysteria had been to nineteenth century doctors and medical technologies became the 'cure'.

With the advent of reproductive technologies as a 'cure' for this 'pathological illness', the concept of infertility as an illness became more enduring. What had once been thought of as God's will became an illness for which the cure was medical intervention. For many people a visit to the doctor automatically implies illness and therefore the treatment of infertility through medical intervention further perpetuates its new status as an illness.

Medicine thus came to view itself as the appropriate 'fixer' of childlessness, an opinion furthered by attitudes such as those expressed by infertility specialist, Patrick Steptoe, who stated in 1989:

Other historical factors have contributed to the development of this phenomena. Simultaneous with the development of reproductive technologies in the 1970s was the decrease in the numbers of children available for adoption due to changes in societies attitudes towards abortion, illegitimacy and adoption. The

availability of reliable birth control also influenced adoption rates. Adoption had been viewed as a legitimate way for the infertile to satisfy their desire for children and this was now becoming increasingly difficult. As a result the infertile couple became more visible in that they did not fit the nuclear family model of 'Mum, Dad and two children'.

## Cultural

Cultural phenomena contribute largely to the social production of disease. For centuries it was the church and religion that influenced the way in which illness was defined, constructed and managed (Turner, 1987, p.85).

Deviance from the norm became an important part of the construction of illness. Another reason for increased medicalisation is when a 'social status does readily fit within a society's cultural systems' (Becker, and Nachtigall, 1992, p.457). Snowden (1983) found that it was culturally expected for both men and women to procreate. However, he also found that women's roles were shaped more broadly on their child-bearing abilities. Implicit in the act of marriage is the desire for a child and this is seen as the cultural norm for any married couple.

Cultural traditions based on the concept of generation are disrupted for those who are childless by symbolically severing connections to cultural systems such as kinship and religion (Becker, et al 1992, p.457).

Miall (1986) and Veevers (1973) both found that the failure to have children may be construed as deviant and childless individuals may consequently embrace medical efforts to end unwanted childlessness.

Continuing with this idea of deviance Douglas (1970) emphasises the importance of the cultural influence of purity on society and its relevance to what may be seen as deviant behaviour. Dichotomy between purity and danger, in which the secretions of the body are held to be morally and religiously threatening to the stability of the social community and the natural environment, plays an important role in the construction of culture. (Douglas 1970, 1973).

For Douglas, the moral management of human bodies and their reproduction are closely related to the social functions of symbols:

... the human body is common to us all. Only our social condition varies. The symbols based on the human body are used to express different social experience (Douglas, 1970 p.7).

Koepping (1985) regards the body, its functions and secretions, as threatening social order by being responsible for deviation and resistance to symbolic management. Culture can regulate our physical existence but the body itself is outside these boundaries. Disease threatens the moral management of our bodies by robbing us of voluntary control and organisation which results in the need for social support of a medical regimen and therapeutic intervention.

Traditionally women's bodies have been regarded as especially threatening to the moral and social stability of society and such attitudes are further evident in attitudes towards infertility. Infertile women are therefore judged as threatening society in that their bodies are outside voluntary control and this in turn threatens social stability. The culture of motherhood places further emphasis on the importance of having children. Raymond (1992) writes about motherhood saying that

It is not a woman's essence, a mystical state of being, or historically unchanging. Motherhood is whatever a given culture makes of it. It is fundamentally social, fundamentally relational ... (Raymond, 1992, p.247).

Our western culture has traditionally been strongly influenced by patriarchal ideology and feminists argue in order for this to continue it has been necessary for society to encourage a culture in which child bearing is encouraged. Child bearing typically means that women must relinquish working outside the home, if only for a short while, causing them to interrupt their careers and become financially dependent upon their partner. In doing so women are controlled through their reproductive function and this will be discussed further in regard to the influence society has on the construction of an illness.

## Structure

As already discussed most societies revolve around the family and rely on this institution for stability. In the family structure women's roles are strongly stereotyped and perpetuated through patriarchy. Patriarchal attitudes view one of women's main functions as to be to reproduce children to continue the family name, to supply the workforce with labour and to populate the land and failure to fulfil this function is regarded negatively. Rowland (1992) suggests that '[m]otherhood is a powerful ideology in a patriarchal, pronatalist society' (Rowland, 1992, p.248). This attitude promotes the view of infertility as deviant and outside the norm.

In Israel the infertile woman is seen as '...physically disabled, a woman in mourning, a tragic figure' (Smith, 1992 p.181). Patriarchal societies have further emphasised this and made it easy for men to dispose of barren women. Under Jewish law if a woman does not produce a child her husband has the right to sue her for divorce. However, a woman cannot sue her husband if he is sterile. The emphasis patriarchal society places upon women bearing children reinforces the notion of childlessness as abnormal and requiring a 'cure'.

Patriarchal influence has played an important part in societies attitudes toward infertility but the importance of children in a child centred society has also contributed. The attitude of society in general to couples who are childless is an important factor in contributing to how these couples view themselves. As previously mentioned marriage is usually seen as an indication of wanting children therefore a married couple without children are not seen as the norm. It has been suggested that the rearing of children is actually a critical developmental task essential for successful personal development (Callan, 1990).

According to Klein (1989), Australian society at large views child bearing as the aspiration for a 'proper' woman. This in turn can lead to many women, and men, feeling like outcasts. A study by Klein (1989) examining women's experiences with In Vitro Fertilisation clearly demonstrates this. Many of the women interviewed reported that they had lost a lot of friends who found them 'odd' or who envied their lifestyles. One woman commented:

Increasingly, I felt displaced at family events. Everyone had children but us. And although I'd just been promoted I know Mum's eyes would have lighted up much more if I had announced 'I'm pregnant.'  
(Klein, 1989 p.12.)

The same women interviewed also commented how they would like to develop friendships with other women without children and how difficult it was to find such women. Such ostracism further emphasises the belief that a couple without children is dysfunctional or ill and drives many to search for a 'cure'.

## Critical

It is also important to critically examine the facts already discussed which have contributed to the promotion of infertility as an illness. One of the underlying themes of the examination of infertility as an illness is that of unequal gender relations. Historically, culturally and structurally this has been a central theme in the discussion of infertility. It has been the general opinion that women are the abnormal or deficient half of an infertile couple and therefore it is they who must undergo the majority of the medical interventions to be cured. As a result of this feminist theory underpins much of the critical literature about infertility.

Feminists are critical of the dangerous technologies used to 'cure' this illness which they believe should be viewed as a social problem rather than a medical one. Many such as Klein, Rowland, Scutt and Corea would

argue that the construction of infertility as an illness by the medical profession is a blatant exploitation of a desire for children both financially and emotionally. Further to this one only needs to look at the real success rates of In Vitro Fertilisation (the number of live births not the number of conceptions achieved which is sometimes put forward) is between five to ten percent internationally (Klein, 1989).

According to Klein (1989), Australian society at large views child bearing as the aspiration for a 'proper' woman. This in turn can lead to many women, and men, feeling like outcasts. Such rates can certainly not be described as successful yet In Vitro Fertilisation continues to be promoted as the 'cure'. This is in opposition to the guidelines established by the medical profession to justify medical intervention being that it will 'cure' the illness. This is not being successfully achieved therefore as medicine is unable to 'cure' the illness of infertility is it correct to call it an illness at all and is it justifiable to continue medical intervention? Further, is it correct to identify a condition in which often there is no physiological deficiency or malfunction present as an illness? This tendency to seek medical solutions to social problems reflects a North American predilection for seeking mechanistic solutions to problems of everyday life. (Kirmayer, 1985) and in the opinion of Becker et al (1992):

Placing social problems within a biomedical framework does not provide a satisfactory solution for conditions that deviate from cultural norms because those norms are replicated in biomedical ideologies about the nature and treatment of disease. (Becker, et al 1992 p.469.)

The perception that it is abnormal to be unable to biologically reproduce and therefore an illness must exist has moulded the treatment of infertility and the patient's response to it. Negative cultural attitudes about childlessness are then further reinforced through its treatment in the health care system. Perhaps the 'cure' lies outside the health care system.

However, there can be no denying that for some women, and men, infertility can be an extremely painful, debilitating if not devastating experience. As one woman in a study by Klein (1989) says: 'I felt emotionally distraught, worthless, extremely upset, and angry. It was a bitter disappointment, social rejection - a feeling of being incomplete' (Klein, 1989 p.10).

They, and society, consider themselves as ill and therefore set about to remedy the situation through the conventional technique of medical intervention. The relationship between medicine and illness is closely entwined - one cannot exist without the other. Western society has long regarded modern medicine as a 'cure all' and with the introduction of reproductive technologies the evolution of infertility as an illness was the response. If children were not valued so highly in our society this phenomena may never have come about. Negative stereotypes of childless couples have contributed further to this. The use of the expression 'childless' in itself has negative connotations implying that people without children are 'less' something than those who do have children.

Infertility will continue to be referred to as an illness with medical intervention devoted to its cure until attitudes change towards the importance, and absolute necessity, of one's own biological children in order to be considered normal. As these values are deeply entrenched in our patriarchal society this change will not come about overnight, if at all. Until society is able to realise that it is perhaps not so important to be the biological parent of a child but that parenting in some shape or form is the more important quality. It is only perhaps then that infertility will no longer be viewed as an ill health experience and the exploitation of the desire for children by the medical profession will cease.

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*Penelope Clarke is a Registered Nurse Midwife with a particular interest in women's health.*

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### Infertility on the Internet:

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### Will Women be

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### United or Divided by the New Technologies?

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#### ***Kristen Booker***

The information super highway, like any social structure, reflects the current power imbalances of our society in most respects, but this new technology presents women with an opportunity to find strength through communication. In particular, the internet allows infertility patients a degree of interaction with each other that has the potential to raise their awareness of the risks and amount of pain involved with most of the assisted reproductive technologies (ARTs). This interaction is problematic in that peer group pressure has a tendency to valorize the act of risk taking in the quest for a viable pregnancy, whilst talking up the joy of the longed for biologically connected family unit. The power imbalance between the medical profession and their patients makes women unwilling to speak critically about the ART programs in public, driving the dissent underground, but through the Internet women do have the ability to access each other privately, and the more private the forum, the louder the dissent.

Women undergoing treatment for infertility are isolated in many ways. The physical and emotional toll of pharmaceutical side effects, painful surgical treatments and frequent medical appointments results in many women leaving the paid workforce (Hopkins, 1992 and Klein, 1989a). This leads to a significant decline in their social contacts particularly as most daytime activities for women are centred around children (play groups, coffee mornings, school activities) or are aimed at an older population (senior citizen's associations

and community day centres). Many infertile women speak of being unable to visit family and friends comfortably due to the pain they feel when watching their siblings or friends achieve pregnancy, and the strain of responding to social pressures to start a family.

Relationships between partners may become strained through the stresses of ART which

demand a greater commitment from the female partner, who is generally responsible for charting daily fertility cycles, remembering dosage and medication combinations, requesting sexual intercourse at the appropriate time, attending clinics and hospitals for routine and invasive tests or treatments, and (if conscientious) doing her own research into her own particular hormonal cocktail. Many practitioners are uncomfortable performing invasive procedures in the presence of the male partner and deliberately exclude them from these processes, leading to a lack of shared experience and understanding between partners (Mason, 1993).

Women on ART programs have been actively encouraged to isolate themselves from other women undergoing the same treatment protocols (Klein, 1989, p.78), and the trend towards treatment by private practitioners in suburban clinics rather than in public research clinics will further distance these women from each other. The Internet provides a place for these women to find each other, and share experiences. There are varying degrees of privacy and intimacy provided through the Internet, with newsgroups (such as alt.infertility and misc.health.infertility) being the most public spaces, email lists (such as ilist, fertility and panfert) providing a greater degree of security, and private email between individual women being regarded as the most intimate form of cybercommunication.

While it is (ethically) impossible to monitor private email, monitoring of the other two types of forum suggest that there is a vast difference in content between them with the newsgroups being the least tolerant of public criticism of ART (as a whole, not of individual protocols, especially those which are seen as outdated), the most vigilant about upholding the rights of the infertile and the least critical of the medical profession. People posting articles to the newsgroups tend to be extremely careful about being supportive of each other's choices and are rarely critical of the medical profession or procedures except where such criticism can be well referenced and supported. Topics on the newsgroups tend to be very objective and quantitative, comparing dosages, results, selling surplus drugs, comparing prices, and social issues, such as dealing with friends and family.

By sticking strictly to the facts women are able to share their knowledge and gain strength through numbers even in this public arena. When a woman recently expressed her concern at taking 200mg of Clomiphene Citrate (a dangerously high dosage of a drug with potentially lethal side effects) other women were immediately able to legitimate her concern and suggest possible courses of action, such as requesting closer monitoring of her ovaries to prevent hyperstimulation or ovarian cysts, or changing physicians. It is difficult for the medical profession to deny the existence of side effects when the only women to respond to a request for stories of women who had not experienced side effects while taking Clomiphene Citrate were three women who had been taking Clomiphene Citrate for less than one cycle (the effects are cumulative). Women communicating on this newsgroup are able to see that the possible side effects are more accurately probable, and may have more confidence when reporting such symptoms to their physicians.

The experimental nature of ART was demonstrated during a discussion of eye flashes on Clomiphene Citrate. The presence of this side effect is an indication of a dangerously high dosage and while some physicians responded by requesting immediate cessation of treatment and further testing, other women were advised to ignore these danger signs (postings on alt.infertility). Some women change their prescribed treatment protocols following discussions on the newsgroups (for example taking Clomiphene Citrate Days 3-7 instead of 5-9, and adding Robitussin (expectorant) to Clomiphene Citrate), indicating their trust in the knowledge of their fellow patients. It becomes more difficult for the medical profession to claim superiority on the grounds of access to objective scientific knowledge, when women demonstrate that this objective scientific knowledge is capable of being interpreted differently by different physicians.

Responses to requests for information on particular treatment centres are almost always positive. This would seem to be a reflection of a fear of repercussions (particularly litigious repercussions in the United States), but also reflects the fear of being labeled a problem patient in the knowledge that physicians with an interest in the area monitor the infertility newsgroups. One woman complained that her physician had read her public comment that his clinic's World Wide Web (WWW) site was a little self-promoting, and that at her next appointment with him he had then proceeded to basically defend himself about how they have to strike a balance between coming on too strong and letting people know about their unique organization, etc. Other women, hearing of this story, will be wary of expressing their doubts or criticisms on newsgroups. Infertility patients are a particularly vulnerable group as they are often dependent upon their physician's goodwill for insurance coverage of their condition (some insurance companies will refund for treatment of ovarian dysfunction but not for infertility treatment, and the physician chooses the treatment label).

One way in which infertility patients have used the Internet for potentially subversive activities is through the creation of FAQs (Frequently Asked Questions) in which a volunteer compiles a series of questions which are distributed across newsgroups and lists. The resulting responses (anonymous upon request) are then sorted, edited and placed on-line as an easy reference source. These FAQs give patients information with which to confront their medical practitioners, and the Low-Tech Ways to Help You Conceive FAQ is specifically written for those who don't want to start on the cascade of medical interventions.

Email lists are more intimate than the newsgroups because they are less frequented by browsers (casual readers) and for this reason they are less likely to be read by physicians. On one such list a woman whose physician misread her ultrasound and recommended that she abort a viable pregnancy (after years of infertility treatment) posted her story. The discovery of this story on other mailing lists prompted some women to voice their concerns about the privacy of the list, with the result that the lists charter now requires subscribers to request permission before publishing articles elsewhere. The writer of the original article expressed her distress at the thought of her physician being able to read her story (despite her complete vindication of the physician), and this concern that physicians may hear what women say is a fear frequently expressed by women on the newsgroups as well.

Throughout the newsgroups and lists are hints of an underlying current of private email. This is detectable through people's requests for private emails please, through people referring to private emails written to them, and through the occasional quoting of material that has not been sent privately and inadvertently replied to publicly. Sensitive topics seem to attract more private email, with a recent example being a discussion about fetal reduction. While publicly the discussion remained considerate, balanced and calm, an inadvertently published private reply to a woman who suggested that after trying for so long to conceive at all, perhaps the mother-to-be of triplets should let God decide whether or not all three would survive, was not so reasoned. Part of the reply quoted called the woman who queried the validity of fetal reduction in this case an anti-abortion bigot on the grounds that God did not control the IVF process -- her doctor and she and her husband did.

Certainly many controversial topics are banned from newsgroups and email lists (circumcision being a perennial favorite!) and find themselves flourishing underground on private email and unofficial lists. It would be reasonable to suppose that for infertility groups controversial topics would include any negative comments about the ART process and criticism of particular clinics/physicians. These topics will remain invisible to the casual, or not so casual, observer and will remain restricted to private discussion groups as long as they are seen as being potentially threatening to the technology-supportive nature of the infertility on-line networks, but while they exist there remains a growing potential for subversion and dissent amongst infertility patients. While infertility information on the WWW is currently dominated by those with a commercial interest in the area, increasing access to this technology will hopefully result in the formation of additional newsgroups and information sites that will provide support for those who choose to travel the non-medicated route of living with infertility. For this reason it is vital that feminist and women's health care groups maintain a visible presence on the Internet so that viable alternatives to high-tech treatments are publicly acknowledged, and so that the informed and emotional support required to support a low-tech

decision is as easy to find as possible.

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## Federal Inquiry Into Treatment of Potential CJD Victims

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A Senate committee was appointed in June, 1997 to examine the Federal Government's treatment of recipients of human pituitary hormones linked with the rare fatal brain disorder Creutzfeldt-Jacob Disease (CJD). Hearings have been held in Melbourne and Canberra and the committee will report in September.

The Community Affairs References Committee will examine whether the government's response to the 1994 Allars inquiry into the pituitary hormone program was fair and adequate, whether documents related to the inquiry were withheld and why legal aid was denied.

The inquiry will also examine whether the Commonwealth Serum Laboratory (CSL) or CSL Ltd, the National Health and Medical Research Council, the Department of Health and Family Services of any other Commonwealth department, agency or employee failed to adequately protect public safety in relation to human biological materials.

The inquiry was agreed to in the Senate only days after reports that a woman who received the hormone 26 years ago was undergoing medical assessment for possible CJD. The inquiry also comes in the wake of revelations that blood and tissue supplies had included donations from people who later died of CJD.

While welcoming the inquiry, Democrat health spokeswoman, Senator Meg Lees and Independent Senator Brian Harradine had both pushed for a broader inquiry which would have gone beyond products linked with CJD and examined vaccines (for example vaccine testing on wards of the state particularly in Melbourne and the possible contamination of vaccines with live viruses), the manufacture and regulation of blood products, and breaches of proper procedure by those whose responsibility it is to ensure the highest standards in the regulation and manufacture of biological products derived from blood, tissue and organs.

The research of the Rupert Public Interest Movement, especially a weighty report titled Red Alert, has exposed lax standards applied to the harvesting of organs and other human tissues and fluids for vaccines, hormone preparations and other biological products used by millions of Australians. The Therapeutic Goods Administration has been criticised as not up to the task of regulating these products.

However the Opposition backed down on its original intention of holding a more broadly based inquiry which will now be limited to pituitary hormones.

Hormone recipients were essentially guinea pigs in an unlawful, experimental program involving infertility treatment using hormones processed from the glands of cadavers and linked with the rare fatal brain disorder CJD. A form of bovine spongiform encephalopathy (BSE) or mad cow disease, CJD is linked with a similar disease in sheep called scrapie. Five Australian women and one man have so far died from the disease which causes spongy formations in the brain.

A landmark test case seeking compensation for 132 recipients of hormones manufactured by Commonwealth Serum Laboratories and distributed at the direction of the Commonwealth Department of Health from 1967-1985 was settled April 4, on the eve of what was to be a 15-week jury trial.

APQ & Ors. -v - Commonwealth of Australia & Commonwealth Serum Laboratories Ltd was to be heard in the Supreme Court of Victoria but was abandoned following an out of court settlement. The settlement involves no immediate money and no admission of liability on the part of the Commonwealth.

One of more than 1,700 Australian women injected with human pituitary gonadotrophin (hPG), APQ had alleged nervous shock as a result of learning that the treatment had been linked with a risk of contracting CJD. She had received hPG in 1980 and 1985 and suffered a range of health problems.

There is no test to determine whether a recipient may have CJD while they are alive - it can only be accurately confirmed after death by a brain biopsy. Symptoms include loss of balance and coordination, decline of mental faculties sometimes leading to dementia, jerking movements and rigidity prior to death. A period of 9-18 months generally elapses from the first obvious symptoms to actual death.

Law firm Rennick Briggs represented the 132 recipients in their claim for compensation for psychiatric injury arising out of their fear of contracting CJD. Two NSW firms are representing smaller groups of recipients.

The settlement was offered by the Australian Government Solicitor March 27. Without admitting liability, the AGS said anyone who actually contracts CJD would be compensated and costs incurred to date would be paid on a one-off basis. In a statement, Health Minister Dr Michael Wooldridge said:

..the agreed settlement is compassionate, with a commitment by the Commonwealth to compensate APQ in the unlikely event of APQ suffering from CJD at any time in the future.

But what has not been reported is that the settlement offers nothing that was not already available before. As part of its response to the Allars Inquiry Report, the Commonwealth had already said that it would pay compensation to family members if a person who was on the hormone program dies of CJD.

Hormone recipients were frustrated from the outset in their attempt to launch a compensation claim. They were denied legal aid. As the plaintiff's lawyers pointed out, there was an inherent conflict in that the defendant - the Commonwealth - was the arbiter in granting or denying the application for legal aid.

On top of this extreme financial handicap, documents essential to the recipients' case were kept from them.

Professor Allars who was commissioned to examine the use of pituitary hormones in Australia, (*Report of*

*the Inquiry Into the Use of Pituitary Derived Hormones in Australia and Creutzfeldt-Jakob Disease, June 1994*) had deposited the inquiry documents used for her report into the custody of Australian Archives.

However, after the legal proceedings had been instigated, it was discovered that the documents had been removed from archives and could not be easily accessed by the women for the preparation of the case. Some documents were provided with vital evidence removed. Other documents were lost and it is feared some have been destroyed. Of 96 written submissions to the Allars inquiry, only six were provided. CSL's submission - considered essential to the case - was not among them.

Advisers in the case point to other conflicts of interest. For example, the Chief Medical Officer is the signatory to a number of court documents in support of the Defendants (the Commonwealth). He is both the signatory to Defence documents and also determined what documents would be made available to the Plaintiffs' solicitors and advisers.

Sources close to the legal proceedings believe the intense pressure on APQ who was without legal aid and lacking documents necessary to the case, were primary factors in her agreeing to the settlement.

One source believes a major factor in the successful attempt to keep the case out of the court was the need to cover up contamination of the hormones not only with CJD - but also with Hepatitis B. Allars had found batches of the hormone positive for Hepatitis B, including batch 128. However CSL had told Allars that batch 128 was not distributed. At least two of the recipients received batches containing Hepatitis B.

A medical expert involved in the case believes the defendants wanted to ensure the court would not be able to assess what damages may have been awarded to a recipient because of the Hepatitis B contamination.

Some believe APQ was being victimised for being an activist on behalf of other hormone recipients.

The history of the program is a history of broken rules.

Following the first CJD-related deaths in Australia, then Health Minister Senator Graham Richardson established an independent inquiry to be chaired by Professor Margaret Allars of the Sydney University Law School to enquire into all aspects of the hormone program.

Allars found CSL had not met all the requirements of the Australian regulatory authorities to manufacture and distribute the hormones.

Describing the program as 'unlawful and experimental,' she found many participants were not informed of the experimental nature of the program or of the fact that the hormones came from human tissue taken from dead bodies. The first guideline for selecting women for the program was that they should not be ovulating. However ovulating women were given hPG. Allars also refers to other experiments including super ovulation for use in IVF experiments.

A total of 171 091 pituitary glands were collected from dead bodies, with removal carried out mainly by mortuary staff who were paid a fee for each gland collected. Relatives had not given their consent for harvesting the glands.

Australia was the only country to provide for a government sponsored program making hPG available free of charge to patients. Between 1967 and 1998 more than 2500 people were treated with human pituitary gonadotrophin or human growth hormone manufactured from human pituitary glands taken from cadavers.<sup>1</sup> CSL collected the glands, manufactured and distributed them.

A total of 171 091 pituitary glands were collected from dead bodies, with removal carried out mainly by mortuary staff who were paid a fee for each gland collected. Relatives had not given their consent for

harvesting the glands.

Dr P Schiff of CSL's representative on the Human Pituitary Hormone Advisory Committee (HPAC) and responsible to the Minister for Health in overseeing the program, advised the gland collectors that 'unless the body is badly decomposed it is never too late to take the gland.' In other words, decomposing body parts could be removed and processed for use in living humans.

In 1966 CSL issued criteria to exclude pituitary glands taken from people who had died from certain diseases, among them viral hepatitis. In 1971 the College of Pathologists recommended that neurological diseases, including slow viruses, be added to the list.

However according to Professor Allars, neurological diseases were removed from the list of exclusions in 1977. Allars stated that CSL was warned in 1966 that viruses would not necessarily be eliminated in the hormone manufacturing process. There was enough information in 1966 to indicate that the program should not have been allowed to proceed. But it did and women who only wanted help to have babies, lost their physical and mental health - and their lives - because of it.

In a medical article in 1983 (Patterns of secretion and metabolism of the gonadotropic hormones, Monographs in Endocrinology, Volume 25 1983, p. 2), Dr Burger, who was a member of the Human Pituitary Advisory Committee, described the hPg used as 'clinical grade crude pituitary gonadotrophin powder'.

Dr Frank Peters, technical adviser to the lawyers, says that on the information given in Dr Burger's paper, the hPG when compared with an international reference standard was only one percent pure. This meant CSL's hPG was 99 percent impure.

Dr Peters says part of the problem was the lack of standardisation in the hormone's usage and lack of knowledge about correct ratios of two of the major hormones -follicle stimulating hormone and luteinizing hormone.

This was most likely a factor in a large number of multiple births, spontaneous abortions, perinatal and neonatal deaths. One recipient gave birth in 1971 to nonuplets - none survived. However despite this clear warning that something was wrong, the program continued using non-standardised hormones for another 14 years. A number of other recipients are today still grieving the loss of their dead babies, born after multiple pregnancies following injection with the hormone.

The Australian Pituitary Hormone Programme was closed in May 1985 after two hGH recipients in the US died from CJD.

The first Australian woman died in 1988, with two subsequent deaths, yet the Department of Health waited until 1991 to advise recipients of the deaths. Legal proceedings against the Department were launched in May 1993 by recipients and families of recipients who had died as a result of receiving pituitary hormones. The families of the five recipients who died reached financial settlement, with the Commonwealth not admitting liability.

The Allars inquiry was commissioned, the 815-page damning indictment of the program tabled a year later. Calls by then Senator John Coulter for a full inquiry into CSL were defeated.

In 1993 the Health Department sent personal details of pituitary hormone recipients to a range of third parties, without recipients' consent. One of these women known as 'H' was extremely distressed that her name and address had been made public. She was later found dead in a motel room.

Democrat Health spokeswoman Senator Meg Lees and Independent Senator Brian Harradine have asked questions in the Senate about the obstructing of the plaintiff's case through the removal of archived documents and the denial of legal aid.

All overseas cases involving hormone recipients have settled in favour of the recipients. In France, some of those responsible for the French pituitary growth hormone program have been prosecuted and could be imprisoned. But in Australia, no-one has been prosecuted, no one has admitted fault and it's business-as-usual for the human experimentation industry.

©Melinda Tankard Reist

*Melinda is a Canberra based writer with a special interest in women's health, bioethics and the abuse of women in coercive population control programs*

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## "We Cannot win!" Women and the Ethics of Prenatal Genetic Screening

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Alison Brookes

It is no surprise that prenatal genetic screening should be the subject of continuing ethical debate. Linked as it is with issues such as abortion, mothering and disability - all issues that as a community we are often loathe to confront - prenatal genetic screening (or, PGS) has long been the focus of ethical questioning and discussion. What choices are available to women, who decides on what these choices should be and to what use PGS is put are

important moral and social issues. Their discussion challenges us as a community as well as confronts us as individuals. Despite this there remains little public discussion or community awareness about the ethical questions raised by PGS. Gate-keeping of the 'professional' discussion of these issues is one deterrent to the development of a wider, inclusive, debate.

Women developing ethical frameworks with regard to PGS are faced with structural limitations of current screening practices which restrict them from contributing to the on-going ethical debate which fills volumes in medical, philosophical, bioethical, legal and feminist works. This is exacerbated by the 'gate-keeping', intentional or otherwise, of

commentators and researchers largely restricting their discussion to professional journals and conferences. This effectively restrains women as the central participants from entering the debates on terms other than those accepted by these forums, and leaving them few public arenas to address the issues which affect them.

The fertile discourse surrounding the ethical questions raised by PGS has largely not been carried out at a 'grass-roots' community level

in Australia. Nor has it involved to any effective degree the central participants in screening programs and diagnosis:

women making reproductive decisions. This is despite the truth in the claim by Eric Haan in 1993 that:

**women are asked to give their opinions of screening programs after the technology has been developed and implemented to more appropriately 'fine-tune' programs for specific population groups (Lippman, 1992).**

Australians are familiar with and have accepted screening programs which detect children affected by serious disorders. These include... antenatal screening programs for malformations by ultrasound, for neural tube defects by Maternal Serum Alpha-Fetoprotein estimation, and for Down's syndrome by amniocentesis or chorionic villus sampling in older mothers. More recently... maternal serum screening for Down's syndrome [has] been introduced (Haan, 1993, 419).

At the same time it is not unusual for the professional ethical debates with regard to PGS to conclude that decisions in relation to participation and outcome must, as a moral imperative, be left to individual women and/or the families involved. Indeed it is not uncommon for such a conclusion to be the first time to read or hear mention of women's participation at all. This reflects the wider practice of screening and the professional debate: women are largely not involved until they are asked to reach important personal and social ethical decisions. Largely, women are having to make these decisions without the guidance or even knowledge of the extensive list of questions which remain the issue for ethical debate and the marked ethical reservations many commentators possess with regard to PGS.

I believe that we can and indeed should trust individual women to make the best possible decisions for themselves, and on behalf of their families. But it is not sufficient for debate to reach such a conclusion without also including participants (and their families when appropriate) in the ethical discourse. This reliance on the individualisation of the issues ultimately leaves not only the decision, but, importantly the responsibility for the decision, including wider social consequences, with the central participants. Within this framework there is little room for accountability from researchers, practitioners and even bioethicists. All of these groups are involved in decision-making with regard to PGS: decisions as to what testing is developed, what tests are implemented and how, and, importantly, an evaluation of the validity of women's decisions.

This evaluation of decision-making remains a one-way process, with women only being invited to comment on the actions of the other participants in PGS at a 'second order' level. That is, women are asked to give their opinions of screening programs after the technology has been developed and implemented to more appropriately 'fine-tune' programs for specific population groups (Lippman, 1992). This is a superficial and inadequate response to the lack of input from the central participants in the decision-making processes undertaken with regard to PGS.

Assessments of women's choices - and their decisions are assessed - are made within guidelines that have been developed largely by others. The other players in PGS have failed to facilitate the inclusion of these women's voices in the debates. Not only are the central participants in PGS rarely heard, but they are making choices between alternatives with which they have not been consulted, within programs that are often a fait accompli by the time women's participation is considered, and within a social environment in which, as one woman representative of the general consensus of the research participants in my current study said, 'we cannot win'.

Part of my research in Australia has been a qualitative study of women's decision-making around PGS. Ongoing, the research has involved in depth interviews with women who are mothering children with genetic conditions making decisions regarding subsequent pregnancies and women with genetic conditions deciding what level of technological intervention they will seek. Not surprisingly, these women have made a variety of decisions reflecting the social and medical milieux within which they live. Their positions with regard to PGS can be viewed on a continuum: their responses to the possibility of PGS have extended across a wide breadth, often employing similar ethical reasoning for quite apposite conclusions.

I would like to illustrate this with reference to two of the participants in the research. Their experiences and decisions while at opposite ends of this continuum nevertheless have similarities which link their experiences and that of other women.

One woman claimed that if her child was the last born with a particular condition humanity would be advanced to the extent that this would be a reduction in human suffering. Not insignificantly, she saw this suffering in social as well as biomedical terms. She discussed the contribution of discriminatory attitudes and community reluctance to provide supports and services, as well as lack of social acceptance for her child and family as the cause of much of the suffering being experienced.

Another woman who resisted prenatal diagnosis in a subsequent pregnancy after the birth of a child with a genetic condition (and she felt that she did indeed need to resist) cited a similar argument in support of her quite different position. She believed that humanity would be impoverished to the extent that the experience and wisdom of children and adults with similar conditions would not be accessible if prenatal diagnosis resulted in termination.

Both these women felt a community responsibility when making their decision: their decision-making process extended beyond the immediate and directly personal. This calls into question the adequacy of a bioethical approach which relies too heavily on the individualisation of prenatal diagnosis. It is not only inappropriate to expect one group out of all the participants in PGS programs to bear a disproportionate amount of responsibility for deciding the ethical conundrums raised. It may also be a position based upon stereotypes which present women as primarily mothers, whose decision-making and ethical concern is contained within family structures and subsequently ignoring the greater part their contributions play in the social fabric of our wider communities, socially and ethically. None of the women in this research have relied upon expectations, assumptions and experiences confined to themselves individually or to their family alone.

Unlike the development of ethical positions within the professional discourse which involves the exchange of ideas and conclusions, the construction of theories and their ongoing evaluation and critique, women who I interviewed

discussed making their decisions largely in isolation. Previous research has found that women rarely discuss the issues facing them with their peers, and it is not new to claim that women feel restricted within their decision-making. However, we must also begin to look at how women do develop their ethical positions within their specific situations, and consider if the lack of exchange and discussion of issues surrounding PGS inhibits women's development of an ethic to which they can refer to gauge their individual responses.

For women's voices to be heard significantly, for them to be full and equal members of these debates, structural changes need to be made to existing PGS programs and professional ethical discussion. Assumptions regarding what are women's interests, wants and needs need to be challenged by reference to women. This inclusion of women in the decision-making process should no longer be focussed on their opinions and views of existing PGS programs. To ensure adequate representation women should also be included in the decisions that are made with regard to research, with regard to targeted conditions, and with regard to the wider social circumstances which contribute to the construction and constraint of women's decision-making, and, importantly with regard to their own health care and participation in PGS programs.

The women in my current study have identified the practice of existing programs as preventing this involvement. They spoke of ultrasound programs which they participated in to check their 'dates' to then be informed that their fetus had developed indications of either spina bifida or Down's Syndrome, thus denying them the opportunity to decide if this was information that they even wanted to know.

They spoke of the belief that their participation in screening programs was a sign of responsible parenting but that after their diagnosis discussions about how they would parent their child were reduced to statistics without reference to their family and situations.

Others mentioned the routine nature of invasive programs allowing them to be presented as unproblematic, making the raising of ethical questions difficult.

The issue of informed consent was central to the women I spoke to. As one woman said:

I gave consent to the insertion of the needle to retrieve amniotic fluid. I gave consent for that fluid to be tested for specific conditions. I gave consent for the termination of my fetus. But it was not informed consent.

For her, informed consent would include a discussion of the social and personal meaning of all these events in a context not constrained by a biomedical framework. Not just through an exchange with her medical service providers but through a wide public debate where the same effort is made to discuss what research is being conducted, what testing is being developed, and how programs are being implemented as it is to announce breakthroughs in genetic identification. Current practice failed this woman by not informing her before her participation in these procedures of the ethical questions still unresolved with regard to PGS. To find out that her participation was considered by some as a discriminatory and eugenic practice after the termination of her pregnancy was painful and an indication of the grossly inadequate attempts made to include her in the ethical decision-making accompanying the termination.

We need to be aware that we - researchers, ethicists, technologists, practitioners and commentators - are often acting as gatekeepers to the professional discussion. While restricted to journals, to texts and to conferences the debate will necessarily be incomplete. Importantly we need to consider the consequences of this incomplete debate for the central, but marginalised, participants of prenatal genetic screening programs.

References available on request

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# Submission on

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# Euthanasia Laws Bill 1996

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Laurel Guymmer and Renate Klein

The Feminist International Network of Resistance to Reproductive and Genetic Engineering (FINRRAGE) welcomes the opportunity to make a submission to the Senate Legal and Constitutional Legislation Committee. 'Suicide ... [is] a woman's solution...[i]t is by men that women meet their death, and it is for men, usually, that they kill themselves.'<sup>2</sup>

FINRRAGE (Australia) supports the Euthanasia Laws Bill 1996 to overturn the Northern Territory's Rights of the Terminally Ill Act 1995.

'Suicide ... [is] a woman's solution...[i]t is by men that women meet their death, and it is for men, usually, that they kill themselves.'<sup>3</sup>

We are opposed to the Rights of the Terminally Ill Act because of its potential effects on people on the margins of society especially the chronically ill, people with disabilities, aboriginal people and elderly women whose vulnerability, we believe, has increased with the passage of the Act.

We are not taking this position lightly. As a feminist network FINRRAGE (Australia) strongly supports women's own decisions - as individuals and as members of the social group women. However we believe there is much evidence to support a contention that a pro-euthanasia climate will lead to certain segments of society 'requesting' the hastening of their deaths through physician-assisted euthanasia and that women and people of 'lesser merit' in general will be amongst them.

Importantly we believe that the implications for women have not been given adequate scrutiny in the current euthanasia debate nor in the Act itself.

There are many problems faced by women in the provision of health care.

These gender correlated disadvantages have been documented.<sup>4</sup>

In her chapter 'Gender, Feminism, and Death: Physician-Assisted Suicide and Euthanasia' in *Feminism and Bioethics*, Susan Wolf observes:

...dimensions of health status and health care that may affect a patient's vulnerability to considering physician-assisted suicide and euthanasia - including depression, poor pain relief, and difficulty obtaining good health care - differentially plague women.<sup>5</sup>

An American Medical Association report on gender disparities says women receive more care even for the same illness, but the care is generally worse. Women are less likely to receive dialysis, kidney transplants, cardiac catheterisation, and diagnostic testing for lung cancer. The report urges physicians to uproot 'social or cultural biases that could affect medical care' and 'presumption about the relative worth of certain social roles.'<sup>6</sup>

The difficulties of many women in getting good medical care, appropriate pain relief, combined with a higher incidence of depression, and a higher rate of poverty may combine in influencing

women to ask for euthanasia. Women are over-represented in the ranks of the poor and often lack the resources to cope with disability and disease.

FINRRAGE (Australia) would suggest that it is likely many women may request euthanasia because their needs remain unmet.

It cannot be denied that there remains widespread devaluation of women who are sick, disabled and elderly. Ageism and sexism force many older women to experience self-derogation and to feel dejected, degraded, devalued, useless, and worthless.<sup>7</sup> The very fact that women outlive their male partners exacerbates their vulnerability because of loneliness, lack of support and feelings of alienation in couple-preferring society which devalues single women at any point in their lives but particularly in old age.

The Dutch Attorney General, T.M Schalken, stated in 1984 that 'elderly people begin to consider themselves a burden to the society, and feel under an obligation to start conversations on euthanasia, or even to request it.'<sup>8</sup>

The story of an 84-year-old woman who had lived with her daughter for 20 years gives credence to this. In a letter in the Santa Rosa (California) Press Democrat, Sept 14, 1993, she wrote:

Everything went fine for many years but when I started to lose my hearing about three years ago, it irritated my daughter ... She began to question me about my financial matters and apparently feels I won't leave much of an estate for her ... She became very rude to me ... Then suddenly, one evening, my daughter said very cautiously she thought it was ok for older people to commit suicide if they cannot take care of themselves. ... So here I sit, day after day, knowing what I am expected to do when I need a little help.

FINRRAGE (Australia) believes women are particularly vulnerable to euthanasia because of what Gilligan has called an 'ethic of self-sacrifice among women.' Many women remain powerless and have been inculcated from girlhood with the notions that they should 'not make a fuss,' 'not get in the way', 'not be a burden' and always put other people first. These characteristics may make women more 'willing' to 'choose' euthanasia.<sup>9</sup> Submitting oneself to euthanasia could be extolled as the ultimate act of altruism.

The report of the Institute of Medical Ethics Working Party on the Ethics of Prolonging Life and Assisting Death Report stated: 'If ... the doctor is confident that the patient's disabilities, coupled with his (sic) genuine distress about the trouble and expense of the care he (sic) needs, make continued life devoid of any enjoyment, the doctor's response [whether or not to provide euthanasia] will depend on the more general question of how he (sic) regards his (sic) ethical responsibilities in relation to assisting death.'<sup>10</sup> 'She' could also find her 'genuine distress' about the 'trouble and expense of care she needs' exploited for euthanasive gains as well.

Stephanie Gutman, writing in The New Republic, has observed that in Dr Jack Kevorkian's 'medicide' of Sherry Miller and Marjorie Wantz,

one woman seems to have been suffering from depression rather than organic disease, and the other from a particularly self-abnegating sense of the trouble her disease caused others.<sup>11</sup>

Gutmann points out that in the patients approaching Dr Jack Kevorkian, most of the men were declared terminally ill by their own doctors. The women, however 'had more ambiguous complaints'. Gutmann cites a chart compiled by Kalman Kaplan, director of the Suicide Research Center at Columbia-Michael Reese Hospital in Chicago.

[w]e see that most of the Kevorkian women were not diagnosed terminal and had not been

complaining of severe or constant pain. We see conditions like breast cancer (for which there is now great hope), emphysema, rheumatoid arthritis and Alzheimer's (a condition that usually burdens relatives more than the people who have it). Reading the case histories it is clear that many of these women's lives were messy and unattractive. But in all-too-typical female fashion, the patient often seems to be have been most worried about the disease's impact on others. Is it possible that a certain type of woman - depressive, self-effacing, near the end of a life largely spent serving others - is particularly vulnerable to the 'rational,' 'heroic' solution so forcefully proposed by Dr. Death?<sup>12</sup>

For many women, 'choosing' euthanasia could be extolled (by others) as an act of nobility and humble self-sacrifice. There are claims that in the Netherlands 'the highest terms of praise have been applied to the request to die: this act is 'brave,' 'wise,' and 'progressive.'<sup>13</sup>

Women may seek such accolades, even in death.

FINRRAGE (Australia) has always questioned the rhetoric of 'choice'. Many women at best make decisions between often equally poor alternatives. Their so-called 'choice' is influenced by innumerable mitigating factors. We therefore believe that 'choice' is not an accurate word to use when describing women's decision making process.

Wolf has identified this:

In circumstances in which women and others who have traditionally lacked resources and experienced oppression are likely to have fewer options and a tougher time getting good care, mechanical application of the rights equation will authorise their deaths even when less drastic alternatives are or should be available. It will wrongly assume that all face serious illness and disability with the resources of the idealised rights bearer - a person of means untroubled by oppression. The realities of women and others whose circumstances are far from that abstraction's will be ignored.<sup>14</sup>

Wolf argues that the request for death is socially constructed: 'We construct a story that clothes the patient's terrible despair in the glorious mantle of 'rights'.<sup>15</sup>

It is very possible that many requests for euthanasia are symbolic of a breakdown in relationships and social networks, in essence a cry for help. There are already examples surfacing of women who are not chronically ill, being euthanased. A doctor was charged under the Dutch Penal Code with assisting the suicide of a 50-year-old woman who wanted to die because of her grief at the deaths of her two sons and her marriage breakdown. The doctor has not been punished.

Additionally, the nurse's role in euthanasia practices has been inadequately addressed. Johnstone argues that nurses - who are predominantly women - have been excluded from public debate on the ethics of health care. For example, the Northern Territory Nurses Board, in response to the legislation, states that nurses must be aware of their employer's position on euthanasia. The reality is that many employers do not have a position on euthanasia, leaving nurses with no clear guidelines regarding their role and responsibilities to the dying patient.<sup>16</sup>

There is also the issue of conscientious objection: while the Northern Territory legislation provides immunity for nurses who are unable for personal ethical reasons to participate in an act of euthanasia, there is room to suggest that in reality nurses may sometimes find it difficult to express their conscientious objection.<sup>17</sup>

A Harvard psychiatrist has speculated about why those women among Kevorkian's 'patients' who were still capable of killing themselves (suicide is decriminalised in the US) instead sought Kevorkian's help. 'The psychiatrist wondered whether turning to Kevorkian was a way to seek a relationship.'<sup>18</sup>

We believe that the language of euthanasia has been blurred to hide the reality that it is deliberate killing of one person by another. Evidence for this can be seen in the aforementioned Institute of Medical Ethics Working Party report which stated:

... more important is rejection of the word 'killing'. This word is generally used to indicate a violent act in war or crime, rather than to describe a gentle act of merciful clinical care.

de Wachter quotes a Dutch physician as saying that

there are situations in which the best way to heal the patient is to help him (sic) die peacefully and the doctor who in such situation grants the patient's request acts as the healer par excellence.<sup>19</sup>

FINRRAGE (Australia) is also concerned about the possible ramifications of pro-euthanasia legislation because of the traditional power relations between women and the medical profession. Because medical practitioners have often placed themselves in a superior position of overriding authority and because of the privileged position of many in the medical field, women may put aside their own views and submit themselves to the pre-eminence of a doctor's opinions.

FINRRAGE (Australia) is seriously concerned that under the Rights of the Terminally Ill Act, a psychiatrist must certify that the patient is not suffering from 'treatable clinical depression in respect of the illness.' The psychiatrist does not have to determine whether the patient is suffering from depression unrelated to the illness or whether there is depression which is not considered 'treatable'. The psychiatrist also does not have to determine if the patient is suffering from any other psychiatric illness or disorder. The Coroner has no power to investigate circumstances of the euthanasia. We also accept the argument that once euthanasia is legislated in 'voluntary' cases, it becomes practice in many non-voluntary situations. This is demonstrated by the Netherlands experience.

John Keown has examined the slide from voluntary to non-voluntary euthanasia in Dutch practice and the shift in Dutch opinion towards condonation of non-voluntary euthanasia. He writes:

... there is ample evidence from the Dutch experience to substantiate the relevance of the 'slippery slope' argument. Within a decade, the so-called strict safeguards against the slide have proved signally ineffectual.<sup>20</sup>

The Journal of the Royal Society of Medicine reported the following account which illustrates the reality of this slippery slope:

A patient with disseminated breast cancer had severe pain. Eventually, she was receiving more than 2g of morphine a day but was still in pain. Several weeks previously, at an outpatient clinic, she had told the doctor that she would never choose euthanasia because of her beliefs. She was admitted one Saturday under the care of the same doctor and treated with intravenous midazolam<sup>21</sup> and morphine. She became unconscious, so the dose of midazolam was decreased. She woke up and said she was free of pain. After a weekend on duty, the doctor went home on Monday morning. The patient died 30 min later. Next day, a nurse told the weekend duty doctor that another doctor had ordered a 20-fold increase in the dose of morphine. Her family had been asked to leave the room, the order was given verbally and the doctor refused to confirm it in writing. When challenged by the weekend duty doctor, the second doctor replied 'It could have taken another week before she died: I just needed this bed.'<sup>22</sup>

Another example from the Netherlands is also illustrative of the potential devaluation of patients once euthanasia becomes established practice:

A general practitioner called to a patient's home, and seeing her for the first time, immediately asked her to choose between hospitalisation and euthanasia. When the stunned patient could not reply, he gave her one hour to think it over.<sup>23</sup>

In addition to these points we share the concerns of disability rights advocates that the disabled in Australia could become a special target for non-voluntary euthanasia especially in a climate of scarce health care resources and inadequate services for the disabled and chronically ill.<sup>24</sup>

The cover story in America in May last year reported the fears of the disabled that their lives may be ended unwillingly.

Responding to the legitimate fears of handicapped people, the Dutch Patients' Association has deemed it necessary to issue wallet-sized 'Life Passports' intended to prevent involuntary euthanasia in case of admission of the signer to a hospital.<sup>25</sup>

Prenatal screening followed by abortion for genetic and other defects is now widespread. Peter Singer and others advocate infanticide of handicapped newborns.<sup>26</sup> We believe that these practices and beliefs contribute to the creation of a society which will have even less tolerance for those considered imperfect in some way. Many disabled people have testified to attitudes expressed that they would have been 'better off dead'. Parents of disabled children have also spoken of being asked 'Why didn't you have the test'? Those escaping the screening net are already being seen as screening failures. These survivors may be placed under extreme pressure to acquiesce to euthanasia at a later stage. 'Putting us out of your misery' is the unfortunately apt title of an article in Quad Wrangle last year.<sup>27</sup>

Australian disability rights advocate Christopher Newell, wrote recently:

Furthermore, we live in a society which has oppressed people with disability via its very structures and norms, and where the dominant knowledge is that it is 'better to be dead than disabled.' Indeed, unless one is presented with a positive social model which suggests that people with disabilities can achieve, and which challenges dominant stereotypes of the quality of life for people with disabilities, then inevitably it is seen as reasonable that people should either be allowed to end their lives, or have their lives ended for them, voluntarily or involuntarily ... Australian society faces a challenge to inject the same effort into allocating resources and effort to support people, as is found in efforts to facilitate their killings.<sup>28</sup>

FINRRAGE (Australia) upholds the position that the less powerful

cannot be adequately protected in a regime where medical killing is legalised or decriminalised ... such measures could actually increase the oppression experienced by people with disabilities.<sup>29</sup>

We endorse the House of Lords Select Committee on Medical Ethics enquiry which stated in 1993:

We are concerned that vulnerable people - the elderly, lonely, sick or distressed - would feel pressure, whether real or imagined, to request early death. We believe that the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support in life.

This statement stands in stark contrast to the contemptuous words of former Australian Governor General Bill Hayden who said: 'There is a point when the succeeding generations deserve to be disencumbered ... of some unproductive burdens.'<sup>30</sup>

FINRRAGE (Australia) sees in the NT legislation the death of human solidarity, communitarian values and the duty of care.

French psychoanalyst De Hennezel believes society is 'governed by th(e) myth of a good death.' This 'good death' is 'a discreet and rapid death, unconscious, and, particularly, of no bother to anyone else.' Death is

experienced in great solitude and with no guideposts or values ... [a] world of effectivity, efficiency, performance, with priority given to cost-effectiveness [and] consumption...[a] world of objects not of subjects - in short, a world stripped of souls and spirit, a world without love.<sup>31</sup> We foresee a situation where the disabled, ill and elderly will be placed in a position where they will be required to justify a preference to live. As Brock has pointed out: 'the existence of the option becomes a subtle pressure to request it.'<sup>32</sup> For all the afore mentioned reasons this will be particularly true for women.

Melbourne bioethicist Nick Tonti-Filippini understands what this could mean to the very sick:

Those of us who are chronically, seriously ill now look at the costs of our care with real fear, knowing that our continued medically dependent existence is not inviolate. How small a step it would be to move from making us feel guilty about continuing to live, as we now are made to feel, to taking away our access to life support or prescribing death when we can no longer protest. These are fearful times in which to be chronically ill, frail and elderly.<sup>33</sup>

And, we would add - female.

As individuals we have responsibilities to others. The exulting of independence, self-sufficiency and radical individualism has, we would argue, resulted in the breakdown in human solidarity, networks of care, and contempt for dependency.

By exalting autonomy to the degree we do, we systematically slight the very young, the severely ill or disabled, the frail elderly, as well as those who care for them.<sup>34</sup>

The taking of life can never be a private decision between a patient and his/her doctor. It affects all of us. The House of Lords Select Committee on Medical Ethics observed:

We believe that the issue of euthanasia is one in which the interest of the individual cannot be separated from the interest of society as a whole.<sup>35</sup>

**We believe that the issue of euthanasia is one in which the interest of the individual cannot be separated from the interest of society as a whole.<sup>36</sup>**

FINRRAGE (Australia) supports the right to refuse life-sustaining treatment, to be free of treatment considered burdensome and to be free from unwanted bodily invasion.

We strongly support increased funding for palliative care. In our analysis, we believe euthanasia will result in less attention and resources being devoted to palliative care. Palliative care remains underfunded, suffering a 10 percent funding cut in the last budget, with funding after June 1997 in doubt.

The Victorian Association for Hospice and Palliative Care Inc wrote recently:

It would be a sad comment on our society if those vulnerable people facing the end of their lives, sought euthanasia as a release from their suffering, in their ignorance about the enormous developments within the discipline of palliative care over recent years.<sup>37</sup>

In conclusion, we commend to the Committee the words of Roy and Rapin, writing in The European Journal of Palliative Care:

The challenge of civilisation to our societies at the end of this decade is to transform our care of the suffering and the dying, not to legalise an act that would all too easily substitute for the palliative competence, compassion and community that human beings need during the most difficult moments of their lives ...The signs in our society of overt discrimination, latent racism, and utilitarian insensitivity to the vulnerable are too prominent for us to be naive about proposals to decriminalise euthanasia.<sup>38</sup>

It is the duty of the Commonwealth to protect the most vulnerable.

We urge the Parliament of Australia to carry out this obligation by rejecting the Rights of the Terminally Ill Act 1996 and upholding the Euthanasia Laws Bill 1996.

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## Book Review

Edited by Dr. Megan-Jane Johnstone  
The Politics Of Euthanasia: A Nursing Response  
\$20.00 Paperback 182 pages  
Reviewed By Susan Clements

New legislation in the Northern Territory of Australia has recently taken the right to die movement a step further by legalising active voluntary euthanasia, something which no country has done. This legislation carries serious implications for the nursing profession. (Megan-Jane Johnstone, 1996, p.7.)

And so begins the introduction to this book which was commissioned by the Royal College of Nursing, Australia (RCNA) as a response to the needs expressed by the College's euthanasia discussion paper entitled 'Euthanasia: an issue for nurses'. The book is divided quite succinctly into five parts. All the chapters are linked and interrelated by virtue of the fact that they reinforce the need for nurses to question. In so doing, consider the implications for nurses in the current debate on euthanasia/assisted suicide. Additionally, the book contains a comprehensive appendix. If you are looking for a simple, easy to follow guide on euthanasia then you will be disappointed. This book does not provide definitive answers to the questions it raises, but I suggest it will assist nurses to think about the nature and implications of the euthanasia debate.

Johnstone introduces an 'important first step in advancing the discussion.' She suggests we need 'to clarify what euthanasia is and how, if at all, it differs significantly from other end of life practices such as assisted suicide and 'mercy killing'.

Meg Wallace warns nurses that 'The Northern Territory legislative innovation creates an urgent need for Territory nurses to be prepared to deal with the many issues that it raises and to ensure [that] they are adequately protected by it.' Issues of protection for nurses raises many questions in this discussion. What is the role of the nurse in euthanasia? What are the implications for nursing practice? Wallace writes about the role and expectations of the nurse in this legislation. Caution needs to be taken so that they don't end up in court defending their decisions.

Olga Kanitsaki provides a brief overview of differing cultural and religious perspectives. This chapter is crucial because as Kanitsaki so aptly reminds us 'consideration and inclusion of culturally diverse points of view occurs as a matter of course and cannot be assumed'. Additionally, we need to be reminded to alert nurses to the existence of diverse (cultural) perspectives on the subject of euthanasia/assisted suicide and to raise awareness of what legitimating the practice of euthanasia might mean to people in a multicultural society like Australia. It is clear that the euthanasia debate and arguments put forward to support it, reflect the dominant view. This failure to consider diverse perspectives and viewpoints further adds to the vulnerability of marginalised groups by the mainstream debate.

Margaret O'Connor confronts the current debate on euthanasia. She argues that it has not recognised the central role that nurses play in the care of the dying. Of particular note is her reference to the notion of 'disempowerment of the nursing voice [which] negates the skill of nurses in being able to relieve much suffering at the end of life'.

Johnstone leaves the reader clear that the issue of euthanasia/assisted suicide 'is not - and never has been - morally or legally 'clear cut' and remains as controversial as it is complex, and as divisive as it is daunting'. We are reminded that whilst nurses may have a 'special' relationship with those suffering the end stages of their illness, this in no way implies they have any more 'special' moral abilities than do any others to decide and judge on the matter of the moral 'rightness' or 'wrongness' of euthanasia/assisted suicide. The reader is reminded that this 'presumes that nurses are a homogenous group with homogenous and uncomplicated views on the matter'. This book left me thinking that when one considers the political, legal and cultural issues of euthanasia/assisted suicide how can the nursing profession take a 'position' which incorporates a worldview. The editors of this book should be congratulated for making a much needed contribution to the debate on euthanasia/ assisted suicide and a positive addition to nursing scholarship.

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(Footnotes)

- <sup>1</sup> hPG is the fertility hormone, hGH a growth hormone administered to children of short stature.
- <sup>2</sup> Ibid, p.23.
- <sup>3</sup> Ibid, p.23.
- <sup>4</sup> Dorothy H. Broom, *Damned if We Do, Contradictions in Women's Health Care* Allen and Unwin Sydney NSW 1991; Charlotte F Muller *Health Care and Gender*, Russell Sage Foundation New York 1990.
- <sup>5</sup> *Feminism & Bioethics; Beyond Reproduction*, Susan M. Wolf ed New York and Oxford University Press p.283.
- <sup>6</sup> Council of Ethical and Judicial Affairs, American Medical Association, 'Gender Disparities in Clinical Decision Making' *Journal of the American Association* 266 (1991), pp.559-62.
- <sup>7</sup> Nancy J. Osgood, Susan A. Eisenhandler, *Gender and Acquiescent Suicide: A suicidologist's perspective* *Issues in Law and Medicine*, Vol 9 (4) 1994, p.370. The authors discuss the concept of 'acquiescent suicide' which, they write 'emerges when individuals yield to the contact surrounding them ... institutionalisation may become the social context conducive to acquiescent suicide for older women'
- <sup>8</sup> Margaret A. Somerville, *The Song of Death: The Lyrics of Euthanasia*, *Journal of Contemporary Health, Law and Policy*, Vol 9 (1), p.47.
- <sup>9</sup> Carol Gilligan, *In a Different Voice: Psychological theory* Cambridge, MA: Harvard University Press p.132.
- <sup>10</sup> 'Assisted Death'. Institute of Medical Ethics Working Party on the Ethics of Prolonging Life and Assisting Death *The Lancet*, Sept 8, 1996, p.611.
- <sup>11</sup> Stephanie Gutman, 'Death and the Maiden', *The New Republic* June 24, 1996, p.24.
- <sup>12</sup> Gutman, *op cit*, p.27 emphasis added.
- <sup>13</sup> Somerville, *op cit*, p.47.
- <sup>14</sup> Wolf, *op cit*, p.299.
- <sup>15</sup> Wolf, *op cit*, p.300.
- <sup>16</sup> Megan-Jane Johnstone (1996) *Euthanasia puts nurses on ethical razor's edge*. *Nursing Review*, November, p. 6.
- <sup>17</sup> Megan-Jane Johnstone, *op cit*, p.6
- <sup>18</sup> B.D. Colen, 'Gender questions in assisted suicides' *Newsday*, Nov 25, 1992: p.17.
- <sup>19</sup> Somerville, *op cit*, p.46.
- <sup>20</sup> John Keown, 'Euthanasia in the Netherlands: Sliding down the slippery slope' In *Euthanasia Examined Ethical, Clinical Perspectives*, John Keown ed, Cambridge University Press, 263, p.269.
- <sup>21</sup> Midazolam is a sedative often combined with morphine intravenously, used in Intensive Care settings often for its amnesiac properties.
- <sup>22</sup> Robert G. Twycross DM, 'Euthanasia: going Dutch' *Journal of the Royal Society of Medicine* Vol 89 (29) 1990.
- <sup>23</sup> Robert G. Twycross DM, 'Assisted Death: a Reply' *The Lancet*, Vol 336 (8719), p.796-798, September 29, 1990.
- <sup>24</sup> Director of the Linacre Centre for Health Care Ethics in London, Mr Luke Gormally, when in Australia last year referred to a study at Harvard University which linked calls to legalise euthanasia to economic depressions.
- <sup>25</sup> Peter J Bernadi, 'The hidden engines of the suicide rights movement.' *America* Vol 172 n16 p14(4) May 6th 1995.
- <sup>26</sup> See, for example, Peter Singer and Helga Kuhse, (1985) *Should the Baby Live? The Problems of Handicapped Infants*. Oxford University Press, Melbourne and Peter Singer: *Rethinking Life & Death: The Collapse of Our Traditional Ethics*, The Text Publishing Company, Melbourne, 1994.
- <sup>27</sup> Joan Hume, 'Putting us out of your misery', *Quad Wrangle*, Spring 1995. Hume quotes the NSW Humanist Society's position on Euthanasia: A baby 'born with severe mental or physical disabilities, ... should be terminated by legal process before any person becomes emotionally attached to it'.
- <sup>28</sup> Christopher Newell, 'Critical reflections on euthanasia and people with disability', *AQ*, Vol. 68

No.3 1996, p.49-50, 56.

<sup>29</sup> Christopher Newell, 'Medical Killing and People with Disability: A Critique', *Australian Disability Review*, No.2, 1996, p.28.

<sup>30</sup> Bill Hayden, 'A right to live, and die, without intervention', *The Australian*, June 23, 1995.

<sup>31</sup> M. de Hennezel 'The Myth of the Perfect Death: The New Meaning of Death in the Context of AIDS', Plenary Address, 'Caring Together/Entraide: Conference Proceedings', Ottawa, 1991, pp.33-38, 34.

<sup>32</sup> Brock, *supra*, note 25, p.17, referring to Velleman, D.W. Brock, 'Voluntary Active Euthanasia', *Hastings Center Report*, 192; 22(2) pp.10, 19.

<sup>33</sup> Nicholas Tonti-Filippini, 'Human rights must precede State rights', *The Australian*, October 28, 1996, p.9.

<sup>34</sup> Mary Ann Glendon, *Rights Talk: The Impoverishment of Political Discourse* (New York, NY: Free Press, 1991), p.74.

<sup>35</sup> House of Lords, Report of the Select Committee on Medical Ethics, HL. Paper 21-1, London: HMSO, 1994.

<sup>36</sup> House of Lords, Report of the Select Committee on Medical Ethics, HL. Paper 21-1, London: HMSO, 1994.

<sup>37</sup>Letter, October 1996

<sup>38</sup>Regarding euthanasia', David J Roy, Charles-Henri Rapin, *European Journal of Palliative Care*, Vol 1(1). Spring, 1994.