End of Life Decisions and the Severely Handicapped Neonate

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Abstract

This dissertation outlines several important issues concerning end of life decisions and the severely handicapped neonates. The value of life, decision making and euthanasia are analysed in order to arrive at a best possible scenario for severely handicapped neonates in the future. The first task has been to analyse the problems faced by severely handicapped neonates and non-autonomous persons. The question of non-autonomous human beings' value of life and whether they can be considered persons has been discussed. It is undoubtedly difficult to assess the quality of life for non-autonomous persons however; by using philosophical analysis, it has been shown that they do have a value of life and that they are indeed persons. The second question that has been raised is decision making. This issue is complex because decisions lie with surrogate decision makers. In order to arrive at the best possible solution for the neonates, the views of the parents, courts, and medical staff need to be examined. The third question is euthanasia. Although euthanasia is not recommended for severely handicapped neonates, it can be argued through ethical considerations that it may be morally permissible. Finally, by analysing the problems raised at each stage, the possible trend for severely handicapped neonates is discussed. The thesis concludes with the thought that genetic screening and gene therapy may be the solution in the near future.

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Introduction

Many of us find it difficult to associate with severely handicapped neonates. The difficulties lie in comprehending their physical and psychological condition, and in appreciating their struggle to maintain their lives. It is easier for the rest of us, that are born normal and healthy, to assume that the severely handicapped neonates' lives are lives that are not worth living. We merely observe their condition or, at best, try to take care of them as much as we can. However, the visual impact of their sometimes severe handicap, leads us to believe that perhaps they are better off dead. This thesis tries to point otherwise, and holds the view that severely handicapped neonates have a life worth living, although this depends on the severity of the handicap, and more importantly, have a right to life. The difficulty arises with foetuses detected with anomalies. Even if they are detected to have severe handicaps they may have the potential to lead a life worth living. The decision to terminate or to not terminate a pregnancy will lie with the parents. For without family cooperation it is difficult, if not impossible, for these infants to have a life worth living.

The value of severely handicapped neonates is an even harder question. They do not have, and most likely will never have, a socio-economic function. If they have a value at all it would be because they bring out the more benevolent side of society, and because they have the ability to enjoy life within their means. It would be morally wrong of us to deny them at least the opportunity to try to develop their capabilities, like making value judgements concerning themselves. This can be in the most basic form of moral or 'liking-values'. So long as neonates can appreciate life within their capacity, they have a value of life.

It is however, extremely difficult to make life or death decisions on behalf of these neonates. Their non-autonomy makes it difficult, if not impossible, for us to judge whether they would prefer to live, or to be allowed to die. No one, person or group, can or should make these decisions. Since neonates cannot express their wishes, the best alternative is to allow the parents, along with the medical staff's recommendation, to try to arrive at a solution that is for the best interests of the child. If it is agreed between the parents and the medical staff, that the severely handicapped neonate in question should be treated, then the treatment should be one that is of benefit for the child. On the other hand, if the unfortunate decision to withhold treatment is made, the method of allowing the neonate to die must be considered. Most medical staff and parents choose to limit the treatment to 'nursing care' only, as it is legally permissible, and more importantly allows nature to take its course. Sometimes however, 'nursing care' alone may merely prolong infants' lives unnecessarily, especially if it is in pain and misery. In such a case, it may be more humane to euthanise them through a lethal injection. Death will be swift and painless, thus allowing the neonate to die without suffering longer than necessary. There are, naturally, serious ethical questions regarding whether euthanasia should be made legally permissible for non-autonomous patients. The main problem deals with the fact that they are unable to express their wishes.

Most of us have been fortunate enough to be born with the capacity to appreciate and achieve our aims in life. One of our aims should also be benevolence and kindness towards those that have been born under less fortunate circumstances or conditions. As autonomous persons, we are able to fulfill their needs. Our aim in life then, is not only towards ourselves but towards others as well.

1 The Worthwhile life for non-autonomous persons

The first thing that comes to our attention is that words such as 'handicapped' and 'non-autonomous' immediately places these people into a specific category. We already have an attitude of applying a standard phrase to a common problem of what their worthwhile life is. To tackle this problem, one must first try to discern what the worthwhile life for the autonomous persons is, then try to find a common ground for both autonomous and non-autonomous persons. In order to discern what the worthwhile life for non-autonomous persons is, notions like 'values' and 'persons' should be discussed. Happiness can be seen as a value that aspires both the autonomous and non-autonomous persons. However the main difference is that the non-autonomous persons can only experience happiness at a basic level. Autonomous persons can take the experience of happiness to a more complex and higher level. In this chapter, the severely handicapped neonates' quality of life will not be taken as a separate issue, rather the neonates shall be included as part of non-autonomous persons in general.

The traditional philosophical view of the value of human life was seen to lie in the life of reason and rationality. However, this was written based on specific groups of people with an understanding that the people they were discussing about, were autonomous (self governing). Due to medical advancement, a larger range of human beings are kept alive, thereby necessitating a re-evaluation of the concept of the worthwhile life. Reason and rationality can no longer be the main basis of constituting a worthwhile life, for then we shall need to say that people without a worthwhile life are being kept alive. There has been however, a leniency in this somewhat rigid model of the worthwhile life. To illustrate, both Aristotle and Kant write that humans have a natural inclination to seek happiness. Reason and rationality will thus play an important role in promoting happiness for oneself and for others. There are however a range of values, other than rationality, that are values by themselves.

It would be difficult to say, contrary to the Kantian view, that rationality alone is the human value, for then the perfect being would be a robot. We are more and have capacities other than rationality and therefore a wider range of values. For example, love and courage, which are not always acted out through rationality but are still valued for their own sake.

1.1 Values

What are values? There are a range of ways of understanding value: from the Marxist concept of value, Adam Smith's theory of value in use and value in exchange, to the more basic human values. All the above contribute to the making of society, but the economic evaluation of values will not be discussed here as it does not have a direct correlation in determining what the value of the non-autonomous persons is.

In this discussion values will be analysed as preference and choice. For example, there are two types of values for humans; 'liking values' and 'moral values'. An example made in *Caring and Curing* will be used to explain the differences:

> ...a man who values thrift and enterprise for their own sakes may either simply *like* to be thrifty and enterprising, as a matter of temperament; or he may *approve* of thrift and enterprise in himself and others, be ashamed of himself if he is extravagant or unenterprising, and so on. We can call the first kind 'liking-values' and the second kind 'ideal-values[1]'.[2]

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[1] 'Ideal-values' can be interpreted as part of 'moral values', although 'moral values' is a 'very slippery term' (DOWNIE and TELFER, ref. 2, page 8) Downie and Telfer write that; 'Ideal-values certainly possess some features which are usually thought of as characteristic of morality. For example, they affect conduct: a person's ideal values - his approvals - have a bearing on what he does.' 'Moral values' will be used instead of 'ideal-values' as the broader definition of 'moral values' is more applicable to this chapter.

[2] DOWNIE, R. S. and TELFER E. *Caring and Curing*. Melthuen: London, 1980, pages 7-8

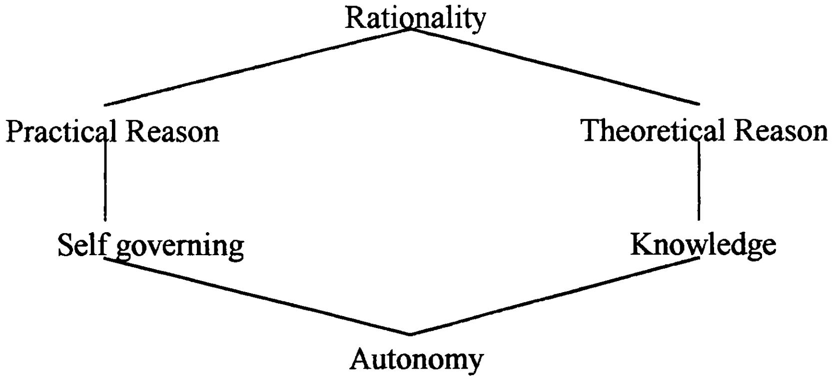
Both exercise preference and choice, and are applicable to autonomous persons, but to a lesser degree to the non-autonomous persons, depending on the severity of their handicap. The liking-value can be applied to non-autonomous persons, as they are able to choose between what they like and what they don't when given a choice. The application of moral values, on the other hand, may be slightly more difficult in the sense that this will require reason and rationality. Thus, non-autonomous persons, in this context will have 'liking-values', but lack in 'moral values' to a certain degree.

If we have the capacity to choose out of preference, then naturally we would choose things that would make us happy, if only for the pleasurable emotions and feelings that we can derive from it. Rational beings would not only choose happiness for themselves but their happiness would incorporate others. As in Aristotle's view of the eudaimon life, we would also derive a sense of satisfaction and accomplishment when we have achieved this. If all values are equally valued for themselves, happiness would be the fundamental component for having a worthwhile life.

The following is a list of basic human values:

1) Autonomy in terms of having rationality and the ability to self govern.

Figure 1.1: Relationship between rationality and autonomy



Autonomy allows for people to choose and make value decisions at a more complex level, such as with legal issues concerning justice (e.g. child custody cases in deciding who would be the better parent, and what would be for the child's best interest).

2) Moral values, pointed out in the example set out in *Caring and Curing,* are what one believes to be right or wrong. This is a reflection of rational agents, autonomous persons, as they are capable of making more complex judgements that would enhance and influence themselves as well as others.

3) Happiness is a value, as humans have a natural inclination to seek it. It is attractive as it encompasses a range of attributes from the basic forms of happiness, such as pleasure derived from eating a delicious meal which is related to feelings and emotions, to the more complex forms of happiness derived from achieving one's aims. A person's happiness and emotions are bound up with those of other people in the sense that peoples' lives are not only worthwhile to themselves but to others as well. People would normally choose happiness over pain, because of the positive feelings and emotions one derives from it, thus happiness will be the fundamental value for both autonomous and non-autonomous persons.

4) Kindness and benevolence could be values to aspire for. They are especially important when applying the concept of the worthwhile life to non-autonomous persons who are capable of kindness, and require kindness and benevolence from others in return. Kindness and benevolence are important for non-autonomous persons. The exercising of these values by autonomous persons will lead to the non-autonomous persons' happiness. They can understand when people are acting out of malice, in contrast to kindness, as they can probably feel pain or happiness at some level of consciousness. Moreover, some non-autonomous persons may be able to show benevolence at least to the limited extent of smiling or being pleasant.

These basic human values depend on what one holds as an important value in one's life. They are on a sliding scale, where people can have more or less rationality on one end (i.e. practical and theoretical reason), sliding down to the values of non-autonomous persons (i.e. kindness and ability to love) who have the ability to experience happiness and pleasure at a basic level. These basic values are not in order of importance but on an equal basis as they are values in themselves. We value the basic sort of moral capacity (i.e. kindness) as well as the more complex forms (i.e. justice) at an equal level.

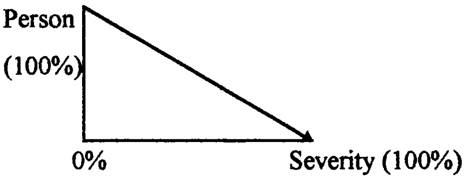
Non-autonomous persons are capable of one or more of the above mentioned values, depending on the severity of their handicap. They are, for example, capable of the basic sort of moral capacity such as kindness and may have the ability to experience happiness to their maximum potential. If they are able to experience even one of these basic human values their life is worthwhile, since these basic human values would give meaning to their existence. If they are in pain and continuous misery they would not be able to feel happiness and may not, as a consequence, be able to act towards others in a kind manner. This would be applicable to autonomous persons as well. The basic forms of values have to be satisfied before one can discuss and appreciate the higher forms of values.

The severely handicapped persons' capacity for moral life may not be existent, but they do experience pleasure from food, water and shelter, and have a degree of awareness of happiness similar to children. The comatose on the other hand, may be seen as not having any value in their non-active state. However their value does not necessarily diminish if one takes the view that the state of coma is similar to an autonomous person's state of sleeping, or when they have fainted and lost consciousness. Patients who are in Permanent Vegetative State (PVS) may also understand happiness and kindness, at some level, although they are in a complicated state of falling between animals and the severely handicapped. We cannot determine whether they are conscious or not, but it is safer to assume that they are, treatment wise. The same would apply to most severely handicapped patients, including spina bifida neonates. One has to keep in mind that these neonates in the future may have the potential to feel the basic forms of happiness, and hence manage to live out their lives within their capacities. It would be dangerous to decide at such an early stage whether their lives are worth living or not.

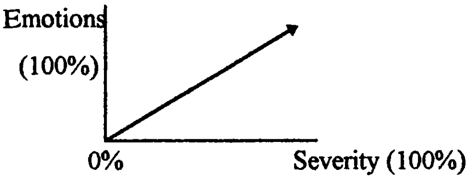
It is difficult to determine whether severely handicapped neonates can or will ever be able to have consciousness, but as mentioned before with PVS patients, it is safer to assume that they will have the capacity to feel happiness at some level in the future. It does not seem to be within our rights to discern whether severely handicapped neonates are capable of happiness or not based on our standards, for their level of happiness is lower than the autonomous persons'. We would, for instance, feel happiness when relieved from pain. This is of fundamental importance in determining the worthwhile life for these neonates and other severely handicapped people. If their lives are going to be full of pain and misery, they will not be able to experience and appreciate happiness to their maximum potential. In this case perhaps euthanasia would be a relief for them. This is a matter of contention and immensely difficult to decide. What could be said at this stage is that if non-autonomous persons are capable of happiness at some basic level, their lives would be worthwhile for them and for others around them. For, as mentioned before, happiness does not only come from the individual alone but from others as well.

Graphs 1.1 - 1.4: Correlation between the degree of severity in handicap and the person, rationality and emotions.

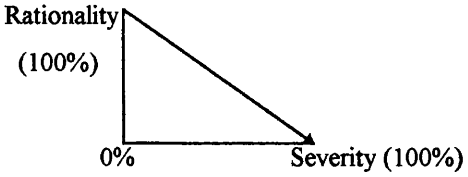
Graph 1.1



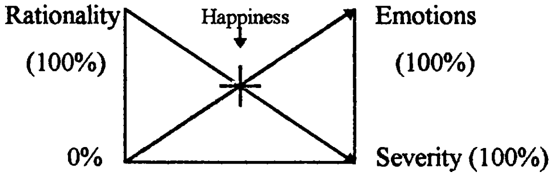
Graph 1.2



Graph 1.3



Graph 1.4



Graph 1.1, 1.2 and 1.3 represent the concepts of person, rationality and emotions in correlation with the degree of severity in handicap. The higher the degree of handicap, the lower the rationality and the quality as a person will be. Expression of emotions on the other hand will increase due to lack of self control.

Graph 4 is used to combine graphs 1.2 and 1.3. The point at which the lines converge is where the common ground for both autonomous and non-autonomous persons lies. These graphs are purely hypothetical and may not apply to individuals. They are merely introduced to find a common basis of a worthwhile life that all human beings share. I have placed 'Happiness' at the crossing point of emotions and rationality as a basis of the worthwhile life for both autonomous and non-autonomous persons, because there is a natural inclination for one to seek happiness regardless of whether one is conscious of it or not. This is simply because human beings derive enjoyment and desirable, hedonistic pleasures from it. If one is too emotional, then happiness is not recognised due to the preoccupation with one's emotions and lack of self control. On the opposite extreme 100% rationality would involve one being too calculating and concerned with acting in the correct manner. As a consequence, one would not be able to enjoy or experience happiness.

1.2 Persons

Before discussing 'happiness' in some detail, the concept of whether non-autonomous beings are persons will be discussed briefly. The advancement of medicine has brought about an increase in the number of severely handicapped neonates that survive. Due to this, the somewhat rigid traditional concept of what constitutes a person has to be slightly modified, and loosened to allow for some variations in order to include non-autonomous persons. Otherwise we are constrained from even approaching the topic of their value as persons.

Non-autonomous persons, like senile patients, mentally deranged, and the comatose are persons because they are firstly; in the human form, and secondly; have characteristics of a person. They have the ability to make choices in at least 'liking values' if not 'moral values'. They have the basic functions as persons, but may lack in the more complex functions, such as having a socio-economic value, consciousness of morality, ability to interact with others and ability to express themselves through language. These functions are important in defining autonomous persons because they have the potential to use them.

The traditional philosophical view of what defines a person has only been based on the autonomous persons. Thus 'persons' were those that were able to function socially. People and children are social beings, therefore they require the above mentioned functions to coexist with others. The factors that contribute to being considered a person is used as a guideline for autonomous persons, and children that are maturing into persons.

The difficulty in determining whether non-autonomous human beings can be considered as persons can be overcome by using the concept of the graph 1.1 (please refer to page

6). As the severity of the handicap increases, their value as a person deteriorates. A person is often seen as having consciousness, the ability to make rational choices, and have a social function. Senile patients, for example, will be seen as persons because they were persons to begin with and have a past of contributing to society. Moreover, depending on the severity of their condition, they will have the ability to choose and at times will be conscious of their surrounding.

Down's syndrome children do not have a past of contributing actively to society, but can show important basic human values such as being extremely loving. They raise protective instincts from people around them and are given back something valuable in return by having a loving nature. They are persons in that they have basic human values and more importantly, because their lives have value to those around them.

Contrary to the above view, there are some radical opinions according to which:

> fetuses and newly born humans, whether they have Down's syndrome or not, are not people, whereas older children and adults, including those with Down's syndrome, are.... One line of argument is that a necessary condition for being a person, and thus for being owed the moral respect due to persons, including an intrinsic moral right not to be intentionally killed by others, is awareness of oneself or self consciousness. It seems plausible that the morally special attributes that distinguish people from animals and other entities to which we do not accord an intrinsic right to life require capacity for self-consciousness. According to this argument self consciousness is not morally important in itself but is a necessary condition of all the remarkable and distinguishing characteristics that endow people worth special moral importance and thus special rights. This argument supposes that all new born infants, like all fetuses, are not

> self conscious and therefore cannot be people and therefore do not have an intrinsic moral right to life.[3]

According to the above quotation from Kennedy and Grubb in *Medical Law,* self consciousness is the basis of a 'person'. To support the above argument would mean that all human beings without self consciousness do not have a moral right to life, therefore it may be permissible for severely handicapped neonates to be killed. This does not seem plausible, for the argument omits to mention the concept of 'potential'. Neonates have the 'potential' of becoming persons and hence developing self consciousness gradually. Self expression through the use of language and emotions is the beginning of self consciousness. The second problem with this argument is that the term 'self consciousness' is vague and difficult to apply to neonates.

It can be argued here that self consciousness develops as the neonate matures into a person. The same can be applied to handicapped neonates, although for them the development of self consciousness would depend on the severity of their handicap. As shown in the correlation in graph 1.1, the severer the handicap the lesser the qualities as a person. Neonates and severely handicapped neonates do not have full qualities as a person. Development will bring about the qualities as a person. This is difficult to determine, but so long as they have been clinically judged as having some potential of leading a 'happy' life, then it would be safe to assume that they will be capable of at least a very basic level of personhood within their capacities.

Although non-autonomous persons, like Alzheimer's patients or PVS patients, may not have any self consciousness depending on the severity of the disease, they have the past of being persons. 'Self consciousness' is merely one of the elements of personhood, and should not be the basis of determining whether infants and severely handicapped neonates are persons or not.

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[3] KENNEDY, I. and GRUBB, A. *Medical Law: Material and Texts.* London: Butterworths, 1989, page 927

Higher animals may be able to display values similar to human ones as well. However since they are in a different category of species they will remain animals rather than humans. The value of having the ability to communicate and interact in society in a harmonious manner could be a distinction raised between basic human values and basic person values. Depending on the degree of handicap, non-autonomous persons will lack in one or more of these social skills. But then again, kindness is also part of the social value necessary in order to coexist harmoniously. If non-autonomous human beings can display kindness or any other basic human value, they should be considered as persons. This is because they are able to interact with others through their behaviour, despite the fact that they may have difficulties in communicating through language. Language and ability to communicate with others is an important social value in determining whether one is a person or not. Non-autonomous persons lack in language skills, but they can live in relative harmony with others without them, since their behaviour towards others will show how they feel.

There are instances when autonomous persons also do not act morally, such as psychopaths. They do not adhere to the moral guidelines, and as a result, they are often seen to be less than human, a 'monster', because they harm other human beings. Psychopaths seem to have less attributes as persons. For although they are in the form of a human, they do not act in the manner expected from a person. They are endowed, unlike non-autonomous persons, with all the qualities as a person, they are rational, yet they have chosen to use their rational will in a morally unacceptable manner.

Non-autonomous persons may lack in rational will and other complex 'person' values, such as social skills, but they do not harm others. They in fact require the opposite, which is protection. They may lack the traditionally understood concepts as a person, but make up for it through other important qualities; by having basic human values like a loving nature and selflessness. These values which are also important for autonomous persons, may even outweigh the difference between autonomous and non-autonomous persons. For although they may lack in rational will, socio-economic functions, the ability to express themselves though language, they will have valuable human qualities that are more important than the above mentioned social skills required as a person. Hence, what they lack is compensated by their more humane qualities.

From this context it can be derived that there is a scale. The scale would range from the more complex functions as a person, to the more basic functions. The optimum balance would be to fall somewhere in the middle, having an equal distribution of the range of 'person' values, but the balance can be evened out even when the distribution is not equal. For instance, a Down's syndrome child. Even if a Down's syndrome child has only 10% rational will, if it has 20% ability to interact with others, 15% ability to express itself through language, and 55% emotions (caring nature), then the balance equals out to having positive person characteristics. Whilst the psychopath, may theoretically have full rationality, have no problems in interacting socially, and in using language, but may completely lack in emotions like compassion. Therefore, although psychopaths may be able to interact socially, they will lack in the human qualities expected from fully autonomous persons.

1.3 Happiness and rationality

'Happiness', as with terms like 'Values' and 'Person', is a somewhat abstract concept. Terms such as pleasure and desire are related to it. Happiness for the non-autonomous person has not been discussed traditionally, as it is only through recent medical advancement that the concept of the worthwhile life of humans has had to be redefined. The worthwhile life has been debated for more than 2000 years, and we have not been able to define what exactly it is. The general concept of happiness has stemmed from concepts such as reason. This can be applied to autonomous persons, as they are capable of rationality and morality. Therefore Aristotle's and Kant's views for example, can be applied to autonomous persons but to a lesser degree to the non-autonomous. This however depends on the severity of handicap.

Traditionally philosophers have taken reason and rationality as the basic component for achieving a worthwhile 'happy' life. Aristotle's view reflected the social structure of his time. Women and slaves were not seen as capable of happiness (eudaimonia) because they were taken to be inferior to men, and because of their lack of education. Children were also seen as incapable of eudaimonia because they are still developing and have yet to cultivate rationality and self control. Children were somewhat exempted from his critical view of women and slaves, for although they are still inferior to men, their rationality and self control are simply immature whilst the inferiority of women and slaves is permanent.

Women were seen to be without authority, and would not adhere to reason. Thus women and children, like slaves, had to be trained to perform their duties in order to achieve eudaimonia, but of a lower kind. This view would not fit into today's society, but it nevertheless presents the view during the time of ancient Greece. What is important here is the concept of eudaimonia which Aristotle believed to be the ultimate aim for autonomous persons.

The eudaimon life has been translated into English as 'Happiness' which can lead to some confusion. The other traditional interpretation is 'living and fairing well'. To understand what the worthwhile life for the non-autonomous person is, the latter interpretation may be more apt. An attempt will be made here to adapt the concept of the eudaimon life to non-autonomous persons.

Virtues and aims in life, for Aristotle, are seen as important for an eudaimon life, whilst reason is used in the social context. It is difficult to apply virtues such as courage, honour, wealth, and reason to non-autonomous persons. On the other hand health can be applied, for then non-autonomous persons are able to lead a worthwhile life. Non-autonomous persons will hence be able to live a eudaimon life by aiming for a healthy life in so far as they are capable of.

The loving nature of the Down's syndrome child, for example, is also a value in leading a worthwhile life. It is a value that should be maintained, if not aspired, by both non-autonomous and autonomous persons. It represents a sort of innocence that the autonomous persons lose as they mature and become exposed to the harsh realities of the world. The eudaimon life for non-autonomous persons would no doubt be on a lower level, but the above shows that they are capable of achieving it partly, and more importantly through support from people around them.

The eudaimon life for non-autonomous persons would be on a more basic level. Firstly, their happiness is important. Their happiness will be based on having food, shelter and comfort. This is the first step to happiness for autonomous persons as well. Without the above mentioned basic needs being satisfied one cannot achieve happiness at a higher level. Reason and rationality will be difficult when faced with hunger, lack of comfort, and shelter. Once these basic needs have been satisfied, the autonomous person can aspire for higher aims such as becoming a politician, teacher, etc. Non-autonomous persons do not have ambitions as the autonomous persons do. They are 'happy' when their basic needs are satisfied. They may also be able to recognise what food gives them pleasure, depending on the severity of their handicap. For example, when they are given a piece of cake, they may enjoy it immensely and feel happy. This seemingly small happiness contributes to an overall picture of happiness for them. It is no different for autonomous persons because trivial things such as viewing beautiful objects, eating good food, enjoying the company of friends also make them happy. As rational beings we should only eat healthy food, although these foods may not always give us pleasure it will be good for our health. Rationally, eating delicious food, such as gourmet dishes that for example taste wonderful but have a high fat content, is unhealthy for us. Indulgence however, does make us happy, because we do not experience it on a regular basis. Happiness therefore does not necessarily have to do with acting rationally. We are complex and not always rational. If we were capable of being rational at all times, we would not feel happiness in indulging in things that were not good for us. But the fact is that we cannot help but feel happiness when eating delicious food. If we adhere to rationality all the time, we would not experience the 'happy' life.

To present another view of the concept of the worthwhile life, Kant has played an important role in presenting rationality and morality as the distinguishing factor of human beings. According to Kant, rationality and morality of autonomous persons allows them to: "Act only on the maxim through which you can at the same time will that it should become a universal law"[4], thus for Kant, the above quote allows them to fulfil duty for themselves and for others. This would result in furthering the end in achieving happiness for themselves and for others. This is what constitutes a worthwhile life for the rational being. Kant's objection to the concept of happiness is that if persons have natural inclinations to make themselves and others happy, this will no longer be a moral duty. He had no objection to people acting out of inclination and in pursuing happiness, but his point was that these were non-moral pursuits.

Duty towards others is important in maintaining and promoting a harmonious society. Non-autonomous persons will have difficulty in acting out of duty, as they may not understand the concept. Their actions will depend on their inherent character rather than from a sense of duty. On the other hand, autonomous persons can understand and value duty and use it to promote happiness for themselves. In this context Kant's concept of duty is applicable. If one acts out of duty, rather than through natural inclinations, then it is purely to promote happiness for others. Hence the act conducted out of duty will be virtuous. In this sense, acting out of duty towards others has two

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[4] Kant, I. *Groundwork of the Metaphysic of Morals.* Paton, H. J. (ed.) London: Routledge, 1991, page 67

positive qualities. The first quality is that one is promoting other's happiness and the second, is that one is also fulfilling one's aim of leading a virtuous, hence worthwhile life as an autonomous person. In this respect of leading a virtuous life, Kant's and Aristotle's views are similar.

Happiness for non-autonomous persons will no doubt depend on the people around them, such as family and care givers. Thus, we have seen that the basic difference between autonomous and non-autonomous persons, is the degree of dependency on others. This is because non-autonomous persons are not capable of independence as their happiness needs to be achieved through help from others. The worthwhile life for non-autonomous persons will depend on the benevolence and kindness of people around them, which in Kant's view cannot be considered as duty but rather as natural inclination.

Kant comments in his work *Critique of Practical Reason* that benevolence and kindness are not moral values, if given through natural inclinations. This is because they no longer apply to the universal law in the sense that the act will no longer be a duty. The act will not be done out of obligation, and is therefore not binding on the will of every rational being:

> Love to God...considered as an inclination (pathological love), is impossible, for He is not an object of the senses. The same affection towards men is possible no doubt, but cannot be commanded, for it is not in the power of any man to love anyone at command; therefore it is only practical love that is meant....To love God means...to like to do His commandments; to love one's neighbour means to like to practice all duties towards him.[5]

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[5] Kant, I. Critique of Practical Reason, Part I, Ch. III, 177. As cited by McGill V. J. *The Idea of Happiness*. New York: Frederick A. Praeger, 1967, page 189

He seems to change his view slightly in his work *Groundwork of Metaphysic of Morals* as he says the following:

> It is doubtless in this sense that we should understand too the passages from Scripture in which we commanded to love our neighbour and even our enemy. For love out of inclination cannot be commanded; but kindness done from duty - although no inclination impels us, and even although natural and unconquerable disinclination stands in our way, - is practical, and not pathological love, residing in the will and not in the propensions of feeling, in principles of action and not of melting compassion; and it is this practical love alone which can be an object of command.[6]

Contrary to Kant's view in *Critique of Practical Reason*, benevolence and kindness are moral values and therefore important. Benevolence and kindness may not be easy to summon up, and one cannot make oneself be kind or benevolent when one does not have the natural inclination to be so. But do we not try to be kind and benevolent towards others? It also seems that our social roles, besides duty towards others, encompass kindness because we are taught from a young age to respect others. The fact is we do try to be kind, such as by giving up seats for pregnant women and senior citizens.

Duty, in the strict sense, can be construed as something akin to chores; something we have to do although we do not want to. But there are certain duties that we may have to perform in the social or political context that can also be virtues (i.e. a soldier's courage), whilst at the same time deriving a sense of satisfaction and pleasure. The key issue here is that virtues and duty are moral values. If we do act out of duty, in its strictest sense, society can function; but it would be a cold world.

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[6] Kant, ref. 4, page 65

If one can act towards non-autonomous persons, out of benevolence and kindness through natural inclinations rather than through a sense of duty, that is the best. For then you make others' ends your own without having to strive for it. It does not matter if one has to see the promotion of the non-autonomous person's happiness as a duty, because the result is the same. There is though a belief that non-autonomous persons may understand the difference between when something is done out of love and care, and when it is done simply for the sake of duty.

It is better, in my view, to act out of kindness and benevolence towards people than out of duty, for then you have accomplished aims for yourself and others at the same time. This seems to be the basis of leading a happy life for both autonomous and non-autonomous persons. For non-autonomous persons, it does not matter whether they are conscious or whether they understand the concept of happiness, as long as autonomous persons do. They will know when non-autonomous persons are, for example, enjoying their food, or taking pleasure in walking in the garden. The autonomous person can also derive pleasure from seeing them happy. As the autonomous persons' duty is to promote the happiness of others, it does not matter whether or not they take pleasure or feel happiness when they see happiness in a non-autonomous person. It can only be said here, that so long as one is doing something positive in promoting the well being of another person, it would be better if one can derive some happiness from it as well.

1.4 Summary

This chapter has tried to determine what the worthwhile life for the autonomous person consists of. Happiness seems to be the basis for a worthwhile life for both autonomous and non-autonomous persons, since positive emotions can be derived from this. Happiness in terms of the traditional philosophical view cannot be applied to non-autonomous persons because their needs are different from autonomous persons'. The level and quality of happiness may seem to be lower compared to the autonomous persons' standards, but this may not necessarily be so, as something trivial as getting a sweet, or an affectionate hug gives them immense pleasure. It seems that autonomous persons, because of their experiences, have different expectations and at the same time require more in order to be happy. When dealing with non-autonomous persons, we should also strive to be kind and benevolent, because it would give happiness to both parties. Perhaps Kant is right in saying that an act no longer is a duty if it is done out of natural inclination. But it does not follow that actions done out of inclination have no moral worth, unless we assume that only duty has moral worth. But this is not plausible.

Rationality for autonomous persons is an important value because we can utilise it for our own good and for the good of others. As mentioned before on the sections on 'Persons', one of the differences between autonomous and non-autonomous persons is that autonomous persons are social beings, therefore Aristotle's and Kant's views on happiness for people can be applied. Autonomous persons have virtues and aims as well as a sense of duty towards others. For without these, human beings will not be able to coexist. Depending on the degree of severity in handicap, non-autonomous persons will lack in rationality and in understanding the necessity of a social role. If they do not have these concepts, they will not be able to be actively involved in the social context. This however, does not mean that they will not be happy and will not make others happy. Non-autonomous persons themselves can be valued for what they are, and for their capability for having one or more of the basic human values. If they lack in certain functions, natural to autonomous persons, it is the duty of the autonomous persons to work around this problem and ensure their happiness as they require it. Unlike autonomous persons, their needs in terms of happiness are simple.

2 Decision Making

The rapid advancement of medical technology, has led to an increasing need for legal guidance in the decision making processes for severely handicapped neonates. The difficulty arises from deciding who has the most authority and knowledge of the patient, so that the best possible outcome can be derived. For autonomous persons this would not be a problem as the main decision making will lie with themselves. The advice given by the doctor will no doubt play a large part in influencing the decision making process of the patient, but there may be less need for court intervention as the patient will be competent to decide what is best for him or herself. Problems however, arise for non-autonomous persons, as the people around them have to decide on their behalf.

2.1 Who should decide the fate of the severely handicapped neonates?

Before discussing decision making, a brief description on the difference between autonomous and non-autonomous persons is required. The difference can be understood from the following description given by James F. Childress:

> Two essential features of autonomy are 1) acting freely and 2) deliberating rationally...First what is the relationship between competence and these two features of autonomy? Logically competence might be viewed as a precondition of deliberating rationally and acting freely or as a summary term for these two (and perhaps other) conditions. A person suffering from mental defects, for example, that would preclude either acting freely or deliberating rationally would be incompetent to make decisions.[1]

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[1] CHILDRESS, J. F. *Who Should Decide? Paternalism in Health Care.* New York: Oxford University Press, 1982, pages 61-62

From the above description we can see that competence in making rational decisions and having free will are what distinguishes autonomous persons from non-autonomous persons. Non-autonomous persons require surrogates to act on their behalf, to arrive at the best solution for them, as they are not competent enough to decide for themselves.

Autonomous persons also have the choice of using 'advance directives', which are advance statements stating their wishes in the event that they are no longer able to express their wills due to their illness. The objective of 'advance directives' is to take into account the wishes of the patients when clinical dilemmas arise, as in cases of having to resuscitate a patient dying from cancer who also suffers from respiratory problems. Unfortunately the use of 'advance directives' is not possible with neonates. One way of perhaps using the concept of 'advance directives' is by preparing expecting parents with the possibility that their child may not be born healthy. Doctors, nurses, or Lamaze class instructors could inform parents of the possibility of them having a handicapped child. This preparation may allow for parents to be more emotionally prepared if their child is born with abnormalities.

Where decision making for non-autonomous patients is concerned, parents or next of kin are usually seen to be the best people to make decisions on the patient's behalf. They are generally believed to know the most about the patient and to want the best for them. The problems here are, of course, whether the parents or next of kin do know best and whether they should have authority to decide the fate of their family member. For it is difficult to say whether family members are the best decision makers when emotions and egoistic reasons become involved. Egoistic reasons are taken here to mean that family members may want to prolong the life of their severely handicapped neonate, because they cannot bear the thought of having a part in ending the life of another human being.

There is no doubt that parents should have the major say in matters concerning the fate of their child, whether it is aggressive treatment or withholding treatment, as they will have to bear the consequences of their decision. There are cases unfortunately, when there is a fine line between severely handicapped neonates that should be given a chance to live, and those that will not benefit from treatment at all. Interestingly enough, court intervention usually takes place when parents want their neonate's life to be terminated, but not when they want it prolonged through extraordinary means. This is probably because of the general humanitarian code where lives should be saved rather than terminated.

2.1.1 Parents refusing treatment for their child

Court intervention is necessary when there is a clear case of dispute between parents and other groups concerning what would be for the child's best interest. Other groups are taken here as medical staff, right-to-life groups, lawyers and so forth. In most cases concerning severely handicapped neonates, it is difficult to discern what sort of life the infant will lead if aggressive treatment was employed, but when disputes arise between parents and others it is usually because there is a marginal chance that the child would be able to lead a life that will be worth living. Life worth living is taken here as the 'happy' life, whereby the child will be able to lead a satisfactory life within its means with minimum pain and suffering. All parties are concerned as to whether the life that the child will lead as it matures will be one that is worth living. More often than not, if the neonate's anomaly can be treated, albeit with some neurological handicap such as Down's syndrome, then the medical staff and courts would promote the life of the neonate. There are unfortunately cases, such as Baby John Pearson and Baby Alexandra, where the parents felt that it would be best for the baby if treatment was withheld. The problem with these two cases, is that both these babies' anomalies were treatable, and once treated the neonates will be able to continue their lives without pain and suffering, as Down's syndrome children.

The case of Baby John Pearson, also known as the Dr. Arthur case, was clearly a case where alternative solutions for the baby could have been found and the death of the baby was unnecessary. To describe the case briefly, the baby boy John Pearson was born at 7:55 am on the 28th of June 1980 in Derby General Hospital. The neonate, although healthy, was found to be born with Down's syndrome and was rejected by his parents. Dr. Arthur issued a note: 'Parents do not wish baby to survive. Nursing care only.' On top of this a pain killing drug was also prescribed although there was no need for one. Gradually the neonate's condition became worse with difficulties such as breathing and three days later he died. Dr. Arthur was charged with murder, which was reduced to attempted murder during the course of the trial, and he was acquitted[2].

For the Dr. Arthur case, court intervention came after the incident. Had the doctor informed the court of the problem of the unwanted Down's syndrome child, the neonate's life could have been saved. The question of who would foster or adopt the baby would naturally pose a problem. However there are couples who want to adopt these babies, as was found in the case of Baby Doe in Indiana, United States. The important point here is that the baby would have had a chance to live a healthy life as no complications that are usually seen in Down's syndrome babies were initially found. Although Baby John Pearson may not have developed into becoming autonomous in the way of making rational decisions, he may have had the capacity to appreciate life in his own way.

Another famous case was Baby Alexandra. Alexandra, as known to the public, was born in July 1981 in the London borough of Hammersmith. Unlike John Pearson, this neonate had life threatening intestinal obstruction which required surgical removal. The parents refused surgery with the view that the kindest thing one could do for the baby would be for her not to have the operation but to allow her to die. The Director of Hammersmith Social Services took the issue to court, where upon the child was made a ward of the court, and the operation was authorised.

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[2] See KUHSE, H. and SINGER, P. *Should the Baby Live?* Hampshire: Gregg Rivivals, 1994, pages 1-3

Templeman LJ, held that if the child's life was not going to be 'demonstrably awful', surgery should be performed.

> ...it devolves on this court...to decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die...Faced with [the] choice, I have no doubt that it is the duty of this court to decide that the child must live... There may be cases...of severe proved damage where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion.[3]

The above statement made by Templeman LJ means, that it would be wrong for the court to allow the deliberate killing of a child, so long as the child has the potential to lead a happy life in so far as he/she is capable of. This statement, like the one made below by Vincent J of the Australian Court, is important and necessary in order to prevent killing in similar situations in the future, and to maintain the stance that no one should be the ultimate decision maker in deciding whether a life is worth living or not.

> No parent, no doctor, no court, has any power to determine that the life of any child, however disabled that child may be, will be deliberately taken from it...[the law] does not permit decisions to be made concerning the quality of life, nor does it enable any assessment to be made as to the value of any human being.[4]

This statement shows the view that the court should not be involved in the allowing of the deliberate taking of life however disabled a child may be. There is a sense that allowing the law or anybody else to decide the fate of another human being would be playing God. This is morally wrong, as it would give a group of people control over another human being's life that is innocent. Of course it is preferable that the law should not be involved at all. Court intervention should only take place when there is a

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[3] MASON, J. K. and McCALL SMITH, R. A. *Law and Medical Ethics.* London: Butterworths, 1994, page 150

[4] Ibid., page 154

clear case of dilemma between the wishes of parents, medical staff and other parties, and act as an arbitrator to arrive at the best possible solution for the patient after considering the various views.

One of the main roles of the court is to protect the rights of the children, as with the Children and Young Persons Act 1933. Under this Act, killing a child by omission could be prosecuted as manslaughter or murder. In this case Dr. Arthur would be found to be guilty of neglecting the Act. There are however difficulties arising with this Act, because medical advancement allows for patients lives to be sustained, when they would have died otherwise. The rising number of neonates that can be prolonged through artificial means has raised questions on the quality of their lives. For although lives can be extended indefinitely there are doubts as to whether they will be living a life worth living, or merely existing. It is however, as mentioned in Chapter One, safer to assume that their lives will have some meaning as long as they have the potential of having one or more of the basic human values. If, on the other hand, the medical team is able to say without a doubt that the neonate's life is going to be full of pain and misery, so much so that they will never have the opportunity to reach some level of happiness, then the withholding of treatment may be a more rational and humane option.

It is indeed very difficult for anyone to decide what is best for another person. Medical advancement is positive in the sense that by having the ability to extend lives, patients are being given an opportunity to regain some, or maybe all of the former functions they had. Or in the case of severely handicapped neonates, they may develop into a stage of being able to lead a life worth living within their means. The court will have to make a clear distinction between those that should have treatment and those that should have it omitted when there are dilemmas between parents and medical institutions and other groups of people, such as right-to-life groups. The guidelines for treatment to be omitted for certain neonates may for example, incorporate the following three points:

a) Parents do not wish their child to survive
b) Severely defected mentally and physically
c) Child would not survive without medical support throughout its life (i.e. bedridden in hospital, pain and suffering though out its life)

Stringent guidelines will be necessary to ensure that the legal and medical system will not be abused and to safeguard against slacking of regulations that may lead to the 'slippery slope'. There is a danger that slacking of regulations may lead to the increase in the types of people, health wise, to be incorporated in the omission of treatment. The parents, the doctors, and the court have to agree that the child's life will be full of pain and suffering even if treatment is continued or undertaken. There may be instances where it would be better for nature to take its course rather than prolonging life through artificial means.

Cases like Baby John Pearson and Baby Alexandra would mainly occur in developed nations where technology and financial resources are available. The moral dilemma of saving lives arises mainly because of these two reasons. Court intervention is important in that it presents a perspective from the right-to-life, and tries to analyse cases as logically and as humanely as possible. Parents' judgement may be reached out of both emotional and economic reasons, and medical staff may base their judgement on their evaluation of particular cases. At this stage, an evaluation of these three views provides a basis for arriving at the best possible solution for the dilemma we face. Without court intervention we may face more unfortunate cases like Dr. Arthur's. If a country has the resources, and as long as there are couples with financial capabilities willing to adopt a child, then severely handicapped neonates should be given the opportunity to live their lives to their maximum potential.

2.1.2 Parents' request for non-beneficial treatment

On the opposite extreme of parents rejecting their child, are cases where parents want to prolong the life of their child beyond advisable means. The physicians' and staff's diagnosis of the neonate may be that the neonate's life should not be prolonged since it would have to repeatedly undergo painful surgery with no chance of leading a life worth living or worse, may eventually die even with treatment. There are many reasons as to why parents may want to opt for aggressive treatment when their child would not benefit from it. Guilt, ulterior motives through a need to reunite an insoluble marriage, reluctance of having a part in terminating a life, last chance of having a child are some of the reasons why parents opt for aggressive treatment. In many ways, these can be seen to be selfish reasons for demanding aggressive treatment to sustain life, especially where pain and suffering for the neonate is involved.

As mentioned before, there are not many, if any cases of the court intervening in disputes between parents and medical staff regarding issues of the above nature. The main reason for this can be taken from the statement made by Vincent J from the Australian Courts, whereby:

> No parent, no doctor, no court, has any power to determine that the life of any child, however disabled that child may be, will be deliberately taken from it...[the law] does not permit decisions to be made concerning the quality of life, nor does it enable any assessment to be made as to the value of any human being.[5]

From the above quotation, it can be seen that the courts hold the view that no one should have the power to deny others' right to life. In addition to the law there is the Hippocratic Oath that physicians are bound to. Their duty is to extend lives, where possible, and defy nature rather than terminate life. The law will have difficulty in involving itself in such cases, and it is better if it does not. However as in the section

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[5] MASON and McCALL SMITH, ref. 3

before, the question of whether neonates with severe handicap or illness with extreme pain and suffering will be able to have a life worth living still remains.

The main debate here is the pain and suffering that the neonates in question have to endure throughout the duration of their lives. If a treatment is of benefit to neonates with the possibility that they may be able to lead a satisfactory life, albeit with the help of the family, then naturally treatment should be given. Otherwise, the pain that neonates have to go through seems somewhat unnecessary. It would consist of futile effort, detrimental to already limited medical resources, and an additional stress on the medical staff that has to partake in the continuous application of the treatment. Parents' wishes will play a large role as they are morally acceptable although not rational, and the medical staff has a duty to extend lives rather than end them. Unfortunately the dispute arises on whether neonates will be able to lead a satisfactory life free of pain and suffering during the time that they live, and whether the parents are making a sound decision based on the best interests for their child.

Two cases cited by Brody in *Life and Death Decision Making* will illustrate the nature and complexity of cases similar to the above:

> Baby E was a term infant born to a 28-year-old woman. It was her first child by her second marriage, although she had several children by her first husband. Upon birth, it was noted that the child had severe dermatological problems which were diagnosed as epidermolysis bullosa, dystrophic type. This skin disease results in painful blisters forming all over the body from minimal trauma, in esophageal constrictions which pose feeding problems, and an inability to swallow. Infection and fluid management is a major treatment challenge for such children. All of this was explained to the parents. It was also explained that while the child's death was not imminent and while there are some reported cases of such children living to their early teens, the child would always be in considerable pain and discomfort and would eventually succumb to the disease.

> In fact, Baby E was obviously in considerable pain and discomfort at the very time all of this was being explained to the parents. The baby had developed a serious infection, and it was suggested to the parents that the pain, but not the infection, should be treated and the child allowed to die. The parents vacillated about this issue but eventually concluded that they wanted the child's infection to be treated. They could not find any justification for not treating a readily correctable infection.[6]

The second case concerns a neonate suffering from hydranencephaly, born to a 16 year old woman.

Baby D was born to a 16-year-old woman who is unsure of the father's identity. None of the more likely candidates has expressed any interest in the baby. The course of the pregnancy was normal, and the infant seemed normal at birth. However, it was noted by the nurses that the baby was excessively sleepy, cried continuously when awake, and fed poorly because of poor sucking ability. A neurology consult revealed that the child suffered from hydranencephaly, a congenital anomaly in which nearly all of the cerebral hemispheres and the corpus striatum are reduced to a sac covered by intact meninges but filled with clear fluid....All of this has been explained to the mother and the maternal grandmother. In order to be sure that they understand the baby's condition, the staff showed them the transilluminated skull. The staff would simply like to keep the Baby D comfortable not ever providing nourishment, until the baby dies. They feel that if they use more aggressive treatment there is a chance that the infant will survive for some time and that these poor people will be required to take home a child who has no chance for any neurological functioning. The maternal grandmother, who would have the responsibility for providing most of the infant's care, totally agrees. Baby D's mother does not. She insists that the baby is alive, and she wants to take Baby D home and give the child as much love as she can.[7]

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[6] BRODY, B. A. *Life and Death Decision Making*. New York: Oxford University Press, 1988, page 206
[7] BRODY, ref. 6, page 203

The obvious difference between these two cases is that one of the neonates has a neurological problem whilst the other does not. One will feel pain and discomfort throughout its life with no neurological impairment, whilst the other will have no neurological functions even if it survives for sometime.

The decision reached by the parents in the first case, Baby E, could be considered egoistic in a way. The child will be suffering throughout its life and will also be aware of its development and surroundings. The fact that they have two other normal children may be made painfully aware to Baby E as it matures, and the child as a result, may feel frustration due to its lack of physical capabilities. Baby E may have to endure psychological suffering on top of the physical pain it continuously has to live with. There is a chance that the neonate will be strong and manage to live a satisfactory life, in that it may simply enjoy the few moments without pain, and value life within its means. Yet, the fact that the neonate will develop with continuous pain seems inhumane. The problem is that the neonate has a limited life expectancy with no cure. The family will have to undergo psychological stress as they watch the condition of their child deteriorate, or if not, at least watch it in pain. The question is whether a life of continuous physical and later psychological pain is a life worth living.

The parents may feel a sense of satisfaction in simply having their child alive, and that they are doing the best they can to make their child better. This aspect of the parents' wishes should undoubtedly be respected. They are being morally sound in insisting that infections that are treatable should be treated. No one however, can judge the pain that the neonate is going through. Parents, and medical staff have to act as surrogate decision makers in judging whether the pain that the neonate is going through is intolerable to the point that had it been older it would have voiced its rejection of treatment. At the same time, no one as mentioned by Vincent J, has the power to decide the fate of a child, however disabled it may be. Baby E is not disabled, it suffers because of the pain it has to endure. Pain can be controlled through drugs, although whether pain killing drugs are recommended for neonates is doubtful. If the parents of

Baby E had not wanted it, like with Babies Alexandra and John Pearson, then the courts may have intervened and been in favour of withholding treatment if an infection develops. As Templeman LJ pointed out in the case of Baby Alexandra, the courts may be swayed to have a different conclusion, if they knew that the baby's life was 'bound to be full of pain and suffering.' But this is clearly not the case here. The parents wanted their child to be treated.

For the case of Baby E, it seems that the parents' wishes should be respected. The medical staff does not have the authority to judge that a life is not worth living although it may be full of pain. The fact that the neonate does not suffer from any neurological damage suggests that the child will be able to enjoy some activities that we hold valuable in our lives. Another point in favour of the parents' decision is that the parents are willing to support their child at this stage. They may not realise the burden it may have on the family's resources and the effect on their other children, but so long as they do want to keep the child, no one should have the authority to tell them otherwise. The parents will have to live with their decision, and will be the sole providers and care takers of the child. There may be a chance that the child will lead a life worth living contrary to the views of some of the medical staff. Last but not least, the parents want their child to have a chance at life. At least this part of the parents' wish should be respected.

Baby D was born with a neurological anomaly, meaning that the neonate will never be able to function normally. Besides being incontinent, the neonate will never be able to recognise love and affection, and little of its surroundings. Another important issue is the competency of decision making by the 16-year-old mother. The mother is still a minor, and will therefore, be unable to take care of the child fully. The fact that the mother says that she wants to raise the baby with love and affection, which will not be understood by it, shows that she has not fully understood the situation. The mother may also not fully understand the responsibility involved in caring for a child, and may only see the neonate as an extension of a doll that she can show to others. The main care will thus be given by the maternal grandmother.

If the neonate had been normal, there would not have been a problem, as the maternal grandmother would have taken care of the child until the mother matured enough to take care of it herself. But since the neonate has a serious abnormality the care taking of the child would require more attention than usual. Hence it seems clear that the main decision making should lie with the grandmother rather than the mother. The grandmother has to act as the surrogate decision maker for both the neonate and the mother, which is a heavy burden on her. If the grandmother decides to concede to her daughter's wishes, then she will have the burden of taking care of a child whose continued existence would not be a gain for itself. The neonate does not have the potential of becoming a person, such as in finding any sort of joy in its existence, as it lacks in awareness towards itself and its surroundings.

Brody's view that the neonate should only be given basic nutritional support and warmth, or if possible to kill Baby D by injection with potassium chloride, presupposes passive and active euthanasia. Passive in the sense that the neonate would continue its existence if aggressive treatment was adopted, but by withholding treatment it would eventually die. Active euthanasia will be in the form of administering a lethal injection. Either way the intention is the same, in that both seek the death of Baby D. The neonate was unfortunately born with a severe neurological abnormality that cannot be cured, but it is not uncomfortable nor in pain as in the case of Baby E. It may be more humane for the neonate to have aggressive treatment if necessary, and let it live as long as it can, because it is not uncomfortable in its state. Even if aggressive treatment was not adopted perhaps the neonate can continue its existence in the usual manner by receiving nutrition and warmth required for its survival. The life span of an hydranencephalic baby is short, a few months at most. Would it not be better for the maternal grandmother to bring home the child and take care of it until it dies rather than choosing euthanasia?

The consequence of the above option, is the attachment the family may end up having with the baby, resulting in psychological stress for both the young mother and the grandmother, although perhaps their conscience would be at rest with the knowledge that they did their utmost in caring for the baby during its life. The neonate, as pointed out by Brody, will not be able to recognise love and affection, but at least the family is able to provide it. Most neonates will have difficulty in understanding love and affection, but as long as they can live their short lives in comfort, this may be better than adopting aggressive treatment or euthanasia.

Cases where parents insist on aggressive treatment that are not beneficial to the neonates do not require participation of the courts as they are not infringing upon the law. The court cannot intervene in these cases as the parents' intentions are usually good, and even if they were only for their own selfish reasons, no one has the right to authorise the death of an innocent child. The main decision making will lie with the parents as they will be acting on behalf of their child.

The burden on the medical staff also have to be considered, since they have to deal with watching and treating a neonate in pain. But their role would be to concede with the parents' wishes even if it is against their beliefs of what they see as a life worth living. Although medical staff's advice is important, the advice they give should be based on medical expertise rather than on moral judgements. Medical staff, like judges are not in a position to pass judgement on whether a child's life is worth living or not. The parents will have to take the medical staff's advice into consideration, and judge for themselves whether their child will be capable of leading a life worth living, and whether the family can cope with the decision they will make. The parents have to understand that their decision has to be made based on the child's best interest rather than their own.

2.1.3 Legal proceedings for unwanted infants

In the unfortunate circumstance that the parents do not want their child to survive, the court will have to intervene in order to arrive at a solution that is for the child's best interest. A trial will be held between the state and the parties that do not want the infant to survive. As in cases like Baby John Pearson and Baby Alexandra, their chances of leading a life worth living, albeit within their means, are good. The role of the court is to decide whether the infant in question should get treatment, and if so, what the consequences are. As described in the previous section, the law will be inclined to support the view that the babies continue their existence, as the courts do not have the authority to allow the killing of children.

In the case of Baby Alexandra the child was made a ward of the court during the trial. The court however, has limited responsibility concerning the care of infants after trials. The caring of infants will lie with an agency of the community that handles handicapped children. The standard procedure is that a care order will be issued by the court whereby the infants would be placed under the care of a designated local authority. The usual procedure after this would be that these infants would be placed up for adoption or foster homes until a permanent home can be found. Another option, although not a favourable one, is to place them in institutions where they can be taken care of by a qualified staff. The costs of maintaining these places are high and also unpleasant for these infants; as they will lack the love, affection and attention naturally seeked by children. It would be best if a home could be found for every handicapped neonate rejected by its parents, but the fact is that most of them end up in institutions. Infants like Baby Alexandra, who get publicity have higher chances of being adopted, but the rest have very slim chances of ever living with a family.

2.2 Parental role in decision making

Parents are generally seen to have automatic rights over their children concerning their general welfare. Parents have the duty to care for their children in terms of giving them love and affection, feeding them, clothing them, providing them with education and health care. There are doubts however as to whether they should be the ultimate decision makers where severely handicapped neonates are concerned. According to the Children Act 1989 in the United Kingdom, the following applies to parents concerning their responsibility towards their children:

> In this Act 'parental responsibility' means all rights, duties, powers, responsibilities and authorities which by law a parent of a child has in relation to the child and his property.[8]

But does the above Act extend to parents having the right to make life or death decisions for their children?

Neonates and young children are not thought to be able to make competent decisions regarding their welfare, though it is clear that they very quickly begin to formulate their opinions by expressing themselves through body language, or through limited vocabulary, on what they like and do not like. They are developing their autonomy over themselves. There is a problem for handicapped children however, as their development will be slow, or may never happen. This is especially true for severely handicapped neonates. The question of whether the neonate will be able to live a life worth living is raised, forcing the parents to make critical decisions on behalf of their new born child.

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[8] JONES, M. A. and MORRIS, A. E. (eds.) *Blackstone's Statutes on Medical Law*. London: Blackstone Press Limited, UK, 1992, Children Act 1989, page 158

Emotional status, economic status, religious beliefs and a variety of other factors contribute to the decision making process of parents. These parents will naturally be traumatised to a certain extent in finding that their child was born with abnormalities. If they choose to keep the child, they will have to bear the responsibility of a child that will be dependent on them financially, emotionally, and physically throughout its life. There will be a substantial financial burden on them. If there are other children in the family, their needs also have to be considered. It may be possible that due to the infant's condition, much of the attention will go to the infant rather than to the other children, thus making them feel neglected. On the other hand the family may develop a stronger bond because of the cooperation required by everyone.

There are a variety of factors that need to be considered when parents make decisions for their severely handicapped neonate. The first issue to consider is the neonate's medical condition, such as whether the neonate will be capable of leading a life worth living, and whether it requires continuous medical attention. Other factors to be considered include the number of surgeries it will require, whether the treatments will be painful, and what the life expectancy is. Advice will probably be given by the medical staff as to what course of treatment or non-treatment may be for the best interests of the neonate. Following this the parents will have to quickly decide what course of action should be adopted.

Parents will be affected greatly at finding that the child that they had been awaiting for, was not born normal. As was shown in the case of John Pearson, the mother was heard as saying to her husband, 'I don't want it'. The husband either shared her view or accepted her opinion, and advised the paediatrician in charge, of their wish. The neonate was thought to be a Down's syndrome with no complication at the time. This was found to be false after an autopsy was performed following the neonate's death[9]. Clearly this is a case where the neonate would have been judged worth living had the

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[9] RAPHAEL, D. D. Handicapped infants: medical ethics and the law. *Journal of Medical Ethics*, 1988, vol. 14, pages 5-6

court been able to intervene. The parents of Baby John Pearson may have believed that they were acting on the best interests of their child by opting for 'nursing care' only, but the statement made by the mother to her husband weakens their case. It seems that their reaction to their handicapped son was selfish. It is undoubtedly true that the parents need not have the burden of looking after a handicapped child if they clearly do not desire their child. Yet this does not allow them to make the decision that their rejected child should therefore die. There are other options for the child that can be considered, such as adoption, or government run institutions designed for children with special needs. Death need not have been the only solution for Baby John Pearson.

As mentioned in the previous section, there is the opposite extreme where parents want the life of their child to be prolonged although it would not benefit it. This is also an act of selfishness by the parents. Especially if it is clear that the child would be in pain throughout its life. The pain that the child has to endure may even be refused by a competent adult. In both of the above cases the parents are not making rational decisions in that they are not thinking in terms of best interests for their child. Thus, the medical staff and/or the court has to intervene so that they can recommend alternative solutions or point out what the decision will mean to the neonate if they wish for aggressive treatment. There is a need for a third party to be involved so that they can assess the situation in an unbiased manner to deduce what may be the best for the neonate.

In most cases, except in Baby John Pearson's case, parents would believe that their decision is based on the best interests for their child. Yet as mentioned before there are other factors such as family beliefs and background that will interfere with their decision making. We would like to believe that parents are the best decision makers; as they should have the natural feeling of kinship and bonding with their new born child that would automatically lead them to want the best for their child, even though their decision may be painful for them. Unfortunately this is not always the case. Then who is the best alternative? Unfortunately or perhaps fortunately there is no one party that could be the best decision maker.

In 1984, in the final version of the Baby Doe rules in the US, the Department of Health and Human services incorporated a proposal from the American Academy of Paediatrics. The proposal recommended the adoption of an 'infant bioethical review committee'. The committee comprised of the following members:

1. a practicing paediatrician, neonatologist, or paediatric surgeon
2. a hospital administrator
3. an ethicist or a member of the clergy
4. a lawyer or judge
5. a representative of a disability group, developmental disability expert, or parent of a disabled child
6. a lay community member
7. a member of the facility's organised medical staff
8. a practising nurse.[10]

The proposal sounds promising, and may function well as an advisor from a third party's point of view. There are however, practical problems with such a committee in that it may be difficult to always have a committee ready on hand to make decisions within the limited time span given by the medical staff. The neonate's condition may be such that the decision has to be reached within 24 hours. There also seems to be more external involvement than necessary. It is doubtful whether the following; a lawyer or a judge, a member of a clergy, a lay community member, are really necessary. They may confuse and broaden the issue unnecessarily, and waste precious time. Medical diagnosis will be the most important at the time, as it assesses the degree of handicap and the neonate's chance at living a life worth living. Therefore, it may be more functional if there is an additional physician involved to get different medical views on the situation. Another fundamental problem is the limit in which the parent - child relationship can be

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[10] KUHSE and SINGER, ref. 2, page 178

interfered with. The rights of the parents as parents, and value of parenthood will be usurped by the involvement of other parties. Downie and Randall in *Parenting and the best interests of minors* write that:

> ...if parental decision making is in same way blocked - say, the child is taken out of the charge of the parents - then it is not thought that the child's interest will necessarily suffer...Rather it is the parents' interests which suffer when their rights of decision making are blocked. This argues for an interest in parenting as such.
>
> Page's claim is that 'parenthood is seen to have a special value in itself and not simply as a means to the care and protection of children and the continuation of the human race. This special value constitutes the ultimate foundation of parental rights'[11] ....Its fundamental place in human life is manifested by the obvious truth that many people choose to become parents.[12]

Therefore, although third party involvement is recommended for arriving at the best possible solution for children, the parents' natural rights of parenthood will be eroded somewhat. Involvement by other possible decision makers will mean that parental rights and their interests will be interfered with. It can be argued that parental interests and their children's interests are closely linked, thus there should not be a requirement for third party interventions. It must be pointed out however, that parental interests will diminish, where life or death decisions are concerned. The child's best interest comes first then the parents'. The role of the medical staff, and if need be the committee, would be to point this out to the parents so that together they can arrive at a solution that would benefit the neonate.

Parental role in decision making for their children would usually take the highest place without question. No one should interfere with the way that a family may raise their child, unless the child is being harmed physically or psychologically from them.

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[11] PAGE, E. Parental Rights. *Journal of Applied Philosophy*, 1, 2, pages 187-203. As cited by DOWNIE, R. S., and RANDALL, F. *Surrogate Health Care Decisions involving Children*, August 11, 1996, page 7

[12] DOWNIE and RANDALL, ref. 11

Otherwise it is better to allow them to value the role of family and parenthood. In cases concerning handicapped or terminally ill neonates, there may be a need for advice from medical staff and other parties. This would allow the parents a chance to view their situation in a more objective manner rather than based on emotions so that their decision would be a benefit to their child. At the same time the medical staff and other parties should respect the fact that it is the parents who have to live with the decision they make. Therefore, although advice should be given to parents, the final decision should come from them. If their decision is an infringement upon the law, the courts should decide on the child's behalf on the best course of action. It must be stressed however, that interference from other parties should be kept to a minimum so that the intimacy between parent and child would be maintained as much as possible. The decision making for the child in question should be made within a small circle of medical staff and the parents, in order to maintain the value of parenthood and to uphold, as far as possible, parents' fundamental rights over their child.

2.3 Handicapped peoples' point of view

This chapter has so far been discussing the issue of severely handicapped neonates from the view of the autonomous person, namely the parents and the courts. The criterion of best interests for the child has been applied, so that whatever the decision may be, the result would be a benefit for the child. There are not, understandably, many sources from the severely handicapped peoples' point of view. Those that are physically handicapped, however, show strong support for the right of life for handicapped neonates.

There are degrees of severity in handicaps; people that are limited to physical handicap are autonomous and can appreciate and enjoy life at the same level if not more than people without handicaps. But what of those that have more severe physical handicaps such as spina bifida? Most neonates born with spina bifida are judged at the time of their birth that their life would not be worth living. This is because of the pain and suffering they have to endure, along with the numerous treatments they must go through, during their limited life span. It is important to know the severely handicapped people's point of view, as the small minority that survived against the odds will point us in the right direction on whether their life is worth living.

Kuhse and Singer in *Should the Baby Live?* have cited two letters with very different views. The first letter was written by Mrs. Allison Davies in response to an article published in the *Journal of Medical Ethics*. The article proposed a law reform that allowed neonates to die. The second letter was received by the American CBS television network after John and Susan West[13] were featured in one of their programmes. The letter from Mrs. Allison Davies writes:

> In reference to your items on the bill drafted by Mr. and Mrs. Brahams permitting doctors to withhold treatment from newly born handicapped babies, I would like to make the following points.
>
> I am 28 years old, and suffer from a physical disability which is irreversible, as defined by the bill. I was born with myelomeningocele spina bifida. Mr. and Mrs. Brahams suggest several criteria for predicting the potential quality of life of people like me, and I note that I fail to fulfil most of them.
>
> I have suffered considerable and prolonged pain from time to time, and have undergone over 20 operations, thus far, some of them essential to save my life. Even now my health is at best uncertain. I am doubly incontinent and confined to a wheelchair and thus, according to the bill, I should have 'no worthwhile quality of life'.

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[13] Case of baby, Brian West, with Down's syndrome and esophageal atresia. Court order to treat baby was given without parental permission. Baby Brian West suffered pain and misery through out his 18 months of being alive. See: KUHSE and SINGER, ref. 2, pages 141-143

> However, because I was fortunately born in rather more tolerant times, I was given the chance to defy the odds and live, which is now being denied to handicapped newborns. Even so, my parents were encouraged to leave me in the hospital and 'go home and have another' and I owe my life to the fact that they refused to accept the advice of the experts.
>
> Despite my disability I went to an ordinary school and then to university, where I gained an honours degree in sociology. I now work full-time defending the right to life for handicapped people. I have been married eight years to an able-bodied man, and over the years we have travelled widely in Europe, the Soviet Union and the United States. This year we plan to visit the Far East.
>
> Who could say I have 'no worthwhile quality of life'? I am sure though that no doctor could have predicted when I was 28 days old (and incidentally had received no operation at all) that despite my physical problems I would lead such a full and happy life. I do not doubt that they were 'acting in good faith' when they advised my parents to abandon me, but that does not mean that their advice was correct.[14]

The second letter is based on the view that the pain and suffering the patient had to endure was not worth being kept alive.

> You posed the question to his parents, 'What would Brian say?' I would like to answer that question for Brian - I feel I have that right since I was also once a very young child at death's door, undergoing excruciatingly painful medical treatment in order to save my life. I was also 'tied down'; I also screamed for mercy for 'them' (Doctors and my parents) to stop what they were doing - I screamed so long and so hard the medical staff took to taping my mouth shut to cut off the screams (which of course then merely reverberated inside my head)...Ask me now: 'was it worth going through - do you appreciate what they did?'

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[14] KUHSE and SINGER, ref. 2, page 144-145

NO.

My answer for Brian is 'Thank you Mom and Dad for wanting to let me die in my own way, at my own time, with my dignity still intact.'

Death is not so terrible.[15]

The above two letters represent opposite views on whether the pain and suffering they had to endure was worth the life they lead now. The above letters may not be a very good definition of whether we should treat spina bifida neonates in the future. The character and outlook that people have; their present occupation, their marital status, for example, will undoubtedly influence their opinion. Mrs. Allison Davies's life is a positive one because she is a fighter who does not let her afflictions interfere with her aims in life. She has the strength to make her life worth living through considerable effort and will power. In short, she has managed to make her life extraordinary and should be made a role model for other handicap and non-handicap people. The reality however, is that there are more people that may agree with the second view.

In a survey conducted by John Lorber, none of the young adult spina bifida subjects would want their children to be treated if they were born with the same afflictions[16]. This could be in line with the opinion shown in the second letter, where the writer clearly felt that the pain and suffering was not worth the effort. This view is understandable and should be respected considering the fact that, had they been able to voice their opinion earlier, they would have refused treatment in the same way that most competent adults may.

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[15] Ibid., page 145

[16] KUHSE and SINGER, ref. 2, page 145

There is an important dilemma here in that none of us are in a position to judge whether one option is better than the other. An argument for treating all spina bifida neonates would be that there are people like Mrs. Allison Davies, who survived against the odds, and made her life worth living. She can be considered an unusually lucky case, for she obviously does not suffer from brain damage, and has a high IQ. It would be difficult to judge the IQ of neonates suffering from spina bifida. If this was possible, it could be a measurement used for selective treatment in the future; as those with an IQ of 60 and higher would have a better chance of leading a life worth living. They would be able to enjoy and feel some satisfaction at the aims they achieve; and find enjoyment and value in things in the same manner that autonomous persons do. There are ethical dilemmas in assessing whether IQ should be a basis for selective treatment, as this may raise issues of eugenics, for example, whereby only those with a certain IQ and higher are treated. Measurements based on IQ may also have the problem of ignoring the pain and suffering a patient has to endure during treatment.

What is important at this stage, is whether minority cases like Mrs. Allison Davies should be considered and adopted, so that in the future all severely handicapped neonates would be treated. The positive aspect of this would be that they would all have a chance at life. This course of action would not be economically viable, and may be considered as being a waste of medical resources that could be used more effectively in other sectors, such as for neonates that do have the ability to live a life worth living but require funds for treatment. Another objection to treating all severely handicapped neonates would be that, in the end of it all, the subjects may feel that it was wasted effort. This does not mean that all neonates suffering from severe handicaps should not have a chance to live, but their condition should be clinically analysed, whilst at the same time considering the wishes of the parents. If the parents do wish for treatment, then it should be given, for at least then the parents' interests will be respected. It is perhaps cruel that the fate of these neonates lies with others, but this would be the case for any non-autonomous persons suffering from terminal illnesses.

2.4 Palliative Care Teams - A possible solution for severely handicapped neonates

Palliative care teams are steadily becoming adopted by affluent countries. It is being seen as a favourable development in medical institutions for terminally ill patients. Palliative care focuses at 'comfort care'; "whole person or holistic care or care aimed not just at a medical good or a psychological good, but at the patient's total good, or best interests."[17]

It may be beneficial for neonatal units to adopt the same ideas for neonates that are either born with an incurable illness, or are severely mentally and physically handicapped. The role of the palliative care team, or neonatology palliative care team (referred to as NPCT herewith), will be to keep neonates comfortable and free of pain as much as possible throughout their lives. Consultation with parents, who will act as surrogate decision makers on behalf of their child, will be important in order to ensure that the parents understand what the process of the medical treatment or non-treatment will mean to their child. The adoption of NPCT is seen here to be as a better alternative than adopting passive euthanasia that results in infants dying a painful and prolonged death due to their disease. This does not focus on the neonates' comfort, but on how to speed up the process of death without breaking the law.

2.4.1 What the NPCT would comprise of

The NPCT should comprise of experts in neonatology to ensure that the parents can be given advise(s) that would benefit the neonate. The parents would be an integral part of

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[17] RANDALL, F. and DOWNIE, R. S. *Palliative Care Ethics - A Good Companion*. New York: Oxford University Press, 1996, page 18

the team to ensure that the value of parenthood, and intimacy of the parent - child relationship will be maintained as much as possible.

A model of the NPCT may comprise of the following personnel:

1. two paediatricians to give medical advice
2. practicing nurse(s) with experience and knowledge of neonatology
3. psychologist to help parents cope with their distress
4. developmental disability expert
5. the parents, acting as surrogate decision maker on behalf of their infant.

A NPCT should be ready on hand, and be assigned to the neonate that faces complications from the beginning.

The main difference between NPCT and normal palliative care team is that the first team will have a shorter time to make decisions. The time allowed for deliberating on the course of treatment may be limited by the pressing condition of the neonate. The palliative care team on the other hand, will have the chance of getting to know their patients better, so that their wishes can be respected. Once the decision to not treat a neonate has been made, the most comfortable way that the neonate should die needs to be discussed. A lawyer or judge may be necessary at this time to ensure that the law is not broken.

Naturally stringent guidelines should be adopted at this stage, to ensure that neonates are not subjected to unnecessary harm or threat to their lives. The neonate must have an incurable illness or severe physical and mental handicap, that has been clinically diagnosed by the paediatrician and nurses, that the neonate would not be able to lead a life worth living. Parents must give consent to their team's recommendation. At the same time the developmental disability expert must agree with the paediatricians' analysis. There will be difficulties in judging whether a life is worth living or not, and there are morally negative implications by making life or death decisions on behalf of a neonate, but unfortunately this is unavoidable. What could be argued on behalf of the team is that their aims, like the palliative care team's, will concentrate on child's best interest and no one else's.

2.4.2 Difficulties faced by and with neonatal palliative care teams

There will be moral and practical problems faced with and by the NPCT. The main problem will be that the team will have to make decisions based on their clinical diagnosis of a neonate's condition and future potential. Firstly, they will have to make a decision on what the best possible chances at life a neonate has, and if it has no chance, what would be the possible alternatives. The team, in short, will be making the main life or death decision. This may present a heavy burden and emotional stress on them. Secondly, by acting as a team, the individual staff may sometimes be placed in a situation where they will be forced to agree with a particular method of course, which they may not necessarily agree with. Yet they may have to agree with the rest of the team, in order to maintain a harmonious working relationship with them or in order to respect parents' wishes. There may be situations where it would be less psychologically stressful for them to agree to a majority view than to argue, especially where time constraints are involved. Thirdly, the establishment of a team may be such that team members will gradually have the same value judgements, hence becoming narrow minded. The staff may have initially had different views, but as the team works together over a period, they may come to accept, predict and/or respect another predominant view, thus resulting in the team having one strong view concerning what constitutes a life that is worth living.

There is a critical danger in this, as the neonates' chances of survival may very much depend on external factors, such as the hospital that they are born in and the team that is assigned to them. Lastly the problem with NPCT, or having any authoritative decision maker for that matter, would be that the parents would naturally be inclined to follow their physicians' advice. For it is easier for parents to believe that the team has the most knowledge and experience in the matter.

Dr. John Freeman noted the danger pointed out above, when criticising Lorber's criteria of selection:

> the parents who go to Dr. Lorber get Dr. Lorber's side of the story and Dr. Lorber says he offers them a chance to go to the doctor next door, but the parents never make that decision. They go along with what he tells them and 75% of the children don't get treated. I provide an equally reasoned and equally compassionate discussion to the parents and the parents go along with what I want to do and 95% of the children get treated. It concerns me greatly that a given child if born in Sheffield has a 75% chance of being alive. And yet this is a decision made by the parents on the advice of either Dr. Lorber or myself. That's scary.[18]

One way perhaps, of avoiding this problem may be to have a rotation of staff, so that the team will not always be comprised of the same members. This may be difficult in smaller hospitals, but possible in bigger ones, facilitating large neonatalogy departments. The changes in staff may maintain the individuality of each member, so that there will be different views concerning what is for the child's best interest. The aim of this is to avoid teams becoming narrow minded.

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[18] KUHSE and SINGER, ref. 2, page 63

2.4.3 Role of the NPCT

The role of the NPCT will be hardest when parents express the wish that they do not want their child to live. If it is a clear case of the neonate being a Down's syndrome, with a treatable obstruction, then the neonate should be treated with or without the parents' consent. Patient's interest comes first then the parents'. If the neonate is diagnosed as having a terminal illness, or have a severe physical and mental handicap, then the parents' wishes should be respected.

The NPCT will have to obtain consent in written form from the parents allowing the team to omit treatment (which would also incorporate withholding of basic needs for the neonate, like: nutrition, warmth, and fluids). The team should not however, simply await the death of the neonate, but provide it with comfort and relief from pain where ever possible so that it can die in peace rather than with pain and suffering. Baby D, mentioned in the earlier section, should be kept comfortable with necessary nutrition and fluids, but no aggressive treatment that would prolong its life needlessly should be adopted. Neonates in this situation should have their condition monitored and maintained in a manner that will ensure that they die without pain and through natural means. It may be possible for some neonates to be taken care of at home by the parents if they wish to. However, this probably will not be advisable to the parents as they may form an attachment with their child and find its debilitating condition unbearable. This may lead the parents to have unnecessary stress added to their already psychologically difficult state.

2.4.4 Physician-assisted death and neonates

The current aim of palliative care is to provide comfort for the dying patient. Euthanasia, in many countries, has not been legalised so the usual form of care would be either to not resuscitate a patient, unless expressed otherwise by the patient, or to omit treatment. There may be times however that neonates will be in so much pain, that had they been autonomous adults, they may have asked to be allowed to die. Even if it has been agreed by both the NPCT and the parents that the best course of action for the neonate would be to let it die, it may not be possible to do so without pain and suffering. The illnesses, as in the case of Baby E, may be such that the infants will have pain throughout their lives thus making euthanasia through lethal injection a more humane option. Or there may be cases where it is not possible for neonates with severe handicaps to die without developing an infection, such as with Baby D. In both cases they will die with pain. A pain killing drug could perhaps be administered to relieve the pain, but this would also result in the active participation of speeding up the process of dying.

If a neonate is going though intolerable pain, even with the NPCT providing the best possible comfort care, then perhaps the more humane option the team could provide is physician-assisted death. The most important requirement is that the parents have expressed wishes for physician-assisted death and have consented to this.

So far, physician-assisted death for non-autonomous persons has not been legalised. The main objection to having it legalised is based on the danger of the system being abused. Patients that are not terminally ill, for example, may be euthanised on the belief that they are going through physical and/or psychological pain and suffering. Dr. Jack Kervorkian's patients may come to mind. In order to safeguard against such abuse, a group of physicians from the United States have written an article called *Regulating Physician-Assisted Death*. The article proposes a policy where the role of palliative care teams or committees extend to authorising physician-assisted death to autonomous patients who are suffering from terminal or incurable illnesses as a last resort. The paper stresses that this procedure is only applicable to fully autonomous patients who are able to clearly express their wishes. This is to ensure that vulnerable patients, such as those that are not mentally competent, will not be at risk.

The policy has the following objectives and regulations:

> 1) to promote comfort care as standard treatment for dying patients; 2) to permit physician-assisted death only for competent patients suffering from terminally or incurable debilitating illnesses who voluntarily and repeatedly request to die; 3) to develop and promote practice guidelines for voluntary physician-assisted death aimed at making lethal treatment available as a last resort for unrelievable suffering; 4) to provide independent and impartial oversight of decisions to pursue voluntary physician-assisted death without undue disruption of the doctor-patient relationship; 5) to provide a mechanism for prospective committee review of difficult or disputed cases; and 6) to ensure public accountability.[19]

There are advantages and disadvantages in having physician-assisted death for neonates suffering from incurable illnesses or severe physical and mental handicaps. The advantages would be that the neonates will be able to die quickly, without pain. Secondly, although this is morally weak, physician-assisted death will be less stressful on already stretched medical resources, rather than using methods like awaiting natural cause of death. An argument in favour of physician-assisted death for neonates may be that whether the course of action is to withhold treatment, await death whilst keeping the neonates comfortable, or injecting with a lethal drug the result and intention is the same. Therefore the option that gives neonates the least pain should be adopted.

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[19] MILLER, F. G., QUILL, T. E., BRODY, H., FLETCHER, J. C., GOSTIN, L. O., MEIER, D. E. Sounding Board - Regulating Physician-Assisted Death. *The New England Journal of Medicine*, July 14, 1994, vol. 331, no. 2, page 120

The disadvantages of adopting physician-assisted death would be that the method is irreversible, hence the chances of finding out if a neonate's condition will improve will be reduced to nil. If other options such as withholding treatment or awaiting natural death are employed, then there may be a chance that a neonate's condition may improve, and treatment could be undertaken to increase the chances of leading a life worth living. The second disadvantage is that there may be an increasing danger of including neonates that do have a chance of living a life worth living into the category of obtaining physician-assisted death. Parents and NPCT may find it increasingly difficult to handle the pressure of the painful treatments that the neonate has to endure. It may become easier and less painful for the parents and NPCT to witness death by lethal injection than painful treatments. Hence the judgement of what is best for the neonates may be influenced by the efficiency of physician-assisted death. Thirdly, because the neonates are not competent adults, their fate lies with the decision made between their parents and the NPCT. The decision will probably lie more with the team, as the parents are likely to listen and follow what the team recommends.

It seems from the above, that although there are clear benefits from physician-assisted death for competent adults, there are higher risks involved for neonates and young children because they are vulnerable patients. The legalising of this policy may increase the risk of neonates that have a fair chance at life to be judged otherwise. On the other hand, it is clear that the neonates that are suffering, will benefit greatly from a swift and painless death. But since the threat to neonates with illnesses that are treatable or handicaps that are tolerable may increase, physician-assisted death is not recommended at this stage. This view may change however, as the processes for selective treatment for neonates with severe handicaps or incurable illnesses, are developed further. A more advanced medical prognosis may be able to judge the future potential of whether a neonate will be able to lead a life worth living.

To conclude, palliative care committee need not be made a special unit of the neonatology department, but their aims and roles could be incorporated in the department, so that there will be some sort of group decision making established. There seems to be a clear need for this, as having only one or two paediatricians advising on the best course of treatment or non-treatment for the neonate, may pose a stress on the medical staff. Having a team would also mean that there would be a better distribution of duties where members with knowledge and experience in neonatology or palliative care can advise the rest of the team on their opinions.

The problem of having a palliative care team incorporated with the neonatology department would be that the staff would require specialised knowledge on neonatology and a general knowledge on palliative care. This means that the already high costs of neonatology will get even higher. However, cost should not be an issue as the community has the duty to provide at least the minimum standards of palliative care in neonatology, to ensure that neonates also obtain a fair share of comfort care. At the same time, the advantages of having a NPCT should outweigh the costs, as faster and more thoroughly analysed decision making will be made possible by having more professionals involved. This type of team may be able to function faster at the decision making level than ethics committees, as they would have been assigned to the neonate from the beginning. The medical team at least will be ready to give their medical analysis on short notice.

If there are any problems with the team they would probably lie with group management. Pressure from other members and time constraints may hamper with the decision making. Or, if the team is comprised of the same members for every case, there may be the danger of having the members formulating the same value judgements on what constitutes a life worth living. Neonates' chances of survival may therefore become dependent on the team that is assigned to them. Having said this though, the establishment of a palliative care team within the neonatology unit would be the best alternative to what is available at present.

2.5 Summary

The aim of decision making is based on the child's best interest principle, and which procedures should be undertaken as a result. Although it is difficult to judge whether a life is worth living or not, it becomes clear, after review of the role of parents, medical staff and courts, that our main role will be to ensure that the child receives the best possible care.

Where a child's disease is treatable, then it should be treated regardless of the parent's wishes. Otherwise palliative care is a solid alternative in terms of caring for the dying. However long or short the life span of the infants maybe, it is essential that their lives be made as comfortable as possible. There are naturally practical problems at every level of decision making. External factors such as time constraint and the involvement of too many people may confuse the issue. It is important therefore that life or death decision making for neonates be kept to the minimum involvement, namely the parents and the medical staff. The intimacy between parent-child relationship should be upheld as much as possible.

3 Euthanasia and severely handicapped neonates

It would not be wrong to say that no one wants to die with pain. If we had a choice, we would opt for a peaceful death, with dignity. Euthanasia meaning 'good death' or 'mercy killing'[1], is brought about by the deliberate taking of a life, with the aim to relieve the suffering of another. Euthanasia is based on two important factors: compassion from others and competent decision making concerning life and death issues for oneself. There are many cases where death is preferable to a life of debilitating illness. However there is a problem in that the issue of what does and does not constitute euthanasia is unclear. At this time, many types of act that result in the ending of another life are classified under euthanasia.

There are many categories under euthanasia, such as; voluntary, involuntary, active, passive, withholding, withdrawing, killing and letting die. This has resulted in a general confusion on the difference between straight forward euthanasia, meaning active voluntary euthanasia, and letting die.

The main concern for ethicists, lawyers, medical institutions and society, if euthanasia is legalised, is the danger of abuse. The aim of euthanasia, which is to relieve the painful sufferings of others in cases where death is preferable to life, is not morally wrong. However, there are 'grey areas' that require clearer definitions in order to protect those that do not want to be, or need to be euthanised. The biggest fear is of course a repeat of the Nazi holocaust. The danger arises through political, social and economic instability. Legalising euthanasia may lead to a down ward spiral effect where more and more people become incorporated under the category of those that can be euthanised. In the beginning it may only be conducted on mentally competent terminally ill patients requesting to die, then severely handicapped people who can be

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[1] KUHSE H. Euthanasia. In SINGER, P. (ed.), *A Companion to Ethics*, Blackwell, 1991, page 294

treated but would be judged as having a life that is not worth living, to slightly handicapped people and so on. The danger of this happening in reality is slim, but many people are skeptical because euthanasia has been abused before and still is. The first group of people that are vulnerable to abuse is severely handicapped and ill neonates.

We would obviously like to avoid any sort of unfortunate incidences occurring, but it would also be illogical not to allow euthanasia as we had already taken a step toward it by allowing the withdrawal of artificial respirator in the Quinlan case, which was, as a result, followed by legalising the withholding or withdrawing of treatment. The argument here is that since we have legalised some areas of passive euthanasia, why not legalise active euthanasia for competent adults who are terminally ill. The result is the same. A valuable counter argument to the above would be that it is not the result that is important, but rather the intent, cause of death and the balance between benefit and burden for the patient. For if it were the result that mattered, then the act of murder or manslaughter would be excusable as well.

3.1 Categories that should not be under the heading 'euthanasia'

The word euthanasia, encompasses a wide range of terminology that do not always have to do with 'mercy killing' or a 'good death'. Some practices may be more suitably placed under the category of 'letting die'. The main reason for this is that the illness is the cause of death, and not the act itself. The act would be conducted out of compassion and clear benefits for the patient. The terminologies in question are; active/involuntary, active/non-voluntary, passive/involuntary, passive/non-voluntary, withholding and withdrawing of treatment. Active, is usually taken to mean that death occurs through the use of aggressive methods, such as through lethal injection. Passive on the other hand, could be interpreted as letting nature take its course, incorporating acts such as withholding and withdrawing of treatment.

3.1.1 Active/voluntary, active/involuntary and active/non-voluntary

Set out below is a table based on the differentiation of active euthanasia. It can be seen from the table, that as the participation of patient decision making decreases, the dangers involved in legalising euthanasia increase.

Table 3.1: Different categories under 'euthanasia'

Categories Criteria	Active/voluntary	Active/involuntary	Active/non-voluntary
Involves:	Competent terminally ill patients requesting euthanasia. Advance directive can also be used.	Patient could consent , but is either not invited to, or patient does not give consent to their own death.	Patient who is non-autonomous and cannot choose for themselves. No advance directive made before.
Does the term mercy killing fit?	'Mercy killing' does fit here as patient requests it, and is suffering psychologically and physically.	'Mercy killing' may fit, so long as it is a benefit to the patient. Doubtful if patient has not given consent.	'Mercy killing' may fit, so long as it is a benefit to the patient. But patient has not given consent.
Decision is based on:	Their own decision.	Physicians and/or family members. Patient could be a minor.	Physicians and/or family.
How safe is it to legalise this category?	Safe.	Doubtful.	Dangerous.
Reason:	Patient is competent enough to make	Social, economic and family burdens may	Social, economic and family burdens may

	decisions concerning their own life. They know what they want and do not want in life.	obscure the view of what is best for the patient. I.e. as old people, severely handicapped infants increase there may be strains on the already stretched medical resources.	obscure the view of what is best for the patient. I.e. as old people, severely handicapped infants increase there may be strains on the already stretched medical resources.

(Table continues from previous page)

An important point that has not been included in the above table, is that the only acceptable form of euthanasia is active/voluntary euthanasia. This is because when physicians make decisions along with their patients it is based on the benefit/burden factor. The same applies for patients that are no longer competent enough to make decisions for themselves but have expressed their wishes through family members or through advance directives. When patients' illnesses are seen as a burden rather than a benefit, then the most humane thing to do could be to relieve their suffering. It must be stressed that their suffering comes from their illness and not death. Patients that request euthanasia are usually terminally ill, in pain both physically and psychologically, to the point that death would be a relief for them. Euthanasia would not be the cause of death but the underlying illness.

The problem with active/involuntary and active/non-voluntary is that the patients have not given consent to their death. It may however be that the patients' prognoses are so poor that physicians cannot avoid judging that the patients would not benefit from their existence even if they were to survive. A swift and painless administration of lethal injection may be at times more humane than opting for passive euthanasia, which involves waiting for the patients to die in pain, while withholding treatment. Pain killers can however be given to alleviate the patients' discomfort.

There is a slight problem with the above however, in that death is certain once a lethal injection is administered, whilst passive euthanasia allows for improvements in a patient's condition in the case that a physician's prognosis was wrong.

To conclude, firstly, a clearer definition of euthanasia is required. Euthanasia taken to mean a 'good death', can only incorporate active/voluntary euthanasia, including physician-assisted-suicide, because only then will the death be good to the patient. Patients would have made the decision by themselves, have their wishes respected, and can die in a dignified manner. Active/involuntary and non-voluntary euthanasia is not euthanasia in the most strict sense as patients in this category have not asked for death. Secondly, the physician's intent in killing the patient is out of beneficence and non-malificence. Thirdly, if the patient is terminally ill or born with a severe handicap like anencephaly, then the direct cause of death is not the lethal injection but the illness or severe handicap. Physicians in these cases, have judged through clinical diagnosis that the patients would not benefit from having their lives continued as they would only die with pain and suffering, or will not benefit from treatment at all. Rather than choosing passive euthanasia, where pain and discomfort may result, physicians may choose a more swift and painless means of death. Medical staff and family members may also prefer a painless death, through active euthanasia, rather than watching their loved ones die in misery and without dignity through passive euthanasia.

3.1.2 Withholding and withdrawing treatment

There is a general misconception, that withholding treatment is morally permissible whilst, withdrawing treatment is not. The reason for this is based on the Act and Omission doctrine, whereby the Act would be the withdrawing of treatment, and the withholding is the Omission. For both withholding and withdrawing the result is the same. Death results in both cases, because the treatment is either seen as not being a benefit but rather a burden so treatment is withheld, or treatment is withdrawn as the patient's prognosis is poor with no signs of recovery.

Most medical staff find it harder to withdraw treatment rather than to withhold treatment, because of the action involved when taking people off treatments such as life-sustaining machines, or respiratory aids. This is mistakenly perceived as being the cause of death. This could be due to the visual impact of seeing the life of a person ebbing away in front of you whilst thinking that the switch you turned off resulted in their death. On the other hand, by withholding treatment, patients die naturally. Hence, there is a difference in the way that death results, in letting 'nature take its course' or through human intervention.

There are two other important issues that have not been mentioned yet. The first is that patients may benefit from having treatment. It usually takes a few days at least to determine whether the patient is benefiting from it. If the prognosis is good, treatment should be continued, if not, it can be withdrawn. Hence in cases where the prognosis is doubtful, it would be morally more acceptable to try treatment and then withdraw it if the patient is not benefiting, rather than not giving the patient a chance at all.

The second issue that is often neglected, or not widely understood is, what the cause of death is. It is often misconstrued, that the act involved in withdrawing treatment results in death, and is hence seen as euthanasia. The argument that would be made here, is that it is neither the withdrawing that is the cause of death, nor should the withdrawing of treatment be called euthanasia.

Firstly, the cause. The cause of death is the illness, not the withdrawing of treatment. The patient would have died earlier had treatment not been given. If a patient dies as a result of withdrawing treatment, it can be argued that the patient was dying anyway, and the treatment did not benefit him/her. The fact that treatment has to be given in the first place, shows that the patients were in need of some life sustaining treatment that may lead to them recovering some of their former potentials. If the patients' condition does not improve then the medical staff have a right to withdraw treatment because the patients are not benefiting from the treatment. Secondly, this results in unnecessary high costs and stress for the family and medical staff. This would mean that the effort of maintaining a life could be outweighed by other socio-economic needs. It is morally wrong perhaps to put the needs of others, especially where money is concerned, before a life of another human being. It is also morally wrong however, to prolong the life of a patient who is clearly not going to get better, or is not improving at all but getting worse. Subjecting the medical staff and family to unnecessary pain and stress, both emotionally and financially, is wrong. In this case it seems logical that treatment be withheld or withdrawn.

In cases where medical staff would not provide treatment requested by family members, such as ventilatory support for a dying patient, Lord Justice Donaldson stated that courts:

> should not require a medical practitioner...to adopt a course of treatment which in the bona fide clinical judgment of the practitioner was contraindicated. [2]

Further to this, Lord Justice Balcome wrote that he:

> could conceive of no situation where it would be [proper] to order a doctor to treat a [patient] in manner contrary to his or her clinical judgment.[3]

If the family's requests are such that they object to the physician's advice, then the patient could be transferred to another physician, who may be able to acquiesce to their wishes. The above two statements was also supported by the new Virginia statute

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[2] PARIS, J. J., SCHREIBER, M. D., STATTER, M., ARENSMAN R. and SIEGLER, M. Sounding Board - Beyond Autonomy - Physicians' refusal to use life-prolonging extracorporeal membrane oxygenation. *The New England Journal of Medicine*, July 29, 1993, Vol. 329, No. 5, page 356

[3] Ibid.

which upheld the physicians position of rejecting patient and family demands when treatment was not recommended. This clearly shows that more and more people are supporting the view that treatment can be withheld without it necessarily meaning euthanasia for the patients.

This leads us to the second issue. Euthanasia is misinterpreted to encompass a wide range of meanings that do not correlate to the original meaning of 'good death'. There is an unfortunate confusion in the term due to the abuse of it by Nazis, and the word 'killing'. It must be stressed firstly that 'killing' is a too strong word for 'euthanasia'. Killing entails an image of murder where there is the role of a killer and its victim(s). Beauchamp and Childress highlight the ambiguity surrounding the term 'killing' in correlation to 'letting die'. The authors write that although in ordinary language 'killing' does not entail an "intentional action for killing"; "killing is any form of deprivation or destruction of life, including animal or plant life." [4]

There are "emotive connotations of moral wrongness"[5] that accompanies 'killing'. Beauchamp and Childress further write that killing:

> represents a family of ideas whose central condition is direct causation of another's death, whereas allowing to die represents another family of ideas whose central condition is intentional avoidance of causal intervention so that a disease or injury causes a natural death.[6]

The argument here is that although the result of 'killing and letting die' is the same, the intention is important. Firstly the connection between 'killing' and 'euthanasia' should be severed, for although it may be true that in ordinary language 'killing' encompasses a wide range of meanings including usage such as "killing a legislative bill"[7], there is a

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[4] BEAUCHAMP, T. L. and CHILDRESS, J. F. *Principles of Biomedical Ethics*. Fourth Edition. New York: Oxford University Press, 1994, page 220

[5] Ibid.

[6] Ibid.

[7] Ibid.

serious moral stigma attached to the term 'killing'. Euthanasia is not about 'killing' someone with malicious intent, but about relieving persons' suffering and pain, with the aim of giving patients a dignified and painless death. To use a trivial everyday example, we do the same for horses that have broken their legs badly. The horse is in so much pain, with little chance of recovering to its former state, that most people out of love and compassion for the horse, shoot it. The killing of the horse here, like with terminally ill patients, is not done out of malicious intent but to relieve its suffering. The terminating of life, is done out of respect for the horse's way of life, in the same way we value the life of a human being. However the example of the horse is not to be used to mean that their value of life is based on our perception of what a horse's life should be about. In the same way, we should not use our individual ideas on what constitutes a life that is worth living, as a basis for conducting euthanasia on others.

Euthanasia is not killing, in the morally wrong sense, but more like allowing people to choose to die in the manner that they prefer. Therefore only voluntary euthanasia or physician assisted suicide, which incorporates the patient's request, should be considered as euthanasia. For only then will the true meaning of a 'good death' be realised by patients and those around them.

Withholding and withdrawing of treatment, should not be under the category of euthanasia, because it is the illness that prevents the treatment from working. If a patient has a good chance of recovery, medical staff would prefer to try to resuscitate and aggressively employ treatment. But if there is a clear case of poor prognosis, treatment would not be a gain for the patient and would only result in a drain of already strained medical resources. Withdrawing and withholding treatment may not always bring about a dignified or 'good death' but it is letting 'nature take its course' when nothing more that would be of benefit to a patient can be given. Therefore, passive/involuntary, passive/non-voluntary euthanasia, withholding and withdrawing of treatment, have no direct relation to euthanasia. They are merely letting patients die, if they opt to reject treatment, or when medical staff see no benefit for them.

3.1.3 Passive euthanasia

Passive euthanasia, as with the issues discussed before, should not be classified under euthanasia. The main reasoning for this is because passive euthanasia is 'letting nature take its course' by disallowing medical intervention when the need arises. An example of this would be, patients that are dying from terminal cancer suffering from respiratory problems who express the wish not to be put on a ventilation machine when their breathing fails. Should the medical staff acquiesce to their patients' wishes, they are in effect, allowing passive euthanasia. They do not have an active participation in causing the patients' death in a way that a lethal injection may hasten death. At the same time, however, they are not using medical treatment that would enable the patients to live for some time. Therefore the distinction between active and passive euthanasia, is whether you hasten death through artificial means, or through omission of treatment which lets patients die naturally. Passive euthanasia is close to withholding and withdrawing of treatment as they let the patients die.

Voluntary, involuntary and non-voluntary euthanasia can be either active or passive. Once again, only active/voluntary euthanasia can be considered as euthanasia, and be made legally permissible. The reason being that this criterion is the only one that involves decisive decision making on the patients' part. Passive/voluntary euthanasia is legally permissible already, in the sense that patients have the right to reject treatment. Patients cannot be given treatment against their wishes even if it may be of benefit for them. Thus passive euthanasia is similar to withholding and withdrawing treatment. Therefore, the argument will be in a similar line as the aforementioned in that, passive euthanasia is not euthanasia because it is letting a patient die through natural means. The underlying cause of death is not because treatment was withheld from them, but because of the illness. The patients with respiratory problems may suffer when dying even if treatment is withheld or withdrawn from them. Withholding or withdrawing of treatment is not killing the patients and neither is it providing a peaceful means of death at all times.

So far a distinction between euthanasia and letting die has been discussed. There is a fine line, between actively bringing about death through injecting a lethal drug, and omitting to treat a patient. What is clear though, is that both do not have malicious intent, although death is the result. This is because the aim is to relieve the patients' pain and sufferings. Euthanasia hastens death, through an active involvement of medicine, so that patients will die swiftly with minimum pain. Withholding and withdrawing of treatment is not euthanasia, because there is no active medical involvement, but a lack of it. Involuntary and non-voluntary are also not euthanasia because they do not involve active decision making on the patients' part, and because the cause of death is not due to omission of treatment or through active euthanasia, but because of their illness. There is a 'grey area' between active/voluntary, active/involuntary and active/non-voluntary, but the method of bringing about death is similar. There is however a difference, in that only with active/voluntary is euthanasia requested. For the other two, euthanasia cannot be requested, or patients are not invited to. If active/involuntary or active/non-voluntary is allowed, it is only because the medical staff, family and medical ethics committee would see euthanasia through lethal injection as a more humane method in letting a person or a neonate die. This would be seen to be better than letting their condition deteriorate slowly and die under painful conditions. In this case, it is not the injection that causes the death but the illness. The lethal injection merely hastens death, only because the neonates or non-autonomous person was dying to begin with. In the case of an anencephalic neonate or an infant suffering from chronic skin disorder, they may survive for a few months or a few years but the burden of their existence may outweigh the benefits in living.

3.2 Withholding MN&H

There is an increasing debate on whether medically administered nutrition and hydration (herewith written as MN&H) can be used as a basis for letting a patient die. MN&H; using needles and tubes to administer nutrition and hydration, can be argued as being an obligatory medical treatment that sustains patients, whilst others may see it as being optional treatment at the same level as respirators.

There has been several cases where MN&H has been withheld from Down's syndrome and severely handicapped neonates so that they would eventually die. The main question that must be addressed is, when is nutrition and hydration a treatment, and when is it a fundamental requirement as a means to survival. For people and infants that are not terminally ill, nutrition and hydration is a basic requirement for their well being. Without it people would die painfully from starvation. For terminally ill patients MN&H is not always a requirement if they are not benefiting from it, or request not to have it. Nutrition and hydration is a basic requirement, whether it is administered orally or through IV lines, only when the patient can benefit from it and require it. Otherwise, the withholding of MN&H does not necessarily mean pain and discomfort for terminally ill patients, or severely handicapped neonates. This is probably because their body has no requirement for usually essential nutrition and hydration.

In the case of Baby John Pearson, the neonate was prescribed 'nursing care only', which consisted of water as well as high dosages of pain killing drugs. Pain killing drugs are not part of MN&H, and the amount given to Baby John Pearson was at toxic level. The pain killers may not have been the result of the neonate's death, but he may have weakened to the point that it naturally developed pneumonia, which brought about death as a result.

From this case we can deduce that, had hydration and nutrition been given in required amounts (the number of times the neonate was actually fed was not recorded), he may have had a fairly good chance at survival as a relatively healthy baby. The neonate's abnormalities of the lung, heart and brain may however, have made him more susceptible to pneumonia. At the same time, it cannot be denied that the lack of MN&H did play a part in bringing about his death. This shows that nutrition and hydration was a benefit, and was a basic requirement to ensure his survival, and not a treatment. It was not withholding treatment or underlying cause of illness that caused the death, but withholding nutrition and hydration, along with the high level of pain killing drugs.

If on the other hand, a neonate was born with severe handicap, such as anencephaly, then MN&H may be treatment because the neonate is dying from the time it is born. Baby John Pearson was not dying from an abnormality. The illness developed as a result of having only hydration and pain killing drugs.

Beauchamp and Childress have written that the withholding or withdrawing of MN&H does not mean starvation in the same sense that a healthy person may perceive it to be[8]. It does not necessarily entail a painful death. This is probably true, but it would not be wrong to say that the patient does become weak from lack of nutrition and hydration, thus making the patient more susceptible to illness and infections. We would not for example, omit MN&H to patients with AIDS, for otherwise we would be hastening their death. Unless the patients are dying already and would not benefit from MN&H.

Omission of MN&H does not mean euthanasia for the patients, although at times it does cause an illness that results in death. Omission of MN&H is a 'means to an end' however, in the sense that the 'end' would be death, and the 'means' the omission of MN&H, it plays a large part in bringing about death. However, it is not euthanasia because firstly, it is not the direct cause of death, and secondly, it does not bring about a 'good death' (which has inferences of painless and swift death).

If omission of MN&H is practiced on neonates like Baby John Pearson, it could be interpreted as murder, because death was the intention on the Down's syndrome

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[8] BEAUCHAMP and CHILDRESS, ref. 4, page 205

neonate that was not dying to begin with. Dr. Arthur was acquitted, but there are still doubts as to whether this was the right decision for the juries to arrive at. The one saving factor for Dr. Arthur is that he respected the parents' wishes. There are undoubtedly many occasions where a physician would be inclined to follow the parents' wishes, as it would be psychologically easier. The physicians' empirical knowledge, concerning the life of Down's syndrome with complications, may amplify this tendency. The infant if lucky, would be adopted but otherwise it would be sent to institutions, where it would live there for life. There are therefore, other social factors that influence physicians, families and society on what would be beneficial to a neonate with Down's syndrome or severe handicap.

To summarise, MN&H can and should be withdrawn if a patient rejects it, or is clearly not benefiting from it. For then MN&H would mean treatment for a dying patient. If however, the patient would benefit from MN&H and would be able to lead a relatively healthy life without additional medical treatment, then MN&H is a basic requirement and not a treatment. Finally, MN&H is not euthanasia because it is not the direct cause of death. The underlying illness prevents MN&H to be positively utilised by the body.

3.3 Euthanasia for severely handicapped or ill neonates

When somebody is in obvious pain and discomfort it is natural for anyone to feel a sense of helplessness and longing to relieve their pain. This feeling is more acute for infants who are helpless to do anything that would make themselves feel better. If they are born with a congenital handicap(s) or severe illness, medical staff can alleviate their pain to a certain degree. The methods they can employ are, however, short term and do not always guarantee permanent freedom from pain and discomfort. In cases where there is no cure for an illness or permanent treatment, medical staff and parents have to act as surrogate decision makers to decide what course of action would be of best interest for the infant.

Many infants, especially spina bifida neonates, were aggressively treated until the 1970's. Questions however arose on whether their quality of life was a benefit to them or a burden. There is a growing trend to see their lives as being a burden rather than a benefit for them. With today's medical technology many severely handicapped and ill neonates can be rigorously treated. However, the number of operations and the difference between the time that they are free of pain compared to the time that they are in pain is great. So much so that medical institutions, families, medical ethicists, and the law have come to the point of having to decide whether aggressive treatment is really the best option for them.

We cannot make life or death judgements based on another's quality of life. There are however cases where it is clear that a neonate would benefit from death rather than life. Anencephalic neonates for example, have a short life span, and do not benefit from life because they would never be able to enjoy anything that is offered to them in life. Spina bifida neonates, depending on the severity of their condition, may also be so mentally handicapped that they will not have any awareness of their environment or the love and affection given by others. Severely ill infants, such as those suffering from chronic skin disorder, will be in continuous pain unless they are given pain killers. But this again, will eventually lead to their death.

When infants' lives are seen to be more of a burden than a benefit, by the medical staff and parents, the method of ending their lives has to be decided. The usual method, and the only legally acceptable method at this time, is through the withholding, withdrawing of treatment or MN&H (which would be considered as treatment if the infant is dying). With this method medical staff and parents will be letting the infants die naturally. This is passive non-voluntary, but not euthanasia, as the illness or handicap is the cause of death. Their lives are only sustained through medical treatment.

Death may be slow and painful by letting an infant die naturally. The medical staff will no doubt ensure that an infant in this unfortunate circumstance will be kept as comfortable as possible, but it may nevertheless be agonising for all parties involved, as they await the infant's death. If this is the situation and the result is the same, would it not be morally more acceptable to permit active/non-voluntary euthanasia for infants? At least this way they will be ensured a swift and painless death. Perhaps it is more humane to allow a swift death for those that are dying slowly in pain. We allow, for example, a horse to die swiftly, why should we not allow the same for humans?

One of the main reasons that hold us back from accepting active/non-voluntary euthanasia, lies with the fact that the patients in this category are non-autonomous. They are unable to give their opinion on critical questions such as: whether they are in pain or not, if they wish to be allowed to die, or whether they prefer euthanasia. All decisions have to be made by surrogate decision makers, and this makes us feel skeptical about accepting active/non-voluntary euthanasia.

There seems to be a general fear of allowing others to have the authority to make life or death decisions about another's life. We have seen that euthanasia can be abused. For example, the Nazi's concept of euthanasia. We are afraid that the slippery slope scenario might occur again. There is little chance of another Nazi holocaust occurring, but that was genocide and not euthanasia to begin with. One of the main problems we face with accepting euthanasia is that the Nazi holocaust began with the concept of euthanasia. The term was quickly abused and used to commit genocide on the basis that they were making quality of life decisions for others:

> The beginnings at first were merely a subtle shift in emphasis in the basic attitude of the physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely ill and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans. The infinitely small wedged-in-lever from which this entire trend of mind received its impetus was the attitude toward the nonrehabilitable sick."[9]

The presence of doctors like Dr. Jack Kervorkian may also be a problem. The doctor's intention is undoubtedly well meant, as his aim is to relieve people of their physical and psychological sufferings. This can be appreciated to a certain extent. However his clinical and psychological diagnosis of his patients seem to be unusually short. The doctor does not seem to be making a differentiation between patients that are psychologically depressed, and would benefit more from having psychiatric consultation rather than physician-assisted suicide, and patients that are really suffering from a severe illness or debilitating condition. The one saving factor for Dr. Kervorkian, is that all his patients have given their consent in writing and verbally, on video tapes. They have clearly indicated their request to be euthanised as mentally competent adults.

Non-autonomous persons cannot give their consent, thus active/non-voluntary euthanasia may be standing on a fine line between murder and providing a 'good death', for these people. One wrong step by a physician and he/she would be prosecuted for murder. Physicians may argue here that it need not necessarily have to be their responsibility to conduct euthanasia. Anyone can in effect do so, so long as they are autonomous adults. This is true, but there is a general belief that because doctors

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[9] BEAUCHAMP and CHILDRESS, ref. 4, page 231

develop a close relationship between patients and their families, it would be easier for the families to accept active/non-voluntary euthanasia.

From the arguments raised above, it can be understood that active/non-voluntary euthanasia should not be legalised, simply because the groups of people that are included in this category are unable to express their opinion, and secondly, because their life or death decision is based on the quality of life as judged by others. It is clear, therefore, that active/non-voluntary is legally not permissible. There are doubts however as to whether the same applies morally.

Morally it is wrong to end another's life, but it is also wrong to sustain a life that is full of pain. The former could be equivalent to murder and the latter to torture. Moral judgements, however, are based on the intention behind the act. If there is malicious intent involved in the act of killing, it is murder, but if the intention is good it is not murder but euthanasia or assisted suicide. The same goes for torture. Torture is morally wrong because the intention is to harm someone, on the other hand, if a treatment is painful but would result in net benefit for the patient then it is not morally wrong. The intention in this case is to cure the patients, not to harm them, therefore it is morally permissible. In the same way, if neonates are suffering from an incurable illness or severe handicap with no prospects of leading a life worth living, then it is morally permissible for their lives to be terminated. Neonates, in these unfortunate cases, would be freed from a life that has no prospects of enjoyment or appreciation of it. There is no need to continue a life that is so full of pain and suffering that the burden outweighs the benefits.

There will undoubtedly be difficulties in resolving the issue of why something that is morally permissible should not also be legally permissible. Perhaps the difference lies in the threat to the rest of the society. If active/non-voluntary euthanasia became legally permissible, who is to say that when we become non-autonomous or terminally ill, our lives would not be threatened? Our lives may also be judged as not worth living. The chances of a slippery slope scenario occurring are slim; however, if there is political, economical or social instability euthanasia can be abused to terminate many lives. Therefore, although active/non-voluntary euthanasia is morally permissible, it is not legally permissible because of the threat to the rest of society.

3.4 Abortion or infanticide?

Abortion is legally and morally permissible, but infanticide is not. There does not however, seem to be a moral difference between abortion and infanticide, in that both result in the death of a potential person. The obvious difference between abortion and infanticide is that one is done before birth, and the other, after birth. Why should this distinction make infanticide so intolerable to society?

The definitions of abortion and infanticide in 'The Concise Oxford Dictionary' are as follows:

> abortion - 1) the expulsion of a foetus from the womb before it is able to survive independently, 2) a stunted or deformed creature or thing.[10]
>
> infanticide - 1) the killing of an infant soon after birth, 2) the practice of killing newborn infants, 3) a person who kills an infant.[11]

It is interesting to note that the second definition of abortion describes, in some ways, a severely handicapped neonate. There are negative connotations from the use of the word 'creature' as if there is something wrong with a life that is born with abnormalities. This definition is however not important in our discussion. The first

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[10] *The Concise Oxford Dictionary.* Ninth Edition. New York: Oxford University Press, 1995, page 4

[11] Ibid., page 695

definition of the word abortion is, 'before it is able to survive independently'. This is important in the context of severely handicapped or ill neonates as they do not have the capacity to survive independently. All infants and children need support from their family for basic survival, but the infants that we are concerned with, will never have the capacity to survive independently. If a infant's prospects are such that it will never have the opportunity to have a life that is worth living, and will never have the chance to survive independently, then infanticide cannot be any worse morally than abortion. The only difference is that infanticide takes place after the birth.

As with many of the controversies concerning euthanasia, it is the perception that mar's the truth. The term infanticide conjures up images of innocent healthy infants being killed through malicious intent. It is unfortunate that there are cases where healthy normal infants are killed for reasons that can only be seen as perverse. All infants should be cherished, loved and protected, but this could also mean that if their lives are full of pain and suffering without a chance of leading lives that are worth living, then love for them may sometimes have to be expressed in the form of allowing them to die.

It can even be argued that at times, infanticide for severely handicapped or ill infants is morally permissible, but abortion is not. This will be best highlighted by an example:

> Ultrasonography is now commonly used during pregnancy to establish gestational age and to detect abnormalities. Mrs. Smith, age 23 and healthy, is 24 weeks pregnant with her first child. A sonogram reveals that the infant's ventricles are large. What does the physician tell Mrs. Smith? 'Your infant probably has hydrocephalus, water on the brain. We do not have enough experience to know if this will get worse or leave your infant with severe impairment, or leave your child normal or with only the need for a shunt at birth. Most infants with shunted hydrocephalus can do very well. A major determinant of your child's outcome may be the cause of the hydrocephalus, are high. If the hydrocephalus is due to a small abnormality blocking the outflow of fluid, then, if the hydrocephalus does

> not become to severe, we can put in a shunt at birth, and your infant has a high probability of being normal. Some surgeons are placing shunts into the fetus in utero, but this experimental technique in no way assures a normal child. You have to decide soon, because now we could terminate the pregnancy. In a week or so this can no longer be done, and the infant will have to be carried to term.[12]

Mrs. Smith is placed in a very distressing and difficult position. The doctor has a moral obligation to recommend abortion in light of the situation surrounding the infant, but there is doubt as to whether the infant will benefit from being terminated so early in its life.

Freeman writes in his article *If Euthanasia were Licit* the following:

> ...physicians, together with parents, may elect to terminate a pregnancy to prevent the birth of a catastrophically impaired infant - even without certainty that the infant will be catastrophically impaired. They are willing to sacrifice a possibly normal infant to avoid the likelihood of a potential disaster.[13]

By aborting a potentially handicapped infant they are not giving it, if normal or only slightly handicapped, a chance at life. Do we not have a moral obligation and duty to at least give infants, that are in doubtful situations like the example described above, a chance to be born so that a better diagnosis on the infant's condition can be made then? Since the result of both abortion and infanticide is the same, it should be permissible to allow the infant to be born, then if the diagnosis is not good it can be allowed to die at the parents' and medical staff's discretion. For the above case of hydrocephalus, the infant will not be able to live for long, since the underlying severe condition is the cause of death, and not the withholding of treatment.

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[12] FREEMAN, J. M. If euthanasia were licit could lives be saved? McMILLAN, R.C., ENGELHARDT, H. T. Jr., and SPICKER, S. F. (eds.) In *Euthanasia and the Newborn*. Dordrecht: D. Reidel Publishing Company, 1987, pages 160-161

[13] FREEMAN, ref. 12, page 164

Another point that needs to be raised is that infanticide, although not legally permissible, happens daily. Infants born in drought stricken countries or countries in war often die. Are we not committing infanticide by not trying to help those that are born there? Unfortunately not all infants that are born in unstable political or environmental circumstances can be saved. Infants that are born in these severe situations have a lesser chance of survival, but this cannot be blamed on any one, unless it is a war. The rest of the world is not committing infanticide by being unable to help them. This is because firstly, it would be physically impossible to help all them, and secondly, there is no malicious intent from the rest of the world to bring about these infants' deaths.

Infanticide is morally wrong only when there is malicious intent involved. Withholding treatment when the infant will not benefit from it, including MN&H, is not infanticide because the intention is not to harm the infant, but to let the it die as painlessly as possible. The withholding of MN&H, as stated earlier, does not mean pain or starvation in the sense that we understand it. Abortion, on the other hand may mean harm and can be taken to mean active/non-voluntary euthanasia, because death is immediate and done through some medical intervention. Even worse, abortion of a healthy foetus can be interpreted by some life support groups as being the equivalent to murder! What is of issue here is at what stage life as a human begins. Some may hold that life begins at the point of conception, whilst others may believe that it starts at birth. However, this is not important for pointing out the distinction, since the result brought about by abortion and infanticide is the same. So long as abortion or infanticide is done for the best interests of the infant and with parental consent, it is morally permissible.

There are marginal cases where it would be difficult to decide between abortion or to carry the foetus full term. In the example of Mrs. Smith, it was clear that the infant may be born with hydrocephalus. This may make it easier for the parents to allow the infant to die if the diagnosis is not good. On the other hand, there may be cases where a foetus may seem to have spina bifida, but the severity is not known. In the event that an infant is born with spina bifida the physician can treat it by covering the area of the spinal cord that is protruding. If the infant is born and found to have the capacity to live by itself without medical support after the treatment of the spine, but suffers from severe brain damage, the parents will have to live with the care taking of the infant for as long as it lives. The best course of action that would probably be recommended by doctors then, is to withhold treatment and MN&H, and let the infant die naturally. Another argument may be that the parents, at the point of rejecting abortion, had made the decision to keep the infant and take responsibility in the caring of it even at the risk of having financial and emotional burden as a result.

These marginal cases makes it difficult to decide what is the best interests for the infant. But by aborting the foetus, the foetus will not have a chance at life. At least by allowing infanticide the infant was given a chance. We have a moral obligation to give foetuses, that have the potential to lead a normal life, a chance at life but no one but the parents have the legal right to dictate whether their baby should be aborted or not. As for infanticide, it is morally and legally permissible to let an infant die, if the medical staff and parents find that the infant will not benefit from any type of treatment. Finally, the difference between abortion and infanticide may be similar to the distinction made between withholding and withdrawing of treatment, in the sense that abortion is the withholding of life, and infanticide is the withdrawing of life. They are both not morally or legally wrong.

3.5 Summary

Euthanasia is a highly controversial subject, because it results in unnaturally induced death. There is also the confusion in terminology where the word 'euthanasia' has been used to define any act that ends life. This chapter has arrived at the conclusion that only active/voluntary euthanasia can be called euthanasia in the strictest sense of the term.

It has been argued in this chapter that both active/voluntary euthanasia and active/non-voluntary euthanasia are morally permissible so long as the patients are terminally ill and no longer benefiting from any sort of treatment. However there are difficulties with active/involuntary and active/non-voluntary euthanasia as the patient has either not been invited to request euthanasia, or is incapable of doing so. Autonomous persons can naturally consult with their physicians and arrive at a decision that would be of benefit for them. This is not possible with non-autonomous persons. Surrogate decision makers, family members together with medical staff, have to make the decision on their behalf based on the benefit/burden factor. There is also the danger of having euthanasia abused. To avoid this, euthanasia for non-autonomous persons should not be legalised, although it is morally permissible.

Withholding of MN&H has generally been misunderstood to mean death by starvation. This is not always the case since patients that are terminally ill may not have any requirements for nutrition and hydration.

Traditionally, infanticide has not been accepted by society. This is due to the visual impact of seeing the baby and then terminating its life, in contrast to, ending its life before birth. There may be cases however, where infanticide is morally more acceptable than abortion, as it allows for the baby's condition to be diagnosed before making the judgement of whether its life is worth living or not. Finally, if the decision to terminate a life is made, then it should be made on the benefit/burden factor for the patients whereby the burden of their existence outweighs the benefits.

4 Future of severely handicapped neonates

During the early 1960's there was a trend to treat as many spina bifida neonates as possible. Early treatment was seen as vital for spina bifida neonates to ensure that the neonate does not suffer from further irreparable nerve damage. For 12 years in Sheffield, neonates born with spina bifida were actively treated, but this soon gave rise to questions concerning their quality of life. This led to selective treatment of severely handicapped neonates, whereby those with the best chances of leading a life worth living, would be treated.

Today we face ethical dilemmas quite different to those that were previously faced. In the past, philosophers and ethicists, debated on the quality of life for neonates born with severe handicaps. Medical advancement has brought about a new challenge; pre-natal screening, genetic screening tests and gene therapy. In many ways, medical advancement has been positive in that it has given us more choices and chances for leading a life worth living. At the same time, however, the increasing numbers of choices; whether to undertake screening and whether to abort the foetus, has led to more decision making for the parents and medical staff. Socio-economic factors may also influence decision making. In countries where there are scarce medical resources abortion may be recommended compared to countries that have resources. Other problems that may arise from genetic testing are: confidentiality of reports and impact of results on couples. What needs to be reminded here is that what ever decisions are made, they should be based on the child's best interest first and then others'.

4.1 Extraordinary Preventions

One of the best methods for solving the problems, concerning severely handicapped neonates, is through prevention. For whatever life support groups may argue, it seems that prevention is better than having to terminate a life that has been judged as a life not worth living. Medical advancement has made it possible to detect handicaps through pre-natal diagnosis. Even then it may never be possible to have all children born in a mentally and physically sound condition. It may also be that we do not want this, because it would seem morally wrong to have perfect babies only, even though all parents would like their child to be born both mentally and physically healthy.

What handicapped children have done for society is to bring out its best side. The humane, benevolent and caring side of our otherwise impersonal society. Families, as well as society, have a responsibility to provide the best medical care, education, and opportunities towards a worthwhile life. Through prevention of severe handicaps, the infants would not only have lower mortality, but a better chance of leading a life worth living. The decrease of neonates born with severe handicaps may also make it possible to allocate higher standards of care to each child.

Medical advancement has made it possible to prevent and treat many neonates born with severe handicaps. Prevention is undertaken in the form of pre-natal screening. This can be done in the form of genetic screening or ultrasonography.

Ultrasonography for pregnant women is generally known to find the sex of the foetus, but more importantly it diagnoses the pregnancy, assesses the gestational age, and finds congenital abnormalities of the foetus. It is a widely used and accepted method of detecting foetal abnormalities. Many major structural deformities can be detected by ultrasound in the second trimester of pregnancy, at about 16-20 weeks of gestation.[1] When an abnormality is detected, the parents can opt to have further tests carried out through amniocentesis.

The main aim of the first screening test is to determine the protein α-fetoprotein in the maternal serum. This is because foetuses with neural tube defects , spina bifida or anencephaly for example, secrete an excess of the α-fetoprotein into the amniotic fluid. 80-90% of neural tube defective foetuses can be detected in this way. However most medical staff would use this as a basis for recommending further testing using amniocentesis. It has also been found that a low maternal concentration of α-fetoprotein is related to the occurrences of Down's syndrome in foetuses. Combined with other environmental factors such as age of the mother and family history, medical staff are likely to recommend further testing through amniocentesis and chorionic villus sampling[2] depending on the condition of the mother and her environmental factors.

Amniocentesis is the most widely used technique of prenatal diagnosis and is usually carried out at 15-18 weeks of gestation. The procedure consists of firstly using ultrasound to locate the placenta. A small quantity of amniotic fluid, which contains cells shed by the developing foetus, is withdrawn through a needle from the amniotic cavity.[3] Before chromosome examination, to detect Down's syndrome or DNA analysis can take place, the cells have to be cultured. There is a low risk to the pregnancy and neonate, although exact figures are not known yet. It has been found so far, that there is a 0.5%-1% risk of spontaneous abortion occurring following amniocentesis, as well as higher incidences of mild respiratory problems in neonates.

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[1] Nuffield Council on Bioethics. *Genetic Screening - Ethical Issues.* June 1996, page 115

[2] See, MASON, J. K. and McCALL SMITH R. A. *Law and Medical Ethics.* London: Butterworths, 1994, page 130

[3] Nuffield Council on Bioethics, ref. 1

There are several other types of prenatal testing. The following table represents the types of screening tests available to detect abnormalities in the foetus. Some tests can be done pre-pregnancy in order to ensure that couples are not carriers of a genetic abnormality.

Table 4.1: Current Genetic Screening Programmes in the UK (Sept. 1993)[4]

Age group	Disease	Population screened	Type of screening test	Confirmation required	Other comments
Pre-marital and pre-pregnancy	Cystic fibrosis	Pilot projects in general practice	Direct	No	Detects 85-90% of carriers
During pregnancy	Rhesus haemolytic disease	All mothers	Indirect		
	Diabetes mellitus	All mothers	Indirect		Foetuses have expert foetal anomaly scanning
	Congenital malformations	Most foetuses	Routine ultrasound	Yes fetal anomaly ultrasound	
	Down's syndrome	1) All mothers in some areas	Serum screening tests	Amniocentesis with chromosome tests on fetus required for confirmation	
		2) All mothers over 35-37	Chromosome tests on foetus		
	Neural tube defects (spina bifida and anencephaly)	All mothers in many areas	Indirect	No	
	Haemoglobin disorders	All mothers not of North	Indirect	Fetal anomaly ultrasound	Detects carriers

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[4] Adapted partially from Nuffield Council on Bioethics, ref. 1, page 27. Please refer to appendices for descriptions on the disease and the screening tests involved.

		European origin			
	Cystic fibrosis	Pilot studies	Direct	No	Detects 85-90% of carriers

(Table continues from previous page)

The above testings are widely practiced today, and are the basis for conducting further genetic testing when necessary. Information in the form of leaflets are given out in the UK to inform expecting mothers on screening for spina bifida and Down's syndrome. Set below is the content of the information leaflet produced by 'West of Scotland Prenatal Screening Service', to give an example of the type of information available, for expecting mothers or couples planning pregnancies. Information is given in a question and answer format[5] .

Table 4.2: The Screening for Spina Bifida and Down's Syndrome

(Table continues for 3 pages)

Q: Will my baby be healthy?
A: Happily most babies are healthy. A small number however are born each year with abnormalities such as spina bifida and Down's syndrome. Couples may choose to have a test during pregnancy which may help to detect one of these rare abnormalities.
Q: What is Spina Bifida ?
A: Spina bifida and anencephaly are the two main types of abnormality together known as neural tube defects. About 1 in every 500 births is affected. Babies with spina bifida have an opening in the bones of the spine, and the nerves to the lower part of the body are damaged. This can result in difficulties in walking and bowel and bladder control. Sometimes there is also a learning disability (mental handicap). In babies with anencephaly the skull and brain are not properly formed. These babies generally die before or very soon after they are born.
Q: What is Down's Syndrome?
A: People with Down's syndrome (Sometimes referred to as trisomy 21) have an extra chromosome, having three copies of chromosome 21 instead of two. Chromosomes carry genes which pass certain characteristics from parents to their children.

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[5] Reprinted from leaflet produced by, West of Scotland Prenatal Screening Service. Glasgow: Duncan Guthrie Institute of Medical Genetics, Feb. 1996

Abnormalities can occur when there are too many chromosomes. Children with Down's syndrome will have a learning disability and may have other abnormalities such as heart defects. Older mothers are more likely to have a baby with Down's syndrome. For example Down's syndrome occurs once in every 1500 births to women aged 20 years whereas at age 40 the rate is increased to 1 in 100 births.

Q: Who should have the screening test?

A: Women **choose** whether or not to have the screening test. it is a personal choice for you and your partner to make. All pregnant women irrespective of age can have the test. There is no charge for this test.

Q: How is testing carried out?

A: There are **two** stages to testing. The first stage is a **screening test** and depending on the results of this test some women (about 1 in 10) will be offered a second **follow up test**.

For the screening test, a small blood sample is taken from your arm at around 15-16 weeks of pregnancy and sent to the laboratory. There, the levels of two naturally occurring pregnancy hormones called AFP and HCG are measured. Within two weeks of having the screening test you should receive a letter telling you the results, - whether you are a **low risk** or **higher risk** for spina bifida or Down's syndrome.

If the screening test is **'low risk'** there is only a very small chance that your baby will have spina bifida or Down's syndrome and no further test is indicated. **9 out of 10** women will be low risk.

Q: Will the screening test detect all abnormalities?

A: No. The screening test can identify about 4 out of 5 spina bifida pregnancies and bout 2 out of 3 Down's syndrome pregnancies . Occasionally, other rarer abnormalities are picked up by the screening test.

Q: What happens if the screening result is high risk?

A: If the screening results are **'high risk'**, this indicates that there is an increased chance that the baby has either a neural tube defect of Down's syndrome (it is very unlikely that the pregnancy will be at increased risk for both types of abnormality) and that further investigation will be offered. You will be asked to return to the hospital where the results will be discussed with you, your questions answered and the type of follow-up tests explained.

High Risk of Spina Bifida

This screening result means that the AFP level was high and that there is some increase in the risk of spina bifida. About 1 woman in 20 will have this result but this does not mean for certain that there is an abnormality and most women with these results will have normal healthy babies. The most common causes of a high AFP result are:

- The pregnancy was further along than was thought.
- There are twins.

- Normal variations in the level of AFP in the blood.

A **follow-up** test, usually a detailed *ultrasound* scan, is offered to show whether an abnormality is present or not.

High Risk of Down's Syndrome

This screening result means that the combination of AFP and HCG results together with a woman's age show a higher risk of Down's syndrome. About 1 in 20 women will have this type of screening result. This result does not mean for certain that there is an abnormality and most women with these results will have normal healthy babies. The most common cause of this type of screening result are:

- The pregnancy is not as far along as thought.
- Normal variations in the level of AFP and HCG in the blood.

Follow-up tests, such as amniocentesis or CVS are offered to show whether the baby has Down's syndrome.

Q: What are follow-up tests?

A: These tests are used where the screening test result indicates that further investigation of the pregnancy should be considered. They include:

Ultrasound (also known as 'Scanning'): Almost all women have a routine ultrasound scan at some stage in their pregnancy. Sound waves are used to make a picture off the baby on a special TV screen. It can show the age and position of the baby and also if there are twins. It can also detect certain abnormalities such as spina bifida but at present cannot detect Down's syndrome. There is no known risk to the baby from ultrasound.

Amniocentesis: This follow-up test is used where the screening result shows an increased risk of Down's syndrome. For most women amniocentesis takes only a few minutes and causes little discomfort. First, ultrasound is used to find a safe place in the womb and then a needle is inserted through the abdominal wall into the fluid (called amniotic fluid) surrounding the baby. A small amount of fluid is removed and sent to the laboratory where it is used to examine the baby's chromosomes. The result of the amniocentesis test takes around 3 weeks, and will tell whether the baby has Down's syndrome or normal chromosomes. There is a 1 in 100 chance of miscarriage following amniocentesis.

CVS (Chorionic villus sampling): This follow-up test is offered in some hospitals instead of amniocentesis and is carried out in a similar way. A needle is used to remove some cells from the placenta, which are then sent to the laboratory where the baby's chromosomes are examined. The result of the CVS test takes around 2 weeks and will tell whether the baby has Down's syndrome or normal chromosomes. There is a 1 in 100 chance of miscarriage following CVS at this stage in pregnancy.

Q: What happens if the follow-up test finds and abnormality?

A: In most cases follow-up testing finds a healthy baby. If spina bifida or Down's syndrome is found this will be discussed fully with you and your partner and you will be able to choose what you feel is best for you and your partner. Some couples will decide to continue with the pregnancy while others feel that termination of the pregnancy is their preferred choice. There is no pressure from hospital staff to influence you in your decision, only help and support.

From the content it can be seen that the leaflet provided by the West of Scotland Prenatal Screening Service is informative. General aims and methods are described so that there is as little surprise as possible for the expecting mothers when they ask for the test. The language use is gentle with the focus on the needs of the mother. The words 'choice' and 'choose' are repeated often, emphasising that the ultimate decision making rests with the expecting mother and her partner whatever the result may be. It is interesting to note the last sentence of the leaflet: "There is no pressure from hospital staff to influence you in your decision, only help and support." This stresses that the decision will ultimately lie with the mother, in that no one can force her to have an abortion. It is, however, known that medical staff's advice and suggestions will play a large part in the decision making.

4.2 Ordinary Preventions

Not all preventions need to be complex and concerned with medical tests. Ordinary prevention of handicapped neonates can be achieved through having a nutritional diet and taking supplements to compliment the needs of pregnancy. Dietary supplements based on the needs of pregnant women are readily available. Folic acid has been recommended for preventing neural tube defects in foetuses, and is being publicised through advertisements and information in magazines for women.

It has been recommended that all women capable of becoming pregnant should consume 0.4mg of folic acid daily to prevent neural tube defects in foetuses later on. On the other hand, it is important that physicians and women understand that women's consumption should not exceed the recommended daily allowance. Too much vitamin A by pregnant women may cause birth defects. It is found to be beneficial for pregnant women to consume supplements limited to a single multi-vitamin preparation containing folic acid and no more than the recommended daily allowance of 8000 IU of Vitamin A[6].

4.3 Ethical and Technical Problems

Amniocentesis is the most popular method of detecting abnormalities in the UK with more than 1% of mothers undergoing the test[7]. There are however a number of practical problems. Firstly, the number of centres practicing amniocentesis is limited. At present, it is not seen to be feasible to offer everyone amniocentesis as there would be little or no benefit in terms of positive results. There would also be a strain on man power resources in operating amniocentesis everywhere. In order to make the system more feasible, amniocentesis should only be offered to mothers with problems detected at the first screening test; consisting only of a blood test, those that have already had a neural tube defect, have a family history of neural tube defect, or chromosomal abnormality, and mothers over the age of 35[8].

The readily available information on screening tests, in the form of leaflets, informs us that screening for congenital defects in foetuses are recommended and are widely implemented in the UK. This is a positive indication that the public is made aware of the possible complications for expecting mothers. The medical profession with the cooperation of the government is trying to aim for less severely handicapped neonates and more healthy, normal babies. This would also be a benefit for the government in

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[6] OAKLEY, G. P. Jr. and ERICKSON, D. J. Vitamin and Birth Defects - Continuing Caution Is Needed. *The New England Journal of Medicine*, Nov. 23, 1995, Vol. 333, No. 21, page 1414
[7] MASON and McCALL SMITH, ref. 2, page 131
[8] Ibid.

that medical resources allocated for neonatal care and social services for severely handicapped and handicapped children, would be cut down so that each child would get better attention that is catered to individual needs.

The main ethical problem that arises from amniocentesis is through the duration it takes for the result to be available. Even with the best medical or technical staff, an adequate amount of fluid can only be taken after the 14th week of pregnancy. In 5-10% of cases, adequate fluid is not obtained and the test has to be repeated. Considering the time factor, of taking three weeks until results are obtained, the foetus would have developed to a gestational age that is close to a viable infant. This will result in a more complicated and dangerous operation for the mother in the event that termination of pregnancy is chosen.

The main medical concern involving testing in chorionic villus sampling is that it has a high risk of miscarriage compared to other tests. Early sampling may also result in facial or limb abnormalities in an otherwise normal foetus. Therefore chorionic villus sampling should be limited to those that are at greatest risk, who are likely to seek termination of the foetus, or for cases where there is a single gene defect that requires diagnosis.

Screening has been proved to be a powerful medical tool, in detecting congenital defects, to avoid further development of a foetus that will most likely not be able to lead a life that is worth living. This is naturally difficult to judge, through foetal diagnosis, and there are clear limitations to screening and tests. There are also, inevitably, some false positive and false negative results which will increase with the complexity of the tests required. One way of preventing these problems is to obtain information on underlying environmental causes in multifactorial diseases. Multifactorial diseases are disorders that result from both environmental factors and from one or several genes. Neural tube defects are the most important multifactorial diseases.

Although modern gene marking techniques have reduced the number of severely handicapped neonates, there are still more tests that need to be developed. Normal male children at risk of x-linked disease, for example, are still legally aborted[9]. Screening and tests that indicate the level of raised α-fetoprotein level are unable to clearly show the degree of neural tube defects. In the same way, the low maternal concentration of α-fetoprotein, will not be an indication of the severity of Down's syndrome. This means that routine testing with positive results will result in abortion of foetuses that may be treatable after their birth, or will be able to lead a life worth living even with some degree of handicap. There is also the problem of neonates that are born through false negative results. 10-20% of the neonates will be born with severe handicaps that will require extensive treatment[10].

Testing of gene abnormalities could be considered as a flood gate to ethical problems. It is for example, possible to detect chromosomal abnormalities through genetic screening tests. Most of these abnormalities are related to severe diseases, but some are also related to behavioural patterns. According to chromosomal testing, XXY boys, for example, are prone to vicious behaviour. There are also others that are related to infertility or mental dysfunction. Even if there would never be the likelihood of foetuses with chromosomal abnormalities, related to disagreeable behavioural patterns being aborted, there is the question of whether medical staff should recommend abortion of all foetuses with abnormalities related to handicaps or severe diseases as a precaution. Should doctors, on the other hand, inform the parents of the risks and let the pregnancy run through naturally? The parents will have to face the rest of the pregnancy with anxiety, and in the event the baby is born with severe handicaps, they will have to face the difficult decision of whether to treat the baby or

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[9] MASON and McCALL SMITH, ref. 2, page 132
[10] Ibid.

allow it to die. Difficulties also arise with foetuses detected to have Down's syndrome. It would be difficult to determine the severity of the handicap, thus making the decision of whether to abort the foetus or not a highly complex and emotionally stressful situation for both the medical staff and parents. The decision making should however rest with the parents as they may have specific beliefs on the quality of life. Some parents may not be able to accept any level of abnormality, even if it is treatable. Whilst others may prefer to give their child a chance at life, even if the severity is found to be great. Medical staff should advice parents on the likely condition of the infant when born and the types of treatment available.

There is also the question of 'slippery slope'. Once we start aborting foetuses because of their congenital defects that are not accurately measurable, there may be the risk of increasing the boundaries for foetuses that can be legally aborted, such as XXY boys and those with mental dysfunctional chromosomes.

Information to expecting mothers, and couples planning pregnancies, should be as detailed as possible. Leaflet alone cannot cover all the difficult and complicated medical and ethical issues involved. The main consultation will lie with the medical staff. The expecting mothers should be made aware of the nature of the testing, and what the result may indicate, especially if the result shows information that are related to late onset diseases, such as Huntington's disease, or mental illnesses such as Alzheimer's. These are not severe handicaps in the sense that they affect the quality of life from birth, but will end up causing much distress to the individual and its family later on in life.

Screening tests for cystic fibrosis raise ethical issues that become involved at a personal level. In a study done on 2207 women in Edinburgh, 85% accepted whilst 325 (15%) declined. Half of those that declined did so because they objected to termination of pregnancy. During the tests it was found that carriers showed high anxiety levels and depression whilst awaiting for their partners' results. The tests were only conducted on partners if the pregnant woman was found to be a carrier. The level of anxiety and depression will naturally be significantly lowered if the tests on both partners are done simultaneously[11].

Positive results for both partners from this test, can effect their relationship towards one another, and affect any future decisions to have children. This type of test can be done before marriage and pregnancies, but as with any sort of genetic testing, there is the ethical question of how much information people should have on the genetic condition of their bodies. Their future will be affected by positive results as a consequence of taking genetic tests, and will also result in becoming part of their 'family history', which in return will affect future generations. Medical staff may feel that they have an obligation to advise other family members, including relatives of those with serious genetic disorders which may run in the family. The carrier on the other hand may prefer the information to remain confidential. There is a complex dilemma here for the medical staff and carriers. External factors of the family, such as family unity may have an effect on whether the carrier would want the information divulged or not. Therefore, medical staff should maintain their obligation to the carrier and not inform other members, however serious the genetic disorder may be. The information must be given from the carriers themselves to others. There is a delicate balance of trust between the medical staff and the patients. Once the trust of keeping information confidential is lost, there might be increasing hesitancy in taking genetic screening tests at all.

If treatment for specific genetic disorders are not found yet, it is difficult to assess whether the carriers should be informed of their genetic disorder. Their future plans may be somewhat marred by having this information. To illustrate, by having genetic testing for cancer during your mid-twenties, and finding the result to be positive, it may affect future plans of having a family. Some individuals that come from a family

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[11] Nuffield Council on Bioethics, ref. 1, page 24

with high instances of cancer related illnesses may feel that they prefer to know so that they can plan their future accordingly. Others may feel that 'ignorance is bliss' and prefer not to know. The decision of whether to take any sort of genetic screening tests should be left to the discretion of the individual. Education may be necessary here, to inform society of the positive and negative impacts of having genetic screening. Once tests confirm positive for a certain genetic disorder, there is a danger of increasing anxiety and severe depression, which may lead to suicide and other unhealthy social and psychological implications. Genetic screening test counsellors have the duty to inform individuals of the possible implications in having positive results. This should be done in a similar way as getting AIDS testing, so that the individual would be informed of the potential risks involved in undertaking such tests and what implications it may have on insurance, and employment. Although, legally it should be made implicit that information be kept highly confidential at all levels. Perhaps testing could be made in such a way as to remain as anonymous as possible so that the individuals would not have to give any information about themselves. This way, the information can remain confidential without having serious set backs for those taking the tests. Once the tests reveal results that indicate cancer genes, for example, it is up to the individuals on whether they inform their partners, and family members of the result. Consultants, at this point should advice on the best course of action, and recommend that others know the result, so that other family members can also have the opportunity to have the tests.

As genetic screening tests become more wide spread, society may gradually put emphasis on having genetic screening tests. Genetic screening tests are positive in that they can prevent the disease from developing through early prevention treatments. At the same time however, if there is no treatment, people with genetic disorders will have to bear the burden of knowing about their potential future at a very early age. Confidentiality is crucial so that social pressure will not interfere with the persons' decision on their lives. To illustrate, a couple may find that one of them has tested positive for a cancer gene. Without education and confidentiality, society may begin to stigmatise couples that decide to have children despite the results.

Although genetic screening tests have many positive aspects; such as in preventing unnecessary births of infants with severe handicaps who would not have the potential of leading a life worth living, there is an equal number of negative aspects. There is an increasing number of tests that are being introduced. The option of whether to take the tests should be left to the individuals, but recommended only for those that have higher chance of having the genetic disorder. Family history, for example, could be used as an indication for recommending tests. Here again though confidentiality is important. Family practitioners, or gynaecologists can recommend couples planning pregnancies and individuals to take tests, and refer them to genetic screening test sites. Counsellors can then advice them of the pros and cons of taking the test(s). The information to be given by the individuals should be limited, to perhaps the family history only, so that counsellors can advice whether tests are necessary or not.

Parents, depending on the doctors that they consult with, may generally tend to seek the doctors' advice and go along with their recommendation. Social pressure, where healthy, normal children are seen as the norm, may add pressure to the expecting mother and her partner to terminate the pregnancy in the event that the result of the tests indicate abnormalities in the foetus. Socially and morally birth should be recommended and supported compared to abortion, but with strained medical resources, recommendations may be made in favour of terminating the pregnancy. Society is also becoming increasingly demanding on the performance level of children, and the 'perfect baby' may be encouraged and wanted by parents if they were going to have children at all. Families are also becoming nuclear, hence parents may want to have as perfect babies as possible so that the best opportunities of life can be given to them. There is a multitude of reasons that may make termination of pregnancy more easier after an abnormality is detected. As was stressed in the leaflet though, the ultimate decision making has to be made by the expecting mother and her partner, with as little outside influence as possible.

4.4 Gene Therapy

It seems that we have come around full circle concerning our relationship with severely handicapped neonates. In ancient times and till quite recently, handicapped neonates were killed or allowed to die, as they were not seen as economically viable. The same still occurs in developing countries as there are not enough resources to maintain severely handicapped neonates. The developed countries have the resources and technology to encourage the survival of neonates and treat them, but we have reached a point where it has become uneconomical, and also morally wrong to sustain a life that is not worth living. So now we have the technology for selective treatment after the birth of the child, but also before, through foetal diagnosis. Hence in this case, the quality of life judgements are made before birth using medical tests that cannot yet clearly define the severity of the disease or handicap. This poses ethical questions on whether we may be acting a little rashly in aborting foetuses that have been 'detected' as having some abnormalities. If there is genetic testing, then there should also be some level of therapy or engineering that can be used to treat the fault, so that the number of needless abortions can be lowered in the event that abnormalities are detected.

Gene therapy is relatively new in that it has only been in existence for less than a decade. It is the newest form of treatment for rare inherited diseases and common acquired disorders, including cancer, heart disease and the acquired immunodeficiency syndrome. Gene therapy will be the main influence for future medical practice.

There are two types of gene therapy, somatic and germ-line. Both gene therapies are still in the experimental stage as there is little evidence of the clinical efficacy of the them. Yet considerable ethical and emotional debates have been raised. The main concern for gene therapy is that there is genetic manipulation involved. This raises fears for future populations, and gives us visions of having genetically engineered children.

Somatic gene therapy is used in treating a disease within the patient and involves the insertion of genetic material which will replace the genetic material that has failed to operate its function. Germ-line therapy has two ways of functioning. One way is through the insertion of genetic material into the pre-embryo. The aim of this method is to treat the embryo and their future offspring. The second way is to insert the gene into the germ cells of the individuals. The function of this second method has no direct influence on the individuals themselves but it will ensure that their subsequent children will be born with or without certain characteristics[12].

Both therapies will be effective in eliminating severe and not so severe handicaps, and would ensure that all children are born normal and healthy. It may be possible to use somatic gene therapy for severely handicapped neonates, and germ-line therapy for foetuses with abnormalities. This may, in the future, make it possible for all neonates that are born with handicaps to be treated. This is revolutionary in that in the future there would not be any need for neonatal intensive care, but only embryonic care, or pre-pregnancy care for couples that are found to have genetic abnormalities that could be transmitted to their children.

In 1992, the ethical implications of somatic gene therapy, was analysed by the Committee on the Ethics of Gene Therapy (the Clothier Committee). Contrary to the fears expressed in general, the committee did not find gene therapy as being controversial, and 'felt that it gave rise to no new ethical challenges'[13]. Mason and McCall Smith agree that the aims of gene therapy are no different to other forms of treatment, 'provided that they do not involve undue risk to the patient or to others'

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[12] MASON and McCALL SMITH, ref. 2, page 145
[13] Ibid.

and that it is 'ethically as acceptable as is drug therapy or surgical intervention.'[14] Even if somatic gene therapy was used to treat behavioural disorders, ethical considerations will be similar to those that were raised concerning the use of psychotic drugs or psychosurgery.

Somatic gene therapy also has a positive aspect in that it uses the synthetic machinery of the patient's cells to produce therapeutic agents. Since the body will be used in curing its own disease, there will be no need to manufacture highly purified proteins, and repeatedly administer proteins or drugs to the patients[15].

There are more risks and ethical controversy with germ-line therapy as it has the potential of manipulating future generations. The main line of argument in favour of using germ-line therapy is that it would be effective in both eliminating and treating serious genetic disorders from being transmitted on to future generations. This idea of elimination of disease within humans has always been striven for and has been achieved through other forms of treatments and preventive medications. They all have influence on the natural order of thing. Firstly, if we find that eradication of diseases is unethical, we would never have the capacity to live as long as we do today, and secondly, medicine would or should never have existed then! It is natural that we want to find treatments for our ailments.

The main problem with allowing gene therapy lies with the 'slippery slope'. If we allow germ-line therapy to eliminate serious diseases, then where would the limit be placed to prevent the elimination of undesirable genes, such as those that are linked to behavioural characteristics? This problem is clearly outlined in the following quotation from Rifkin in '*Algeny*':

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[14] MASON and McCALL SMITH, ref. 2, page 145

[15] BLAU, H. M. and SPRINGER M. L. Molecular Medicine; Gene Therapy - A novel form of drug delivery. *The New England Journal of Medicine*, Nov. 2, 1995, Vol. 333, No. 18, page 1204

> Once we decide to begin the process of human genetic engineering, there is really no logical place to stop. If diabetes, sickle cell anaemia, and cancer are to be cured by altering the genetic make-up of an individual, why not proceed to other 'disorders': myopia, colour-blindness, left-handedness? Indeed, what is to preclude a society from deciding that a certain skin colour is a disorder?[16]

The fear of having eugenics interfering with gene therapy is indeed frightening. By creating therapy that uses genetic manipulation we also end up having to face other socially harmful consequences. The double effect of this treatment has to be seriously considered so that only benefit can come out of this new and extraordinary means of therapy. The Council of Europe, for example, recognised the dangers and had subsequently formulated that germ cell manipulation should only be used for therapeutic purposes.[17] In Germany, the total outlawing of germ-line therapy was recommended and this was endorsed in a statement from the medical research councils of eleven European states in 1988[18]. There is clearly a need for international policy making, in order to prevent genetic manipulation of future persons, for political or social motives.

The aim of gene therapy should be achieved and recognised as a new form of treatment because of its many positive aspects. Diseases that have been haunting us for generations would finally be eradicated, meaning that there would be less need for painful medical interventions in the future. This would also mean that everyone would have access to the same level of health. There is nothing wrong in this as everyone should have access to a healthy life. The danger of having genetically manipulated people in terms of behaviour or colour of the skin, can be and should strongly be prevented, in order to ensure that people's individuality can be preserved as much as possible. Therefore a clear policy should be drawn in order to ensure that gene therapy is only used for therapeutic purposes.

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[16] RIFKIN, J. Algeny (1983) as quoted by MASON and McCALL SMITH in ref. 2, Page 146

[17] Council of Europe Recommendation 1100 on the *Use of Human Embryos and Foetuses in Scientific Research* (1989), ass cited by MASON and McCALL SMITH, in ref. 2, page 146

[18] DE WACHTER, M. A. M. Ethical Aspects of Human Germ-line Gene Therapy. 7 *Bioethics*, 166, 1993, as cited by MASON and McCALL SMITH, in ref. 2, page 146

At the same time the policy should stress that the right to choose over having gene therapy should be left to the individuals. No individual should be forced into having gene therapy. This may however, become increasingly difficult as social pressure increases to have only 'normal and healthy' children or worse 'perfect' children. There is a trend towards only having normal and healthy children already, but this is no different from ancient times when handicapped neonates were killed at birth because they were not socially acceptable or not economically viable. Despite this trend people should maintain their right of having a choice, so long as they can take responsibility in the caring of their children, even if they are born with severe handicaps. There is also always the option of the children, as they mature, making their own decisions concerning gene therapy, even if the parents did not want it.

Genetic screening has been shown to be the first step in limiting the number of neonates born with severe handicaps or severe diseases. The positive aspect to this, is that the infant and the families will not be exposed to undue stress and pain, because of the unfortunate circumstances that the child was born under. There would naturally be stress and emotional difficulties, for the couple that has decided to abort their foetus, however the best interests of the child has to be considered first. All children should have the right to a normal and healthy existence so that they can lead a worthwhile life.

The difficulty lies with Down's syndrome children, as they have the capacity for leading a life that is worth leading despite its handicaps, because they are endowed with almost all the values as a person including the added quality of having an extremely loving and caring nature. The only way to deal with this problem, is to allow the parents to make the decision of whether to abort a foetus or not, as they have the main responsibility of caring for their child.

4.5 Summary

The negative aspect of present technology in screening is that there is not enough information that would indicate the level of abnormality in a foetus. This presents problems of possibly aborting foetuses that would have had the capacity to lead a life worth living. Worse, the information may be false, due to technical errors in the analysis of the screening tests, and the foetuses may have been normal. These mistakes are unfortunately unavoidable at the moment. We can only hope that the technology of screening tests would quickly improve to the level that would assess the degree of abnormality, so that undue abortions can be prevented.

Gene therapy is a revolutionary treatment that would change and influence future medical treatments. The aims of gene therapy are positive in that it seeks to eradicate common acquired disorders as well as rare inherited diseases, which would in return ensure a healthier population in the future. This form of therapy may also have the possibility of treating severely handicapped neonates, or to treat the abnormality at the pre-embryonic stage, so that unnecessary termination of pregnancies would be avoided.

The main concern, that cannot be stressed enough, is the interference of eugenic motivations that would abuse gene therapy and use it for genetic manipulation in order to change the natural condition of human beings. This may lead to lack of individuality, the eradication of race, colour and behavioural patterns that represent individual characteristics. The only way to prevent abuse of this otherwise positive form of medical therapy is to formulate a strict international policy to ensure that gene therapy would not be misused for genetic manipulation in future populations. Since the risks are high it would be wiser not to develop gene therapy any further, however positive this line of treatment may be, if a demarcation line cannot be held.

Conclusion

Severely handicapped neonates, have been discussed here as having a value of life, as long as they are able to appreciate and enjoy life within their means. Our role, as autonomous persons, is to try to fulfil their aims and appreciate whatever value they have as a potential person. They may never be able to fulfil all the values required as a person, but so long as they are able to recognise love and affection, and derive pleasure from living, it would seem that they have at least the basic values as a person.

When the severity of the neonates' handicap is such that they cannot appreciate life's basic values, the question of whether their existence is worth continuing, becomes crucial. At this point, parents, with the recommendations from doctors must make the painful decision of whether to prolong a life that is not benefiting the neonates, or to allow them to die. This is indeed difficult, and if possible, should be avoided.

Medical advancement, in the form of genetic screening tests and gene therapy, may have come up with a solution. Genetic screening tests have already been developed and are widely implemented in the UK. There are still further developments to be made in this field, such as a more accurate measurement of the severity of the abnormality in the foetus. In the future, genetic screening tests will be offered to everyone and would have a valuable function in preventing severely handicapped neonates. The medical staff will have the duty of informing parents of the likely condition of the child, but the decision of whether to carry the foetus full term, or to have an abortion, should lie with the parents. There are many types of genetic screening tests available, and the decision to take the tests, should also lie with the individual, for their future may be affected by knowing too much.

Gene therapy is an alternative form of treatment, and should be developed and used for severely handicapped neonates and patients that cannot be treated otherwise. Severely handicapped neonates would benefit greatly from this treatment, as it may be possible for their abnormality to be treated through the use of somatic gene therapy or germ-line therapy. Germ-line therapy can however be abused to alter genetic codes in persons. Because this may affect future generations, this form of treatment should be limited to therapeutic uses only. International sanctions is vital so that no country would enter into a 'slippery slope' scenario, and threaten other nations as a result. However, the possibility and advantages of gene therapy are great, and should be utilised in a way that would benefit human kind.

The problem of severely handicapped neonates will continue for a while. Hopefully in the near future, by ensuring that all neonates with abnormalities can be treated, there will not be any need to make painful life or death decisions. This way the neonates will have a chance at enjoying and appreciating life to its fullest.

Appendices

Types of Screening available in the UK:

Chorionic Villus[1] Sampling: A procedure whereby a small sample of chorionic (placental) tissue, which shares the genetic make up of the fetus, is removed for prenatal diagnosis. It is usually performed at about 10 weeks of pregnancy with only minimal discomfort and often allows a genetic diagnosis to be achieved before 12 weeks' of gestation. The obtained cells undergo chromosomal and biochemical studies to determine if any abnormalities are present. This enables the prenatal diagnosis of such congenital disorders as Down's syndrome and thalassaemia[2]. CVS requires first-class ultrasound and an expert and well-trained team. The risks are higher than for aminocentesis: an MRC trial gave 2-4% excess miscarriage risk.[3]

Fetal blood and tissue sampling: Fetal blood sampling is used for a variety of purposes: for example, for the diagnosis of the haemoglobin disorders and haemophilia when DNA diagnosis is not possible, and for the assessment of rhesus haemolytic disease. It can be performed safely only after the seventeenth week of pregnancy and only by experts. The initial, highly specialised technique of fetoscopy has now been replaced by the safer and less specialised technique of ultrasound-guided transabodominal needle puncture of the fetal cord insertion. The risk figure for cordocentesis is 2%.[4]

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[1] Chorionic villus: Function of the villus is to absorb the products of digestion. Chorionic villi are folds of the chorion (the outer membrane surrounding a fetus) from which the fetal part of the placenta is formed. They provide and extensive area for the exchange of oxygen, carbon dioxide, nutrients, and waste products between maternal and fetal blood. (*Oxford Concise Medical Dictionary.* Fourth Edition. Oxford: Oxford University Press, 1996, page 125

[2] Thalassaemia: An abnormality in the protein part of the haemoglobin molecule. The affected red cells cannot function normally, leading to anaemia. Other symptoms include enlargement of the spleen and abnormalities of the bone marrow. Individuals inheriting the disease from both parents are severely affected (*thalassaemia major*), but those inheriting it from only one parent are usually symptom free. Patients with the major disease are treated with repeated blood transfusion. The disease can be detected by prenatal diagnosis. (*Oxford Concise Medical Dictionary.* Fourth Edition. Oxford: Oxford University Press, 1996, page 656

[3] Nuffield Council on Bioethics. *Genetic Screening - Ethical Issues.* June 1996, page 115

[4] Ibid

Rhesus Haemolytic disease and rubella (German measles): Antenatal screening tests are carried out on all women for rhesus haemolytic disease and rubella. Rubella was the first screening programme undertaken with the objective of offering detection and abortion of potentially affected fetuses. Severe congenital disorders can result from rubella infection during pregnancy. Both rhesus and rubella screening appear to be well accepted. Whereas the finding of a rhesus negative blood group results in preventive treatment, a positive rubella test gives rise to the need for very painful decisions.

Insulin dependent diabetes mellitus: The offspring of women with insulin dependent diabetes mellitus have an increased risk of stillbirth, neonatal ill health, and major congenital malformations, especially iof their diabetes is poorly controlled. In many women with diabetes the diagnosis will already be known, but all women are screened early in pregnancy by blood and urine tests to detect undiagnosed cases. Expert fetal anomaly scanning by ultrasound is offered to all those having the condition.

Cystic fibrosis: Pilot studies of screening during pregnancy for carriers for the common disorder cystic fibross are currently being undertaken in a number of centres. In the UK, 85-90% of carriers can be detected by a simple DNA screening test based on a mouthwash sample.

Maternal serum screening: Maternal serum screening tests have been developed that can be offered to all pregnant women to detect those who may be at increased risk of having a child with Down's syndrome regardless of age, in order to offer them the choice of amniocentesis and chromosome testing. This type of screening is now entering widespread practice and it is estimated that nearly 70% of British districts and health boards have opted to introduce such screening. There are, however, major problems. There is a high false positive rate (about 65 false positives for every true positive or about 1 pregnancy in 10) and false negative rate (about 40%).

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