

**THOSE DIFFERENT FROM US:
ETHICAL THOUGHTS ARISING FROM DISABILITY AND
DIFFERENCE**

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DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

ABSTRACT

This assignment grapples with ethical aspects concerning those disabled, 'abnormal', visibly different living in a Procrustean society where to be visibly different is to be marginalised. In the first section, creating narratives, I introduce the reader to *The Elephant Man*, Joseph Merrick. The purpose of this introduction is to create a bond between the reader and the disfigured subject, to give a human face to one who is deformed. In the second section I place Merrick, deformed and disabled, in the *status quo* position of the slippery slope argument: we prohibit the killing of deformed or disabled members of our society. But are there any reasons why this position should be maintained? To answer this question I pivot the arguments of Professor Peter Singer, challenging this position and identify complaints rising from disabled agents concerning his hiring by Princeton University. Because the emotional arguments focus on the claim that if the acceptance of Singer's stance is accepted, then the result will be eugenics, personified in another Holocaust, I explore the eugenics movement. Finally, I conclude that Singer does not advocate the killing of disabled humans who live their lives in accordance to their wishes. Yet, I caution that to avoid the final moral degradation in the emotive form of the slippery slope argument we must realise with Foucault: "My point is not that everything is bad, but that everything is dangerous, which is not the same as being bad. If everything is dangerous, then we always have something to do. So my position leads not to apathy but to a hyper and pessimistic activism."

OPSOMMING

Hierdie opdrag worstel met die etiese aspekte aangaande die kwessie van diegene wat gestremd, abnormaal en sigbaar verskillend lyk, maar wat leef in 'n Procrustiaanse samelewing waar diegene wat duidelik verskillend is, gemarginaliseer word. In die eerste deel van die opdrag stel ek die leser bekend aan die Olifantman (*The Elephant Man*), Joseph Merrick. Die doel van hierdie inleiding is om 'n band te smee tussen die leser en die misvormde (verminkte) subjek, met die doel om 'n menslike gesig te gee aan die misvormde individu. In die tweede deel plaas ek 'n misvormde en gebrekkige Merrick in die status quo posisie van die *slippery slope*-argument, naamlik dat ons die doodmaak van misvormde en gestremde lede van die samelewing verbied. Is daar egter enige redes waarom hierdie posisie gehandhaaf behoort te word? In antwoord op hierdie vraag, fokus ek op die argumente van Peter Singer, daag ek in die proses sy posisie uit en identifiseer klagtes wat na vore gebring is deur gestremde individue, na aanleiding van sy aanstelling by die Universiteit van Princeton. Die emosionele argumente fokus op die aanspraak dat eugenetika of rasverbetering die gevolg sal wees indien Singer se posisie aanvaar word. In die lig van hierdie argumente ondersoek ek dus die eugenetiese beweging. My gevolgtrekking is dat Singer nie voorstel dat gestremde mense wat hulle lewe volgens hulle eie wense lewe, doodgemaak word nie. Om egter die finale morele degradasie, in die emotiewe vorm van die *slippery slope*-argument, te vermy, moet ons saam met Foucault besef: *"My point is not that everything is bad, but that everything is dangerous, which is not the same as being bad. If everything is dangerous, then we always have something to do. So my position leads not to apathy but to a hyper and pessimistic activism."*

Dedication

To 'Joum', most excellent husband, my *eudaimonia*
and remembering
Alberta Esther van Bogaert, 'Alli'
1992-1999
our dog-person, dearly loved.

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SECTION ONE

VISIBLE DIFFERENCE

INTRODUCTION

“Finally, between Eleusis and Athens, Theseus met the brigand Procrustes who possessed a hammer, a saw and a bed. He compelled travellers to lie on the bed, and those who were too long for it he would cut down to size those who were too short he would hammer out until they fit it exactly. He too perished at Theseus’ hand in the way he had killed his victims”.

-Morford and Learndon: 1996: 459

Procrustes, conjectured by Donley and Buckley (1996:1) serves as the exemplary ‘tyrant of the normal’ (Fielder: 1978: 2)- fitting people into societal standards of the body normal. However, in the example of Procrustes there is only one type of enforcement of ‘normalcy’, namely that of height. Yet, the differences in people categorised as ‘disabled’ are as vast as the differences in the type of social, physical and psychological handicaps they have. And the differences in the type of handicap reflects conversely on the way in which society evokes its response to them, and thus, effects their responses to society. In addition, particular societies, in particular historical periods may also evoke distinctive patterning. It seems that we, (who are relatively ‘normal’) even close to the twenty-first century, seem to have a need to see ugly ducklings transformed into beautiful swans and wrinkled toads become smooth and dashing princes. In fact, we seem to believe that such ‘deviants’ should somehow make these changes, and if they cannot be made our tendency is to cast them out.

We can cast out *afflictions* through a variety of means as the human genome project brings with it, among other things, the ability to make abnormal people more like us, to ‘fix’ abnormal genes, to elicit genetic engineering, growth hormones, in-utero surgery and so on. Our ability to make people convenient to societal standards is far ahead of our contemplating about who decides what is abnormal and what is normal, who decides whether normalising is the best thing to do, who has the right and authority to make any of the possible changes and, of course, financial boundaries.

Society works as a tool controlling human differences and change occurs in response to the biomedical technology available plus cultural wishes, values and desires. With advanced technologies come additional ethical issues. For example, biotechnology gives us the opportunity of knowing if a fetus is abnormal, and we can opt to have or not have an abortion, raising a spectrum of ethical issues. Adding more complications

to the (already complicated) issue of abortion, insurance companies may threaten to refuse to pay for care if an infant is born with a known abnormal ‘pre-existing’ condition (Donley and Buckley: 1996: xi). Those infants who slip through the industrialised technological network and by chance are born defective also present us with choices. For those born with birth defects of such an extent that they are not expected to live (with even the most aggressive and sophisticated interventions) the probable quality of their lives is assessed and basically two moral options are argued: use all available means to keep them alive, or let them die painlessly (Kluge: 1998:242-249). Infants born with relatively ‘minor’ defects (‘relatively’ and ‘minor’ being entirely subjective) present their own ethical sets of questions. The idea of a disabled infant, ‘socially nonviable’ also relies largely upon historically variable values as opposed to technological precepts only. Factors involved in decision making concerning ‘adjustments’ may include family and individual demands for services, the desire to prevent people from being unproductive ‘drains’ on society, or working in a general perceived mandate to ‘protect the aesthetic standards of the culture’.

WRITING THE FACE OF DIFFERENCE

How does one write the grossly disfigured face, the deformed body, and the bearer of Visible Difference? As Edgerton (1973:124) writes, “ There is no simple equation that exists for calculating the impact of the outer man on the inner; or the impact of a deformed body upon soul, no matter how such concepts might or ought to be used in modern medicine.” Indeed, in calculating the impact of the outer man on the inner there is also a complex correlation between what one desires to say and the selection of a genre or form in which to say it. In writing traditional ethical textbooks, for example, a current popular genre is the case study.

Case studies are of course adaptations of narrative form. Through exploring case studies, case discussions and case methods, it is argued that the reader best learns in general how to connect insights to “appropriate sets of concepts, principles, and theories that control the selection and analysis of cases”(Beauchamp and Childress: 1994: 99). To use other forms, such as those ‘literary’ in the teaching of ethics, some philosophers argue results in an unwelcome situation where *the* ethical point is obscured. After all, the exercise is to argue clearly, consistently, logically, and well one’s *point*. To illustrate this, let us look at the format of many case studies used:

Mr X., institutionalised, is severely disabled to the extent that he cannot even sleep in a supine position. He is aware that if he lies in this position he will die. He asked, and was informed by his physician that there is no cure for his disease. One day he is found dead on his bed, in a supine position. No foul play is indicated.

From this case study, we could argue points such as allocation of resources, asking should or should not society bear the cost of maintaining severely handicapped persons. Or we could raise the issue of competence (making reference to classic cases such as *Cruzen* and *Casey*, for our case studies are, by and large, contextually placed in wealthy industrialised democratic societies with legal and health care infrastructures well in place). In considering the ethical aspects of competence, we would ask if the physician carefully justified the many values used in determining competence. Perhaps we could also discuss if the physician should have referred Mr. X. for psychiatric evaluation as possibly suicidal. Considering suicide, we could argue pro or con the moral justifiability of suicide, tracing the arguments for, example from Seneca (4 -65 CE) to contemporary times. The list is not meant to be exhaustive.

While there are both positive and negative arguments concerning the use of case studies in the teaching of ethics (Banks: 1996:76), the objective of this paper is not to repudiate or discredit their use. From the simple format of case studies, ethical topics may be easy to extrapolate. And certainly, there are certain advantages to clinging to straight clear case studies: they remove us from the messy world of complexity and allow us to detach- to live in a world simpler, logical, and deducible.

Yet, I always seem to feel that there is something missing. Indeed, many case studies appear out of touch when faced with applying ethics on the ground level. What is missing, is the complex and very human face of medicine's sub-text, a suffering patient who demands expression. Am I arguing that case studies should be tossed out of ethical teaching? No, for there is a legitimate place for them. My suggestion is that creative forms such as literature, art, film, and dance add special and broader dimensions to the teaching of ethics and their use should be added to teaching curriculum. At the same time, in a class room situation, I suggest that if a literary work is read alone (a film viewed alone, an artwork viewed alone), then these

parameters may thwart the mutuality and exchanges necessary to enhance the philosophical conversation (Nussbaum: 1990: 240).

With Nussbaum (ibid: 3), I agree that very often the expression of humanity, the face of humanity cannot be identified within the “expositional structure conventional to philosophy”, but may better be articulated through a good story: a story that holds the power to awaken us to the humanity in others and the humanity in ourselves, so that the ideological difference between ‘them’ and ‘us’ becomes unimportant.

SCOPE OF THIS SECTION

In the first section of this paper, I will demonstrate that art forms, such as literature, open the traditional boundaries of ethics allowing the reader to engage in a broader ethical understanding. Emphasised is a particular priority granted to agents, actions, and the role of emotions in deliberations and self-knowledge (Nussbaum: 1990: 3). I suggest that narrative drama is an interesting and viable addition to the use of case studies and in this commentary as a whole, argue a case for literature as a healing art.

“There are stories”, write Graham and Oehlschlaeger (1992:1) “so compelling that they resist closure, so richly suggestive that they defy containment.” Such stories persist and change independent of the individuals that have lived their reality or contrived their fictions. Indeed, although they may inspire enduring poetry, prose, music and art their own durability has comparatively little to do with the particular works presenting them. These stories live on in us probably because we read ourselves in them, in both crooked and straight ways. The ‘truths’ they proclaim and the situations they prospect are primordial, but each new age, each new interpretation adds facts and figures, and variants to the archetypal catalogue. The evidence for such a claim is that, having pierced the bounds of fiction or fact, they proceed to evolve and inspire, to recreate themselves in a diversity of modes.

Such is the story of *The Elephant Man*, the tale of Joseph Carey Merrick. It is the telling of a *self* imprisoned in a body being continuously and grotesquely remade through a cause neither he nor medical experts at the time could neither contain nor comprehend. Yet, he faced daily what every human being in any time growing old or infirmed, permanently maimed or disfigured faces: the exclusion from the world of those healthy and ‘normal’. His personal dilemma, of whether to accept his blighted body as an attribute of his personal identity or reject it as a misleading masquerade, remains the same of those disabled in today’s world. Like Merrick, those who suffer visible difference articulate painful questions of cause and effect, personal guilt or the cruelty of the cosmos.

People with disabilities, as Robert Murphy (1995:140-158) explains, suffer a “contamination of identity”. Their conditions are understood to be embedded within the very fabric of their physical and moral personhood. The reflections of their

disability are mirrored in the eyes of society by situating the disabled person apart, as one who harbours more than just a physical / cognitive limitation or difference. It infuses every aspect of his or her social being and creates a tautological link between biology and self that cannot be unmoored. Living in the physical world provides the material evidence of an inner life (polluted or virtuous) that remains fastened by the imprint of visible difference. Present within the many writings concerning people born with or having acquired defects, and particularly present within those disabled writers, repeatedly rises the fear of total societal exclusion (Donley & Buckley: 1996).

Using the genre of literature as a vehicle, in this section I re-interpret interpretations and create anew a dialogue of some ethical considerations rising when interacting with those visibly different. I use the example of Joseph Carey Merrick, son of Joseph Rockley Merrick, Warehouseman, and Mary Jane Merrick, née Potterton, born in Leicester UK, August 5, 1862 (Howell & Ford: 1980), known in plays, songs, narratives, poetry, medical digests, films and art as, "*The Elephant Man*".

It is the purpose of this section to show that disease, deformity and even identity are in part social constructs, mutable expressions of cultural and personal values. *The Elephant Man*, in literature, shows deep mythic truths, a story incredibly familiar that underpins many of our most enduring questions: Who are we? Where did we come from? Why are we here? What is it to be 'human'?

MENS SANA IN CORPORE SANO-Juvenal, 1st Century AD

From the time of the ancient Greeks, the aesthetic body corporeal was of great importance. Plato, in *Symposium* 201 (63:93-98) says, “ The deformed is always inharmonious with the divine and the beautiful harmonious...for (man) in deformity will beget nothing and naturally embraces the beautiful rather than the deformed body above all as he finds there a fair and noble and well-nourished soul. ” Further, Plato concludes, that the ascension of the soul could be hampered if constrained within a weak physical body or a congenital defect.

The Romans carried with them similar thoughts believing, as Cicero put it “ It matters greatly to the soul by what sort of body it is placed; for there are many conditions of the body that sharpen the mind, and many that blunt it” (Cicero, quoted in Carey: 1989: 261). The presence of deformity and its relation to Godliness also was a concern of the early church. It was debated hotly whether deformed individuals were capable of resurrection and, as St. Anthony put it, even possessed “reasonable souls”. St. Gregory took this position further saying that deformities must be understood as “sins”- *contra naturam*. He took a stand and forbid those deformed to become members of the clergy because “ a man who is ravaged by his own sins, cannot expiate the sins of others ” (Carey: 1996: 31).

Those ordinary deformed people, who by chance survived the then common practice of infanticide, were denied the sacraments. The point is, holiness was equated with those beautiful; God was not to be defiled by those with corporeal imperfections, no matter how sincerely they might profess their faith. Such arguments with their implicit and explicit assumptions about the aesthetic body centre around the image of God and man- *imago Dei et hominis*- as the earlier assumptions focused on the soul’s or character’s relationship to a comely body.

In 18th century England the traditionally “reliable church as an immensely powerful ideological form was in big trouble” (Eagleton: 1994:44). Attendance waned and as the masses turned from the church there evolved a subtle (but not entirely erased) shift from the emphasis of deformity being considered a ‘sin’ on the part of the mother or the deformed child to deformity as a consequence of maternal imagination. Interest in

monstrosities has been present throughout all human history. Its fevered pitch was perhaps most evident throughout the 17th and 18th centuries in England. “From the highest to the lowest” the English were so “fond of sights and monsters, and liberal in rewarding those who *shew* them” (Todd: 1995:5). The particularly enthusiastic response to those monstrous, according to Todd (*ibid*: 107) was grounded in the unsettled nature of the Victorian notion of self-identity: “muddled in uncertainties and vexations largely because people feared their bodies excised a prominent but infinite power, one that called into question the integrity of the self”.

BRIEFLY, HISTORICAL FACTS OF MERRICK'S LIFE UP TO THE TIME OF HIS REUNION WITH MR. TREVES

From birth Joseph Merrick's head, right arm and feet were larger than normal. As a child, much of his skin became thickened, loose, and rough and, according to his family, at the age of about one and a half years, Merrick began to develop tumours (Montagu: 1971: 110). In spite of these afflictions, Merrick was schooled until the age of twelve (Graham and Oehlschlaeger: 1992:158). Joseph's mother gave 'Carey' as a middle name. She did this to honour a famous Baptist missionary, William Carey (1761-1834), who influenced greatly her life. Merrick was also a devoted Christian. After difficulties faced with employment because of his deformities (*ibid*: 159), he worked for his father delivering coal, in a cigar factory, and as a hawker to the lower working class area called Whitechapel-road, London.

Following the death of his mother from bronchopneumonia on May 19, 1873, his father remarried his landlady (Howell and Ford: 1980:113). After Merrick's disabilities became too pronounced his relationship with both father and stepmother deteriorated, as he was no longer able to assist the family (Graham and Oehlschlaeger: 1992: 158). He entered one of London's institutions, the Leicester Union Workhouse (Howell and Ford: 1980: 89). In the Workhouse his worsening condition and the problems encountered with 'normal' others became so pronounced that Merrick initiated contact with a “vendor of curiosities”, Mr. Sam Toor (*ibid*: 169).

He was exhibited throughout London, as well as in Whitechapel-road where he lived in a ‘small room warmed only with a brick heated by a lamp’ (*ibid*: 105). It was in this small room, painted primitively with scenes of jungles and exoticism that Mr. Treves,

a then young surgeon attached to London Hospital, first met “The Elephant Man”, Joseph Merrick. Following his first private exhibition to Treves, he was engaged by him to be exhibited as a ‘case’ to the London Pathological Society on December 2, 1884. The medical establishment wrote articles concerning his condition published in the *British Medical Journal* (Montagu: 1971: appendices 1-8). Although Treves hoped Merrick to be an imbecile, Merrick proved him wrong. A relationship was established between the two men then they parted company. In the following two years, Merrick toured as a spectacle with a variety of ‘freak’ shows in England and the Continent. In Belgium he was robbed of his savings by his Austrian manager, had a most difficult passage but finally returned to London. It was at this juncture that the two men met again.

From this point, I add a creative edition to the story of Joseph Carey Merrick, incorporating some aspects of near-millennium medical ethical issues concerning people not like us, those visibly different.

MERRICK RETURNS TO LONDON

“No!” he cried. “I am not an elephant! I am not a beast! I am a human being! I- am- a- man! I AM A MAN!” It was as if his scream of self-articulation drained him of his last resources, for Merrick then collapsed, sobbing against the urinal’s walls of London’s Liverpool Street Station. The crowd remained, still fevered by the race to ritualistically purify their now-polluted world. Take away the unholy, the contaminated, and the abominations; excise this intruder from our sanctuary of normalcy. Destroy such monstrous antagonists who cause us to question our society, and our very concept of self. What we cannot name, we cannot own. What we cannot comprehend, we must destroy.

Yet, from the mulling crowd, a woman ¹ walked towards Merrick, bent and placed a hand on his shoulder. “Card, pocket”, said Merrick. However, the woman could not understand his words as Merrick’s speech was slurred from both exhaustion and his physical condition. “Again, say the words again,” ² said the woman. “Card, there” Merrick said slowly, gesturing to his pocket painfully with his functioning left arm. The visiting card, dirty and much-thumbed, was retrieved and read: “*Mr. Frederick Treves, Surgeon. Rooms: London Hospital*”.

“This card, dear God” Treves uttered when it was delivered. “It has been two years since I last saw him.” It took Treves twenty minutes to reach London Station. Rushing, pushing, flaying his arms through the crowd he screamed, “Move on, out of the way, clear away” until he stood, gowned still in his black surgical coat stiff with blood, in front of the collapsed shrouded figure. Treves went down to the floor, his back to the now dwindling crowd. “Help me by holding his shoulders” he said to the woman, “while I raise his head”. This was done. It was as if time had stopped and another world was entered. No noise. No people. No time. “John”, he said quietly. “Mr. Treves, Mr. Treves” Joseph sobbed. The woman said, “Do you know him?” “Yes,” said Treves with tears flowing, “I know him well, he is my friend.” “Then I take my leave” she said and faded from view.

SANCTUARY

A temporary place was found in the overcrowded London general hospital for Merrick. Mr. F. C. Carr Gomm, the hospital Chairman made a public appeal for Merrick's support in the *London Times* published December 4, 1886 (Montagu: 1971: 58). This was because repeated requests to the hospital board for his accommodation was to no avail.

In his letter, Carr Gomm urges to public the support separate quarters from Merrick in hospital because, "his appearance is so dreadful that he is unable to come out by daylight to the garden... is such that all shrink from him...he cannot, in all justice to others, be put in the general ward of a workhouse, and from such, even if possible, he shrinks with the greatest horror" (ibid: 59).

Carr Gomm, according to authors Graham and Oehlschlaeger (1992: 19) was the first interpreter of Merrick to describe some of the paradoxes that have become staples in the subsequent reinterpretations of Merrick's story. Such paradoxes appear as: despite the terror he produces in being seen by others ("particularly women and nervous persons who fly in terror of him" [Montagu: 1971: 60]) he is "superior in intelligence can read and write, is quiet, gentle, not to say even refined in his mind"(ibid). While he shrinks from others, others shrink from him; while he must be protected from others, others must be protected from him.

Merrick's hobby or habit of making cardboard models with his one functioning hand and sending them to those who had shown kindness to him (Graham and Oehlschlaeger: 1992: 19) was also explained by Carr Gomm: industry and benevolence persist against great odds. Merrick, so presented, is blameless of his responsibility for being deformed and is described "as a case of singular affliction brought about through no fault of himself" (ibid: 20). Carr Gomm was the first to present Merrick's condition as worthy of charity based on a theological appeal. He wrote:

"The Master of the Temple on Advent Sunday preached an eloquent sermon on the subject of our Master's answer to the question, 'Who did sin, the man or his parents that he was born blind?' "(ibid: 61) showing why the Creator, in permitting a man to be born to a life of hopelessness and misery, was that the

works of God should be manifested in evoking the sympathy and kindly aid of those on whom such a heavy cross is not laid (ibid). In the passage quoted (John 9: 1-3) Jesus answers, “ Neither has this man sinned, nor his parents”, and implies the separation of sin from disease, the timeless custom of equating illness or deformity with divine punishment. Carr Gomm’s theology shifts the freeing sense of the text and releases both Merrick and his parents, particularly his mother, from responsibility for Merrick’s disorder. In the same way, in a sense, Merrick’s story of his mother being struck down by an elephant while pregnant ³ frees both from responsibility. In addition, Carr Gomm establishes a different polarity between subject and object- those who give through charity and those who receive it (Graham and Oehlschlaeger: 1992:20).

The appeal of Carr Gomm proved fruitful and Merrick became a permanent resident of London Hospital. He was described as a person of great kindness, and imagination. Safely secluded from the world, Merrick was able to indulge in his particular loves: the theatre and reading. He became a Victorian *cause célèbre* and was visited by many (for various motives ⁴) including the theatre’s toast Mr. Kendal and royal personages such as the Princess of Wales and Edward VII. Yet, Treves remained his most constant companion, visiting him daily. Merrick’s hobby, that of cardboard construction of models persisted, the most famous being the construction of St. Phillip’s cathedral, seen from his window (and a central metaphor in many interpretations of Merrick’s life [Pomerance: 1979]). We return to the room where Merrick and Treves are in conversation while working together on the construction of his latest model, a mountain.

SOCRATES, MEN AND THE MAKING OF A MOUNTAIN.

“I have been reading about philosophy and medicine and the birth of children, Mr. Treves”, said Merrick. “Wherever do you get such books?” asked Treves, his walrus moustache quivering. (And thinking, concerning children, how difficult it was to realise that Merrick, despite of his appearance, was a normal man, with normal sexual desires and just might imagine having a family. ⁵) “From the library of Mr. Carr Gomm,” replied Merrick “he lets me take from it whatever I wish.” “I see”, said Treves (thinking how utterly irresponsible it was of Mr. Carr Gomm to allow someone with no medical knowledge or philosophical background access to things they could not comprehend! ⁶) and what did you learn? “First, I learned that I have many questions to ask and no answers and secondly, I think everything we do seems to be relative to the time in which we live,” replied Merrick.

“Explain and ask as you will, and do hand me that square piece over there, this mountain isn’t well shaped, with all these crags and chocks it looks like a jutting slope” said Treves. Merrick thought for a few moments and while glue and cardboard were arranged and re-arranged, began to speak. “The ancient Greeks, or perhaps the noble in their society tried not just to live, but to achieve a life in which beauty, honour and excellence were exemplified.”

“Yes, that’s true,” said Treves, “best said by Socrates, ‘The unexamined life is not worth living’.” ⁷ “Well, Mr. Treves, did he mean that every life and death situation should be examined? Because he gives a criterion, but he doesn’t say to whom it applies- I mean, to whom a certain life might not be worth living.” “Oh dear,” thought Treves, “he does come up with questions!” “I’m not a philosopher” replied Treves, “but perhaps Socrates meant that to him, or to all philosophers, that an unexamined life is not worth living. That would mean that he would rather die than give up his inquiry, which as you know, he did, John.” “Yes, I considered that, but could it also mean that to force a person to live a life of inquiry makes such a life more satisfactory to Socrates himself, or if not to Socrates, to that of someone else, or society or the gods? Or perhaps if a life is not examined, then could that life be taken or lost without any grief we ought to feel, or even some punishment we might require for the death of non- inquiries into it?”

“Those are indeed interpretations”, said Treves (a bit confused), “but John, to the point, what is it about the question that bothers you so? Are you examining your life? What have you been overhearing when you take your evening promenade in the garden?” “Much the same as I have heard all my life” said Merrick sadly, “that it would have been better if I had not been born...that I should have been left to die at the time of my birth...that I am an abomination. I even remember you, Mr. Treves, saying the first time we met that you hoped I was an imbecile for if I was an imbecile then you could carry on your life never to consider me again. What did you mean by that?”⁸

“Oh, John”, said Treves after a long delay, “It was just that you look so, er, your looks, your condition is so different- I and all my colleagues didn’t and still don’t know why you have this disease or how it works. (He stumbles over his words) I am a doctor, dedicated to curing ills, the challenge of things I do not know, things I can’t control⁹, I...”

Merrick interrupts, “Mr. Treves, say it, my body is grotesque but on that body alone you made certain assumptions -that I must be backward, stupid or evil. You decided that my life was one of pain and misery, you felt, and I believe I know you know well enough to say, that it would have been best if I did not have a mind to think and dreams and imagination-best, that I would not be aware of how I look- of the things people do and said to me, maybe better if I had not been allowed to live.”

“But”, he muses, “were your remarks meant as kindness? My life, as a ‘freak’, you must have compared to yours as a ‘normal’ and could not envision that within such a carcass there could be a person, what type of life that person has, and what that person thinks about the quality of his or her own life. I think you saw me as a species of *Homo sapiens*, but not as a person capable of physical sensibility or some level of awareness. But, you didn’t really look, Mr. Treves, because if you had, on the day that you showed me to the other doctors and students, you said ‘turn’ and I turned. You said ‘left’ and I turned left. You told me to strip so everyone could see that my genitals are ‘normal’. I stripped, and everyone saw. Could an ‘imbecile’ do that Mr. Treves? I understood. I understand.”

“For the first time since we have become friends, I sense you are angry with me,” said Treves, “perhaps it is justified, but listen to my side.” Merrick interjects, “Oh, no, Mr. Treves, I could never be angry with you, I have never been so happy,¹⁰ I...”

“When I first saw you, I was filled with compassion. I thought your life must be one of misery. Doctors can’t be expected to really know their patients, if we did, we’d lose all subjectivity. But I must also tell you (with shame), finding you also helped my career- exhibiting you to colleagues and students, describing as I did each growth on your body, each disfiguration, offering suggestions, possible diagnosis, well, I felt rather important, to say the least. I needed you to confirm me as bounded, belonging to the ‘proper’ social category; John, you confirm the pleasures and boundaries of my own identity. I could dismiss you as hopefully an imbecile because you served your purpose. You reassured me of my own integrity of the received images of my self. Yet, afterwards two people forced me to introspect, to examine part of myself, to compare my exhibition of you to his exhibition of you in the common freak shows, which I find so horrible and degrading. Then I had to ask myself why I found those shows so distasteful and saw nothing wrong in doing essentially the same only in a different, more refined and (to me) a socially ‘meaningful’ venue. I, like Socrates, was called to not only examine my life, but to examine the *self* in my life. Perhaps that’s what he meant after all.”

“Mr. Treves,” Merrick said softly after a pause for thought, “I never meant to cause you pain. Now you add to my burden. “John,” Treves replied “Knowing you has brought me no burden, it has made me see you as other and my own face within that vision”¹¹. I have failed you though for never in all of our time together have I asked you how you felt, if you felt your life is worth living”. “My friend,” said Merrick, “the unexamined life...whose life is it anyway? People who are not deformed rarely asked that question to those deformed.”

A knock on the door disrupts them. “Good evening Gentlemen. You two are looking particularly sombre, nothing amiss I hope,” Mr. Carr Gomm said as he entered the room. The two men rise to greet him. “Oh, I see you’re working on a mountain, may I join you? It looks a bit crooked.” “Sir, you would be most welcome,” said Treves.

“Now why such faces?” “Well, Sir, ” said Treves, “we were just discussing Socrates, and a bit of reality.” “Socrates”, Carr Gomm replied, “ now there was a mind inside a rather unpleasant body, so I’ve read”. “What!” exclaimed Merrick, I assumed he was very handsome, his writings are very handsome.” “Writings and the bodily appearance of those who write are not always or necessarily compatible,” Carr Gomm replied. “If I recall correctly, it was Lavater and Montaigne’s essays ¹² that expressed the view that from a man’s outward appearance the qualities of his soul could be deduced. Of course, that was really nothing new, ‘had gone on since man had first started to ask questions. Of course, we don’t generally believe in such things, although I do recall that even Goethe admired Montaigne’s thoughts on physiognomy. Do hand me some glue, will you, Treves, you need some assistance with that side of the mountain, as it is it will never do. Now Montaigne, who was very into appearance and its relationship to soul, was particularly troubled by Socrates’s appearance. In fact, Socrates put a cog in his wheel, so to speak. I believe Montaigne said something like this, ‘It grieves me that Socrates, who was a perfect pattern of all great qualities should, as reports say, had so ugly a face and body, so out of keeping with the beauty of his soul, seeing how deeply he was enamoured of beauty, how infatuated he was by it! Nature did him an injustice!’ ”¹³

“Like me”, thought Merrick. Then he said, “But how did Socrates feel about himself, how did others react to him?” “He wrote,” Carr Gomm continued, “that young men should look in a mirror to determine their appearance. If they were handsome, they should act virtuously so as to be worthy of their beauty; if ugly they should conceal their appearance by their moral accomplishments. ¹⁴” “So, it’s the mind and deeds that should measure man, not the external body”, said Merrick happily. “I have always thought so myself. ¹⁵ But knowing it in my head doesn’t always help when I see the reaction to my body mirrored in the eyes of others.” He sighs, “At least Narcissus was alone when he admired his perfection. I am defined by the whole society in their reaction to me- nothing protects me from their mirror.”

“What do you wish for, John? asked Treves quietly. Merrick paused and answered, “Only to melt into a crowd or walk into a room unnoticed. I always worry when visitors come, so I try to keep my ‘good’ side facing them. Sometimes I know they do not understand what I say because I know my speech is afflicted. But they pretend to

understand. I wish they would just say, 'please say the words again, we want to understand what you are saying.' And when their eyes meet, or they make some gestures between themselves they think I don't notice- but I do ¹⁶. Then I get a wave of sadness and it makes me feel more deformed. Sometimes I wish they would all disappear."

"Would it be better for you, John, to stop the visitors? asked Treves. " I had never considered that, " added Carr Gomm worriedly.

"Oh no, please know, I do understand that in the eyes of others everyone looks for the reason for their own existence. This is the measure by which we each judge our own self-worth. But know this, my friends, universal approval or even acceptance of deformity is far less important than what I have found to be of the greatest value - the consistent love and friendship of a few." ¹⁷

After an awkward silence (while the men busily add bits and pieces to the shaping mountain) Carr Gomm says, "It seems you have been examining your life, Joseph, and indeed in consideration of this topic alone, we who are approximately normal should also do the same, for we rarely think of what it would be like to have fate change that which we have so blithely taken for granted. And on that note, I must bid you both adieu, off to the Club. Goodnight, Gentlemen." Both men rise, bidding Mr. Carr Gomm, "Goodnight, sleep well. "

"John", said Treves as he placed his hand on his shoulder, "I too must be off. So, until tomorrow when we resume our discussion I bid you sleep in peace. I will think on the many things we discussed tonight." "Goodnight, my friend," said Merrick looking at the still unfinished mountain. "On that slope I'll add trees and brush and flowers, perhaps a goat or sheep and a cottage. Then we'll build up the other side."

THREE DREAMS: A CONFUSED AND COMPLEX HEAP OF HUMANS

“Will you be staying the night, Sir,” asked the Club’s butler. “Yes”, said Carr Gomm sipping his brandy. “I’ll be up shortly.” “Very Good, Sir” said the butler as he walked out of the lounge. Later, in his room, Carr Gomm, now bathed and gowned in white stiff cotton, reached for the book he had been reading: *The Poetry of William Wordsworth*. Oddly, the book opened up to a poem titled “*The Thorn*”¹⁸ He read for a while and felt somewhat disturbed. Placing the book back on his bed-table, he closed the lamp and, turning on his side, flounced the pillow, sighed, and quickly fell asleep.

THE FIRST DREAM RAISES THORNY QUESTIONS

“I am as old as time itself, stated Thorn, and I have seen and heard from the lichens¹⁹ things both wonderful and terrible. I externalise invisible impulses and create order. Martha Ray comes here to weep and each tear tells its own story. Pomegranate skin, Rue, and Queen Anne’s Lace she drank, to no avail, to expel what she and Stephen begot.²⁰ It has always been so and always will. The weights of the act, the consequences, are borne heavily on the backs of women. From the most ancient times, we plants have been used to remove the unwanted. I think of Silphium, my old friend, long dead, rendered extinct because of her very potency. Was that in the third or fourth century CE? Never mind, but used she was, from slaves to queens.

Of course, some societies did have laws against contraception and abortion. Babylon and Syria, if I recall correctly. They had reasons of course, namely to increase their numbers, to gain more power. But the Greeks and Romans considered contraception and abortion as crimes only if the father objected, the concept of murder being considered only if the man was deprived of a male heir²¹, that is. Of course, the advent of Christianity shifted some focal points, but God remained wholly male: made like man, not woman. Therefore, societal decisions concerning contraception and abortion remained in the hands of men. The very earliest Roman Catholic Church accepted the norms of their particular societies, so abortion and contraception weren’t sins in and of themselves, after all, during those times there wasn’t much debate about ‘souls’. That all changed, of course all based on Aristotle, taken over by Aquinas.²² I believe he somehow deduced that males were ‘ensouled’ after 40 days after

conception, 90 days for females: women of course weren't part of the original creative idea, just second thoughts brought in as an appendage to men. So it has remained.

Infanticide? Equally long in historical practice, similarly linked; a way of controlling population, perhaps a causal link to puerperal madness, getting rid of the unwanted: when it was the norm, the general practice, there was no question of morality. I recall reading in one of Martha's tears a letter written by a Roman soldier to his pregnant wife: 'if it is a male keep it; if a female, expose it.'²³ Now, of course Constantine who converted to Christianity in 300 CE raised the question of infanticide as, shall we say, a social issue. He banned parental infanticide from his empire, but note: it was parental infanticide that was banned. This created a shift in responsibility from the family to others, such as birth attendants, so generally his call for the recognition of life's sanctity didn't work out well in the long run. Napoleon, much, much later, tried to curb the practice as well. He even evoked the law, charging any convicted of drowning an infant in a sack 24 francs. Napoleon started foundling hospitals, complete with turnstiles where the unwanted could be placed, revolved, and institutionalised. If my memory serves me correctly, it is estimated that in 1833 - 20 to 30% of all new-borns of that year were discarded.²⁴

Societies, throughout history have shown that whatever the shifting of a status quo position, be it contraception, abortion or infanticide, did not result in a causal chain reaction throwing everyone into the River Charon. Issues rise and fall, historically and culturally contingent, but one issue does not necessarily, logically or causally slide to moral disintegration. Within their own society, the ancient Greeks, for example, did not move from contraception to abortion to infanticide to the killing of toddlers, to killing children and so on.

Those born defective? From ancient times to even today, they were immediately cast to the garbage heap, or returned, as practised in some African tribes, to the feeding-ground of the animal they most closely resembled.²⁵ If they by chance survived, as dwarfs and giants, hermaphrodites or ogres, society made use of them, for good or evil. Of course, women were to blame for their appearance, for their very being. Whenever have you read that 'He' (or 'they') begot a monster? What have women been taught? Two reasons for their existence: sensual submission to man and the

bearing of children. These were the two reasons for her creation, and should woman fail in either she has no further excuse for encumbering the earth. Giving birth to monsters only confirmed what was suspected, the terrible duality of women. Men consider the great imaginative faculties of women to be the cause of monsters, as you well know, Carr Gomm.

A muddled Carr Gomm interjects:

Whatever are you talking about? Where is this going? How did you know I was here?

Thorn:

Well obviously, it is your dream after all- you're creating it, so you're here.

Carr Gomm:

And I don't like it one bit. Everything is flashing by and mixing up in my mind, my very principles are being jumbled!

Thorn:

But everything you know, everything you've experienced and read and seen are all here. Really, there's nothing new, just re-arrangements, that's all.

Carr Gomm:

It's that poem, "... I've heard the moss is spotted red. With drops of that poor infant's blood; but kill a new-born infant thus, I do not think she could...Oh misery, oh misery." ²⁶

Thorn:

What is it about the poem that disturbs you so?

Carr Gomm (irritably):

It's all the questions, of course. Did she give birth? Was the baby born a person, a human being? ²⁷ Was the baby born dead? If it was born alive, did she murder it? What does it mean to be human being? If it was born alive, how did it look? Was it a monster? If it was a monster, was it still a person? ²⁸ Was it...was it...

Thorn:

Like an Elephant? Was it deformed? If the baby was born alive and well formed, would it have been wrong to kill it?

Carr Gomm:

Thorn, you're going too fast! There are too many questions and too few answers.

Thorn:

All right, then, just answer the last one. If Martha Ray's baby was born well formed and alive would it be morally wrong to kill it?

Carr Gomm:

Yes.

Thorn:

Even though Martha is mad, poor, and single?

Carr Gomm:

Yes.

Thorn:

What kind of life would the child have being raised by a mad woman, cast out from society, single and alone?

Carr Gomm:

Well, I...

Thorn:

Perhaps imagine them living in Whitechapel Market, you pass by there often, "infinitely various lines and contrivances of shops and stalls and gaudy inns and public houses; the overhanging clothes, the mounds of vegetables, the confused heaps of fish, all cast about to catch the pence of the bountiless dishevelled women...shoeless children...leering thin-handed thief, the bully of his court, the silly-Billy of the neighbourhood- on whom the neighbourhood is merciless- endless swarms of ragged children, fill road and pavement." ²⁹ Is that what bothers you? Their quality of life? Whose quality? Whose life? Moreover, since Martha is mad the authorities would probably take her to an asylum and send the child to a workhouse, you know that. Is that what bothers you?

Carr Gomm:

Stop! You don't understand. We created those institutions for the benefit of society, without them what would happen to all those people?

Thorn:

It seems to me that in the creation of institutions you've done something worse. I know you personally have worries about them. You know what they are really like; they rob people of all self-esteem, reduce them to mere things, beasts, numbers, and 'property', entitled to little or no respect. Is that what you want as an alternative for Martha Ray and her child, if in fact she had one? And if she did have one, in a fit of

mental normalcy realised what lay ahead for her would you judge her for sparing her child such a fate?

Carr Gomm:

Stop! Life is sacred!

Thorn:

Gracious, I just experienced such a flashback! I remember a similar dialogue more than two thousand years ago written by Plato in his *Phaedo*. Socrates was asked by Cebes to explain his views about suicide. In their discussion, Socrates said that humans are instruments of the gods, thus to kill another human or to kill oneself would risk the wrath of the gods. This view was adapted, modified by mighty Thomas Aquinas who sought to synthesise church and state. He was quite clear that God subjected all things to the power of man.³⁰

Carr Gomm:

Yes, and I believe this is true.

Thorn:

Dear Carr Gomm, someone wrote that discussions such as ‘immortality’, ‘Domination’ and divine right of Homo sapiens should be confined to the philosophy of religion, and should be separated from discussions concerning ethics.³¹ Yet, I have often wondered if this is possible. It seems to me that we can’t draw a line so easily. After all, organised religions, like medicine and business are largely creations of society and influence and are influenced by the prevailing ethics of the time- no matter when or where one lives.

Carr Gomm:

I do believe the way in which I have been taught. Humans have intrinsic worth.

Thorn:

Have you ever considered why you feel this way? What if the baby of Martha Ray was born severely defective, grotesquely deformed, would your position change? What would you consider the quality of their life to be? Now, you must not concern yourself with this because you claim it’s not the quality of a person’s life that is the problem, it is the sanctity of life. Let’s unpack this. You believe that the deliberate destruction of human life is fundamentally wrong.

Carr Gomm:

I do.

Thorn:

So it does not matter to you what may happen to a person in her life as long as the life is lived, born 'defective' or normal.

Carr Gomm:

Well, I think so, yes.

Thorn:

Is all life sacred?

Carr Gomm:

Yes.

Thorn:

What about animals, then?

Carr Gomm:

Animals? Animals? I hadn't considered them, of course they too live, but..

Thorn:

'Not part of the discussion of these times I suspect, so we'll set it aside.³² What you are saying is that if someone is a member of the human species only then is life sacred. Just being human and being alive is enough. Doesn't that make you a moral-bully?

Carr Gomm:

What! I am certainly not a moral bully. Really, Thorn I've had quite enough of this dream.

Thorn:

Calm down and listen. You say that human life per se has sanctity. This differs greatly from the view that the quality of life may depend on circumstances. So holding to your view, you don't care if Martha Ray (lets say she's visibly normal) and her child (visibly abnormal) suffer and deteriorate in slums or workhouses. Forget about the level and degree of their dependency, wishes, burdens...being alive and human is enough. No other value must override the sanctity of life. Is that what you mean? You can't compare the value of a life- from one most hopeful to one most vegetative. Human life is the ultimate sanctified means that you must preserve it beyond any other considerations, you must prolong it, and in fact you must make as many more human lives as possible. Of course, to accommodate this we'd have to build more institutions, we'd have a real problem with the population growth and...

Carr Gomm:

No! That's not what I mean.

Thorn:

Then what do you mean?

Carr Gomm:

I mean that human life is worth saving. This is not to say that I don't regard intelligence, friendship, or autonomy as important considerations. Its life *qua* life above all that I consider to be the moral foundation.

Thorn:

What would happen, Carr Gomm, if tomorrow you fell seriously ill, went into a coma, lost your capacity to think, feel, experience life? Would your sanctity of life position change if faced with yourself and not an abstract person? Because, remember any human life, in all forms have priority over all other life forms. Holding to this view, 'a vegetative state with vital signs is a sanctified vegetative state.'³³ You never face any dilemma of whether or not to save a human life, it is always saved always prolonged no matter what. But, Carr Gomm, can you answer a theoretical question whether having a heartbeat; 'being alive' can support any moral value alone? Is the life you value really valuable without consideration of its condition, quality, or circumstance?

Carr Gomm:

I would personally not like to be kept alive as a vegetable. I wouldn't be 'me' any longer. I guess what I mean by the sanctity of life is just that I do value deeply human life, but when the prognosis is made that 'life' suggests that it will be one of misery or pain then I diverge.

Thorn:

So, I think you are saying that life is of value and on that position we agree. The problem with people who hold to the sanctity of life position is that everything other than absolute life, such as pleasure, happiness, imagination, must be sacrificed to it. Life must not only be prolonged, no matter how desolate, but lives must also be multiplied. Another consequence of this position is that choices concerning life are immobilised: all human lives are valued equally, even when some are unborn, mad, vegetative and others living, sane and spirited. It fears complexity and is an easy way to run from life's burdens, simply by clinging to absolute avoidance of choice.

Carr Gomm:

Thorn, if I understand you, if the baby was born deformed, a 'monster' the sanctity of life position would require that its life be lived, prolonged no matter what the consequences. Yet, the quality of life position, on the other hand, seems to rely on

rather vague concepts. I think its view is that the value of a life varies with the circumstances. The value then would be contingent on circumstances, absolute, infinite or maximum but only in relationship to the circumstances. Some circumstances would reduce the value others would enhance it. I think it means also that in holding that a life is not worth living does not imply killing just for killing or the taking of a life of value.

I wonder, would it make a moral difference if Martha Ray killed her infant because it was born deformed, destined for what she perceived to be a valueless life most likely of misery? But maybe it is a question of to whom a life is worth living. Martha Ray to the infant...Joseph to his mother...His mother to society...Joseph to me...has his life been worth living? Who decides? Is it society, the individual?

It seems that we can't escape the fact that a judgement that one person's life is less valuable than another's is a standard we set based on our own interpretation of life's quality. Moreover, what we consider the 'quality of a life' is certainly formed, to a large part, on our culture and its particularities. However, shouldn't we consider that the standard should be subject to the standards of what Joseph feels, or that of a normative 'reasonable person'? But, which person, who chooses? Oh misery. Oh misery. Even if we knew ahead of time that a baby would be born defective, should we kill it to spare it a life of pain or degradation? It would of course depend on how bad the disability was, and the scientific knowledge of the times and the society, and their resources and their culture and...and... Anyway, right now we doctors don't take part in infanticide, nor do we play any major part in investigating suspected deaths we don't have to face such difficult decisions, such life and death choices. It's really in all together a different area, left up to the magistrates and midwives, not our business, really. ³⁴

Thorn:

Carr Gomm, just because right now you don't take part does not remove you from the human arena. Besides, logically, when you have patients admitted because of failed abortions or certifications of death you are a definitely a part of the 'business'. Your vocation is society's creation, and as you are part of society, you are responsible to it. Martha Ray chose alone, as women before her and after her are oft compelled to

choose. However, you are a part of the network and like it or not, you can't avoid responsibility.³⁵

Carr Gomm:

Thorn, up until this dream my life was tidy, ordered, reasonable, and rational. You enter and it becomes confused. You force me to consider the role of women, plants, history and most of all, Joseph. Knowing Joseph has taught me to look at deformity differently. While I know intellectually that that nature is capricious in her creation, I must admit when I see him I suffer a confusion of feelings. He reminds me of unresolved feelings about myself. Perhaps we who are normal have become complacent about understanding and accepting that nature makes differences. We position ourselves like Procrustes, trying to make everyone fit into a tidy, comfortably similar, familiar mould. Oh Thorn, where do we draw the line? What will become of us?

Thorn:

You will survive. It is the movement, you see, into the introduction to the awareness of difference that matters and subsequently into the ethical issues that rise as part of the discussion. Celebrate the beginning of the debate, enjoy the conversations arising, and keep them open and alive! Sometimes it is in the mist of confusion or madness that choices are made.³⁶ As lichens know, there are no guarantees as to the absolute rightness of choice, but then, there never were.³⁷

THE SECOND DREAM PUTS TREVES ON THE DOCK ³⁸

Treves unlocked the door of his home on Wimpole Street. “ ‘Tis a shame”, he thought, “that Anne and the children are off to the cottage, I could do with both idle chatter and hugs”. He ate a cold plate left by his housekeeper, bathed, donned his nightwear and climbed between the starched sheets. No sooner than his eyes closed, he was fast asleep.

TREVES:

The most striking feature about him is his enormous head. Its circumference is about 36 inches, that of a normal man’s waist. From his brow, look there, is a projecting bony mass like a loaf of bread, while on the back, turn around if you will, hangs a bag of fungous-looking prickled skin, the surface, you will note, looks like rotted cauliflower and larger than a Tangerine orange. He makes noises, but cannot articulate properly. No doubt, he is an imbecile. From his lower jaw, face front please, there are long dark hairs. From the upper jaw extends a mass of pinkish bone. He had a similar piece of flesh removed years ago in Leicester, to no avail. The nose, you will note, is only recognisable as such by the position. Otherwise, it appears merely as a lump of flesh. Such deformities render his face incapable of all expression. It is impossible to tell whether he is laughing or crying. The back, you will note is quite deformed with the same type of pendulous masses of cauliflower-like skin. The right hand, resembling a reptilian fin, has a massive overgrowth and is useless. By contrast, the other arm and hand, are quite remarkable, so very human, shaped beautifully and covered with normal skin and delicate hairs. From his chest hangs another bag of flesh, like a lizard’s neck. His lower limbs, note please, share common characteristics with his deformed arm. Unfortunately, to add to his troubles, he has a shortening of one leg. This we believe was caused by tuberculosis when an infant. Disrobe, please. His genitals, Sirs, are remarkably normal. Robe, please. Gentlemen, Comments?

MERRICK:

‘ The most striking thing about him is his terribly normal sized head. This allows him to lie down and sleep in a normal position, and therefore, to dream any dream that may enter without the weight of others’ dreams that accumulate, ripen, and having no escape, cause greater deformity. From his brow, we see two alert brown eyes straightforward, looking keenly into a promised successful future; a benevolent

enlightenment rather in a conformed-self enlightened state. He decides for others and when stakes are high, he becomes 'father'. He creates. A good example is in his creation of 'John' Merrick instead of calling me by my given name 'Joseph'. Did he ever acquiesce to me, Joseph, my own wishes or desires? Did he ever grant me autonomy? No! He reinforced the 'Priestly Model', the 'divine right of kings', free consent counts for nothing; he holds the power. He negates the following: the right to full disclosure of needed information, the right to being regarded as a self-determining agent. He negated the duty of fidelity, removed my uniqueness, and disavowed compassion. Look, the mouth, moustached, it is deformed by self-satisfaction, rendered incapable of self-critical speech, and thus the ability to change. His back, turn please, is utterly straight from being kept against a wall ready to reply to any criticisms of his social order and perceived reality- defensive, locked. His hands, as a surgeon, are well developed and ready to carve up anyone to make them fit into the world of the normal. Due, in part to his brain structure, the right arm is stronger than his left; but both are incapable of the charitable act of giving. 'The left arm, as we have noted, is smaller than the right. Its principle purpose is to cover the genitals, which are viewed as a specific area in need of constant restriction, governance, and chastisement. For their own good.' However, the greatest of problems, Gentlemen, is his laggard loss of humanity. This process we ascribe to either one or two diseases, but they overlap under the broad classification of '**Modernity**'. The first disease is called **Volatileidealbodism**. This, as you know, involves removing of self, or being removed from others into a world of biotechnology where one concentrates only on one aspect of life or on one biological organ, obsession with the 'normal' and thus loses the complexity of the whole, be it body or mind. The second possibility is **Bodylogicalone**: removal to the abstraction and logic of philosophy, providing safety from a real and unimagined world (and its variant **Bodylitalone**: Isolated immersion into literature, loosing the ability to enter a mutual dialogue). In summary, he cannot comprehend difference, he has lost empathy, and he has lost humanity. Comments?

TREVES:

No. No. You don't understand. It was like that, but it wasn't. What do you expect of doctors anyway? I do realise now that exhibiting John in the amphitheatre I surrendered his self to his existential condition. He was an object to me, not a person and wrongly used as a means to my end. But that's the way we do things in medicine

today. We present actual cases scientifically, objectively.³⁹ From these paradigms, we learn certain critical lessons and when faced with other presentations, we draw from the composite of our knowledge, our common truths. Knowing John as I do now I see the wrongness of it, the removal of his autonomy and I can but try to change the manner or at least be sensitive to the manner in which we present our ‘cases.’

However, the real problem for me is this: when facing a disease where do we doctors draw the line between being scientifically objective on the one hand and being an advisor, teacher and importantly a friend on the other?⁴⁰

If I move from the position of scientist or information source to become a part of my patient’s life in at least my concept of friendship, then the patient may well gain greater power over the relationship. I mean this in the sense that although she does not have the scientific knowledge of the disease that I have, the emotional bonds of friendship may in fact prevent me from doing what I as an interested, but scientifically distanced physician should medically do for her. Let me give you an example:⁴¹

I am, as you know a surgeon. One night I was called to see Edward, Prince of Wales who was ill with a painful abdomen. I diagnosed acute appendicitis and advised an immediate operation. Now, the Prince of Wales, as you know, was known to be a bit stubborn. He was determined to proceed with his coronation on the following day rather than disappoint the nation. I said to him, “ In that case, Sir, you will go to the Abbey as a corpse.” Ultimately persuaded, he underwent a successful appendectomy. I did not have a personal relationship with him. He was King and I subject, no emotional bonds clouded my diagnosis nor weighed against my insistence upon immediate treatment.

(Treves pauses.)

I had a daughter; she was more than friend to me. One day she complained of a bad stomach-ache. I teased her saying that she must have eaten too many red cherries. Days past and she still complained. ‘It will pass’, I said, ‘you’re just growing up’. It was not that I was too busy, that I didn’t hear, or didn’t care. She was too close to my heart to ascribe any real serious interest. It couldn’t happen. The following day I found her in bed quite feverish, her abdomen hard to the touch. I operated on that very day for appendicitis, but it was too late. Peritonitis had already set in and she died. My

daughter died because I was too close in my love for her to recognise what I scientifically should have.

So, where do you want the power line drawn? How does a doctor, first a human, protect himself against the power of emotion, of being too drawn into a patient's narrative, of loving too much to be of any practical use? You suggest that doctors abuse the relationship of power based on our medical knowledge and that in acting as counsellors or friends we could abuse it more. I suggest the argument is not sound unless one attempts to identify the doctor-patient relationship perhaps in defining the somewhat subjective and illusive parameters of human 'friendship'.

Yes, I call you 'John'.⁴² But you never objected. I did not do it out of malevolence. When I heard you first say your name I really thought you were saying 'John'. Then, when I became involved in your life I suppose I did, in a sense want to re-create you, to take away some of the pain I knew you had endured. It was not meant to take away your personhood. Dying, I wrote my memoirs and I wrote your given name, 'Joseph', then I crossed it out, and above wrote 'John'... 'John'. I believe the meaning of the name is 'beloved of God.'

MERRICK:

My story is finished then?

TREVES:

No, it has begun.

THE THIRD DREAM PLACES MERRICK ON THE TOP OF THE MOUNTAIN

Merrick stood and walked painfully to where his night-clothes were stored. Clumsily, but efficiently changing into them he looked for a moment at his bed. Then his eyes travelled to the pictures decorating his walls, pictures of the 'beautiful normal': a child sleeping supine, head on pillow, The Good Shepherd and His flock, his beloved mother, Mrs. Kendal, the Princess of Wales... "I wonder", he thought, "as kind as Mr. Carr Gomm and Mr. Treves are, if they have any idea of what it is like to be deformed. But the beginning to understanding begins with an inquiry, and for that I am grateful."

He said his nightly prayers and placing a number of pillows on the bed near the wall and to each side, Merrick climbed in the feathered nest. The bony masses and the pendulous flaps of his skin had grown steadily worse; the outgrowth of his upper jaw, the trunk, had increased greatly, and his head had grown so heavy by this time that he had difficulty in holding it up. Rather like in a seated or crouched position, he clasps his hands over his legs and rested his ponderous and heavy head on his knees. For to sleep otherwise, would asphyxiate him. He fell asleep and dreamed....

"Is it not beautiful here on the top of the mountain," said Joseph throwing happily his arms up skywards. "I see! I feel! I perceive the experience of all of life: colours, pain, joy, and noise from outside and within -all here in my real world. Yet, always I dream of things, of body *corps propre*, accessing all that exists. Recognise my structure, expressed in all of nature's physical laws, the vital order, characterised by my aptitude to the world and know I perceive, I have lived experience- which is dynamic and a source of my meaning. ⁴³

Look there, an elephant fights with a dragon; pygmies ride on wings of butterflies ⁴⁴ and see, my mother, Thorn, climbing that slope with Mr. Carr Gomm. And you, my friend, my companion Mr. Treves, look there at the life I have travelled; all within the content of me, but not implicated in it: ahead of what is real, imagined. What is my meaning? I am a deformed body, yet a still-lived being. ⁴⁵ I weigh the quality of my life, the good against the bad. I access all that exists. I cannot change my situation, yet I also do not constantly despair. In thinking of the quality of life, different people will have different ideas concerning in what 'quality' consists- mine is neither theirs, nor

theirs mine. I stretch, I lie down, ⁴⁶ I sleep balanced here, tip-top of the mountain. Pain. MeacupaMeacupaMeamaximacupa ⁴⁷ Pain. The dragon fears nothing except the elephant with whom he will engage in battle, entwining himself around the elephant and inflicting fatal blows. However, as the elephant finally collapses, his fall crushes the dragon to death. I have been loved. I am set free. 'Nothing ever dies.' ⁴⁸

THE DESIRE TO BE LIKE OTHERS

Treves is recorded in his *Reminiscences* as saying that Merrick "often said he so wished he could lie down to sleep 'like other people'. I think on the last night he must, with some determination, have made that experiment" (Montagu: 1979: 64-67). Thus, it came about that his death was due to the longing that had dominated his life- the desire to 'be like other people'.

In the death of Merrick, Treves resists stressing in death what he failed to come to terms with in Merrick's life: his agency and his common bond with all humanity. Wanting to be like other people is a universal, if intermittent desire- as is the opposite impulse, to be regarded as unique. None of us exceeds in either, and Treves' failure in recognising this in himself and Merrick is like us all.

If Merrick's body experienced one sort of transformation, his personal status underwent another. The events of his life were such that they fit into a social narrative we find easily recognisable- that of a worthy but down-trodden being overcoming disfigurement, poverty, race, gender or other handicap finding reassurance of moral worth through the intercession of others-through real people not imagined fairy godmothers, or magical intervention. Merrick's story, as authors Graham and Oehlschlaeger (1992) say, 'is one that defies closure... is reinterpreted and interpreted and with each new telling is added a particular dimension...asking if appearances is, after all, a misleading mask.' His story is also one that heeds the call of the other showing that the virtues of courage and integrity outlast even death itself.

PROTEUS

Ovid wrote (*Metamorphoses* vii 7 quoted in Bauman: 1993: 22) of Proteus that, *“People have seen him at one time in the shape of a young man, at another transformed into a lion; sometimes he used to appear to them as a raging wild boar, or again as a snake, which they shrink from touching; or else horns transformed him into a bull. Often he could be seen as a stone, or a tree...”*

In 1986, Joseph Merrick’s medical disorder was diagnosed and named, ‘The Proteus Syndrome’ (Tibbles and Cohen: 1986:683-685). A type of neurofibromatosis, the Proteus syndrome is a rare disfiguring disease. It occurs as a mutation of the genes of a host, and one who is effected may not have received the mutations from their parents. It involves atypical growth of the bones, skin, head, and a variety of other symptoms.

As of 1986, there were approximately 50 documented cases world-wide. Reported cases have been isolated occurrences, suggesting that the disease is not hereditary. It affects both sexes equally and has no particular racial, geographic or ethnic distribution. It is an extremely variable condition and the severity of the syndrome ranges from mild to severe. There is, as yet, no way to detect the disease in utero.

SUMMARY OF SECTION ONE

In this section, I opened a conversation concerning those ‘visibly different’. The example, using and creating narratives arising from the life of Joseph Merrick, *The Elephant Man*, identified some of the problems confronted when we ‘normal’ confront those ‘not like us’, and vice versa.

In writing the face of difference I sought to identify both some of the emotions disabled people feel and ethical issues that arise when faced with a Procrustean society. To a great extent, this debate is timeless. I further suggest that arguments concerning the ‘sanctity of life’, and ‘quality of life’ are social variables that have always been dependent upon an infinite range of economic, social, technological and political factors. Through narrative form, I suggest that disease, deformity, and even perceptions of personal identity are, in part, mutable expressions of cultural and personal values.

“Philosophers”, writes Singer (1996: 121) “ are human beings, and they are subject to all the preconceptions of the society to which they belong. Sometimes they succeed in breaking free of the prevailing ideology: most often they become its most sophisticated defenders.”

In viewing people who are deformed or disabled, what philosophy has usually emphasised is their difference. As Silvers (1998:3) points out, in searching for limited cases, philosophers have turned to their prototypical portrayals of disability for illumination. For example, whether the congenitally colour-blind understand colour terms has been used to delineate the role direct observation plays in understanding (ibid). This largely sets those deformed or disabled on the fringe, and as was Merrick, marginalised.

In this section, I have illuminated a broader human face to the discussion of difference, emphasising inclusion. I have shown that patients and those who interact with them, their ethics, society, culture, politics, economics, religion, and so on, are woven into rich and sometimes inseparable webs of complexity. Adding my voice to the story of Joseph Merrick, I have further argued in the postmodern perspective, the importance of being for the Other.

Literature, as Nussbaum (1990: 3) writes, shows

*“that life contains significant surprises, that our task as agents,
is to live as good characters in a good story do,
caring about what happens, resourcefully confronting each new thing.”*

The particular style or form in which I presented the face of difference was deliberately chosen. I suggest that in the teaching of applied ethics, literature and literary forms may serve as an important source to broaden human understanding. They succeed, I argue, because they remind us that in daily practise, we all play and balance roles. We constantly must, for example, disentangle (and not always successfully) emotion from logic, set arguments into various systems of justice, while respecting our second sub-text, a suffering patient, who has his or her own story to tell.

In the example of Joseph Merrick, I identified that it can happen that those with disabilities or deformities, betrayed by history, could survive a system in which they were reduced to mere things; property entitled to neither rights nor respect. As shown in the story of Joseph Merrick, his survival was ensured because of the compassion and interaction of fellow human beings, being there for the Other. He survived and retained his humanity as well as his faith that evil and suffering were not the sum total of his identity- or necessarily the destiny of those who would follow. We must ask no less than he did: to fashion an ethic that matches the unique dangers the deformed and disabled face, one that will enable us to recognise in these dangers, opportunities for humane services and committed living.

NOTES TO SECTION ONE

1. In the accounts of Howell and Ford (1980:95-99), Sparks (1980:254) and Montagu (1971:55), a London ‘bobby’ comes to the assistance of Merrick. Retold, the introduction of a woman refers to Gilligan’s theory, *In a Different Voice* (1982:51-56): “Given the differences in women’s conceptions of self and morality, women bring to the life cycle a different point of view and order human experience in terms of different priorities.” (Ibid: 56).
2. Merrick, because of a growth on his palate (Graham and Oehlschlaeger: 1992:48) suffered speech impairment. Normal persons disabled by speech impairments realise that their speech is impaired. Non-speech impaired persons often pretend, usually out of misguided good intentions, to ‘understand’ what a speech-impaired person is saying. This evokes a complex set of messages sent to the speech-impaired person: the appreciation of attention, but a negation of the value of what they are saying. Consequently, the received perception of their self as a disvalue is reinforced. As Strauss (1996:77) writes:” The pretense that all is normal may undermine social interaction and make encounters quite uncertain.”
3. “ *He told an elaborate story of a ‘fright his mother had received shortly before his birth from having been knocked down by an elephant in a circus.’ Treves’ Report to the London Pathological Society in March 1885 (cited in Howell and Ford: 1980:380*

As Todd (1995) identifies, the complex link between birthing and the ‘imaginative faculties of women’ was particularly evident during the 17th and 18th centuries in Britain. Imagination took main stage. It was claimed that imaginative faculties in general caused an interruption into the realm of abnormalcy. Imagination gave self-identity to the realm of spirit and mind and shifted it as an agent of threatened identity. An effect of imagination, presented as a ‘scientific’ fact, is the following (written in 1726 by a Dr. Maubray in his book *Female Physician* [ibid: 65]:

“ But however, to come closer to the IMAGINATION of Pregnant *Women*, who knows not that affects the INFANT in the *Womb*? Whence is it then that we have so many *deform’d Persons, crooked Bodies, ugly Aspects, distorted Mouths, wry Noses* and the like, in all Countries; but from the IMAGINATION of the *Mother*; while she

either conceives such *Phantasms* in her *Mind*, or while she frequently and intently fixes her *Eyes* upon such *deform'd Persons* or disagreeable OBJECTS? Wherefore it is very wrong, and highly imprudent in *Women* that have conceived, to please themselves so much in playing with *Dogs, Squirrels, Apes &c.* carrying them on their *Laps* or *Bosoms* and feeding, kissing or hugging them, as I have both often heard and seen with my own *Eyes*. And besides, the same is the case when the *Natural Faculties* are all at work in *forming*, or ripening the FOETUS: for if the *Woman* be surpriz'd at any sudden Evil, or *frightened* at any unseemly Sight; the *Humours* and *Spirits* presently retire downwards and (as it were) abscond themselves in the *Recess* of the WOMB: From whence immediately a strong IMAGINATION of the disagreeable *Thing* (whether *seen* or *heard* only) seizes her *Mind*; and the *Forming Faculty* (going on in the *Interim*) quickly impresses the *Imaginary Idea* of *That* thing heard of, or the *Shape* and *Form* of *That* thing seen, upon the FOETUS. The same is the *Reason*, that if a *Mouse, Rat, Weazel, Cat* or the like, leaps suddenly upon a *Woman* that has conceived, or if an *Apple, Pear, Cherry &c.* fall upon any part of her *Body*; the MARK of the same thing (be it what it will) is instantly *imprinted*, and will manifestly appear on the same *Part* or *Member* of the CHILD.”

The concept of the power of imagination, specifically that of a pregnant woman's imaginative faculties, with its ability to misshape, blemish, or make a monstrous child began the teratological debate, which in a variety of forms, is present today. Joseph Merrick, in his *Autobiography* writes:

“*My feet and legs are covered with a lumpy skin, also my body, like that of an elephant, and almost the same colour, in fact no one would believe until they saw it, that such a thing could exist*”. (*Autobiography of Joseph Carey Merrick* cited in Montagu: 1971:109-110, Howell and Ford: 1980:168-169).

Tom Norman, one of Merrick's early exhibitors is quoted as saying (Howell and Ford: 1980:83)“But you could indeed exhibit anything in those days [he wrote]. Yes, anything from needle to an anchor, a flea to an elephant, a bloater, you could exhibit as a whale. It was not the show, but the tale you told.” As was the custom of the time, exhibitors often distributed printed brochures containing ‘facts’ about their exhibits. Howell and Ford (1980:89-90) believe Merrick to be the author of this

'autobiography'. Graham and Oehlschlaeger (1992: 27) however, point to 'detachment' as the persistent effect of the composition, suggesting that it was either written by an agent or by Merrick himself, separating his physical body from the spirit within. Even in literature, the mind/body interactionism, first articulated by Descartes, and discussed by contemporary thinkers, may be seen.

4. These non-lexical exchanges are particularly well evidenced in Lynch's film (1979); Merrick becomes a *cause célèbre*. Visitors come to his room for various reasons. Some come to increase their social standing, some out of friendship, some for financial gain, some for evil. All come, on one level or another to satisfy their curiosity. The curiosity theory, according to Carrol (1990:159) rests basically on 'three psychological claims: 1) humans are naturally curious about conceptual aberrations of the sort embodied by 'monsters'; 2) humans tend to experience pleasure in having this curiosity stimulated and rewarded; and 3) the cognitive pleasure associated with the discovery of the horrific is able to sufficiently outweigh, overcome and compensate for the unpleasant emotions of fear and disgust normally evoked.' Another interesting thought concerning the attraction-repulsion paradox is raised by Solomon (1956:34) claiming the underlying desire to view those visibly different rests on a sexual basis: the 'normal' wondering how those 'abnormal' have sexual intercourse.
5. As Carey (1989) identifies, society appears to focus only on the 'outer' man and thus denies those handicapped any of the dreams, desires and ambitions taken for granted in the visibly normal. Indeed, is there any reason why those visibly different, handicapped or disabled should be denied basic human impulses? Why do we tend to raise our voices when communicating to deaf people who we know 'read lips'?
6. The fields of medicine and law, by and large in all contemporary societies, have been granted autonomy. It is important to emphasise that these are social constructs. While both of these professions are powerful lobbies, one may ask if the autonomy granted to them is wholly justified. Society expects " more than morally required " (De George: 1990: 457) of these professionals as opposed to common citizens. With the advent of mass media, the public is, or has the

opportunity to be better informed on subjects such as medicine and law. While it is true that not all citizens have the depth of knowledge that, for example, doctors or lawyers may have, it remains professional arrogance to presuppose that they cannot comprehend what information does exist.

7. "...and if I say again that the greatest good of man is daily to converse about virtue, and that concerning which you hear me examining myself and others, and that life which is unexamined is not worth living- that you are still likely to believe..." Plato, *The Apology of Socrates*, SCR: 39-41.

8. The screenplay by Lynch (1979: 112) clearly identifies the dilemma of Treves: "ANNE: Frederick, why are you so interested in this particular case? TREVES: I don't know. I can't explain it. If this is an intelligent man, trapped in the body of a monster, then I'm under a moral obligation to help him free that mind, free that spirit as best I can, to help him live as full and content a life as possible. But! If he's an imbecile, whose body I can't treat and whose mind I can't touch, well, then my obligation is discharged. They can put him where they will; he won't be bothered, I won't be bothered, and everyone's conscience can remain free and untroubled. And that's my dilemma...what is in his mind?"

Treves makes the claim that his moral obligation to Merrick is based on his possession or not of intelligence. Singer (1996:120) would argue against setting the arbitrary boundary of intelligence as the limit for the concern of other beings. He (ibid) writes:

"If a being is not suffering, is not capable of suffering, or of experiencing enjoyment or happiness there is nothing to be taken into account. This is why the limit of sentience (using the term as convenient, if not strictly accurate shorthand for the capacity to suffer or experience enjoyment or happiness) is the only defensible boundary of concern for the interests of others. To mark this boundary by some characteristic like intelligence or rationality would be to mark it in an arbitrary way."

9. Redding (1996:100) makes this point: "As long as doctors have been able to draw on the conception of science as *the* authority about the world, they have been able to legitimise the claim to 'always know best' for their patients. The equation of

the subjective view based on experience with simple error, to be corrected by scientific truth, has served to keep patients disenfranchised in the governance of their own corporeal selves.” It may be suggested that if a patient is given a voice as its own distinctive authority (challenging the distribution of power based on science-as-*the*-final word) then the control of the doctor is challenged- which I suggest it should be.

10. From-Treves' *Remembrances* (cited in Montagu: 1970:39) “ Merrick, I may say, was now one of the most contented creatures I have ever chanced to meet. More than once he said to me, ‘I am happy every hour of the day’.”
11. In this perspective, “ *Being for* is a leap from isolation to unity; yet not towards a fusion, that mystical dream of shedding the burden of identity, but to an alloy of those precious qualities dependent fully on the preservation of its ingredients’ eternity and identity” writes Bauman (1995: 51). This is reflected in other postmodernist writers such as Levin (1988: 470) saying, ‘ It is only by virtue of our vision, our capacity to see, that Being is made visible: visible as the lighting in the care of which we and all other beings on this planet are destined to live or die.’
12. Michel Eyquem de Montaigne (1533-1592) was a Pyrrhonian skeptic. Pyrrhonian skepticism suggests the suspension of conviction in matters that are removed from appearances. Montaigne, in defence of the Catholic Church, while not adopting this thesis, adapted a skeptic argument to say that the human faculties of sense and reason cannot be used to identify the true nature of things. Because of the fallibility of human reason and sense, we should not use them to judge matters of divine nature. Instead, all pretences of natural understanding should yield to the authority of the Church, which is supernaturally inspired (Blackburn: 1996: 248-249) In his publication *Essais* (1580) translated later in English as *Essays* (1603), while attracted to the metaphysics of Socrates, Montaigne remains troubled by his physical appearance. Drawing somewhat vaguely from the philosophical argument of Montaigne, Johann Kaspar Lavater (1741-1801) a Swiss Reformed Church pastor claimed that from outward appearances, particularly emphasising head shape and facial features, one could deduce the

quality of a person's soul. According to one researcher, B. M. Stafford (1987:185-192), the theological basis of Lavater's claim rests on man being created in the image of God, however, through the sins of man, blemished offspring may result.

13. M. Montaigne. 1958. *Essays*. London: Penguin Books: 336.

14. According to Diogenes Laertius who wrote *Lives of the Philosophers* in early third century CE (Clark: 1997: 4) Socrates cleverly used his appearance as a point on which to open some of his philosophical debates.

15. The following is a quatrain from Isaac Watts' poem 'False Greatness' in *Horae Lyricae* (cited in Graham and Oehlschlaeger 1992:14) Merrick (quoted in Montagu: 1971: 110)was often fond of saying:

“Was I so tall, could reach the pole,
Or grasp the ocean with a span;
I would be measured by the soul,
The mind's the measure of the man.”

16. As Macgregor (1979:115-118) rightfully points out, there are dimensions of communication, “nonlexical” (kenetic, paralinguistical and proximal) usually received by individuals at a subliminal level that may directly serve to both positively and negatively impact on an individual's self-esteem. Komesaroff (1995: 69-77) as well as others identify the importance of nonlexical communicative interaction, particularly in doctor-patient relationships.

17. Lefebvre (1996:63), a disabled person, writes, “ The eye of others is where we seek the validation of our existence, and this is the yardstick by which we judge our self-worth. But universal approval, or even acceptance is far less important than the consistent love and admiration of a few consistent others”. I raise this point again in the next section addressing the case of Elizabeth Bouvia in 'Choosing to Die'.

18. *The Thorn*, a poem written by William Wordsworth in the 18th century raises the question of a possible case of infanticide. According to Lionel Rose (1986:7), the practice of infanticide in England continued during the 19th century. In 1869, for example, of the 3,979 inquests (autopsies) of children under one year old, nearly one-third, were for babies who were 'illegitimate' or 'unknown'.
19. Lichens are among the oldest appearing plant organisms, first appearing more than two billion years ago, according to fossil records. They live in symbiotic association.
20. Plants such as 'Eve's Root', Pennyroyal' and (the now extinct) Silphium were used from ancient times to cause abortions or, as Bilger (1998:38) writes, "to bring down the courses".
21. Present throughout much of history, abortion and infanticide have been designated as 'women's business'. During Roman times, the only interjections occurred when there was a possibility that a male would be deprived of a male heir. See: Luker: 1984: 12-13, Shelton: 1988: 56-78.
22. The official position of the church concerning abortion found its roots in Aquinas. Synthesising the arguments of Aristotle into his own (Ford: 1991: 39), the official church position did not condemn abortion before 'quickening', a formula of 'ensoulment' developed by Aquinas (Luker: 1984: 13).
23. A soldier wrote home to his wife "If it is a boy, let it live; if it is a girl, expose it" (*Oxyrhynchus Papyri 744* quoted in, Shelton: 1988: 28). French (1986:79-80), among others, makes the point that it appears likely during the Roman era that more females were subject to infanticide than males.
24. Third Republic reforms under Napoleon attempted to curb the practice of infanticide. A Napoleonic decree in 1811 required all foundling hospitals to have a *tour*, a combination of a revolving door and a container. Defended by proponents, it was called humanitarianism, by its opponents it was argued that it only promoted abandonment. In early 1800, abandonment reached about five

percent of the total birth rate, by 1840, it is reported to have reached as high as 20-30 percent (Fuchs: 1984: 32). It is also of interest to note that in France before 1800, both abortion and infanticide were recognised as a form of child abuse (ibid).

25. See Raum, O.F. 1960. *Chaga Childhood: A Description of Indigenous Education in an East African Tribe*. London: Oxford University Press. The Sebei Tribe (East Africa, mainly Tanzania) only twenty years ago, according to Goldsmidt (1976: 244) deny practising infanticide regularly. However, a man may divorce his wife if “ she has had children three times and kills them each time”.
26. Stanza quoted from *The Thorn* (Wordsworth: 1979:47).
27. As pointed out by Tooley (1997:43) there is a tendency in philosophical discussions to use the terms ‘person’ and ‘human beings’ interchangeably. This results in what he calls ‘philosophical confusion’ (ibid). Tooley suggests not using the term ‘human being’, but suggests the use of a more neutral expression, “characterised in physiological terms, such as member of the species *Homo sapiens*” (ibid: 44).
28. Robert Wertheimer, quoted in Tooley (1997: 43) says, “ Except for monstrosities, every member of our species is indubitably a person, a human being, at the very latest from birth.” As Tooley argues, the terms ‘person’ and ‘human being’ should be clarified. For Tooley, the concept of a person is,” purely a moral concept, free from all descriptive content”(ibid: 42).
29. The atmosphere of Whitechapel road, where Joseph Merrick was ‘housed’ for exhibition is captured in the writings of Blanchard Jerrod in his book, *London: A Pilgrimage* published in 1872. The direct quote, cited in Montagu (1971:14-15) is as follows: “ It is an ancient neighbourhood, as some of the overhanging houses proclaim: and it remains a picturesque one, with the infinitely various lines and contrivances of the shops and stalls, and gaudy inns and public houses; the overhanging clothes, the mounds of vegetables, the confused heaps of fish, all cast about to catch the pence of the bonnetless dishevelled women, the heavy

navvies, and the shoeless children. The German, the Jew, the Frenchman, the Lascar, the swarthy native of Spitalfields, the leering thin-handed thief, the bully of his court, the silly-Billy of the neighbourhood- on whom the neighbourhood is merciless- with endless swarms of ragged children, fill road and pavement.”

30. “It matters not how man behaves towards animals because God has subjected all things to man’s power.” Thomas Aquinas, *Summa Theologica* II ii Q 64.1 and 11, I Q 102, 6. Quoted in Singer (1993:290).
31. See Singer : 1993: 292. Concerning the role of religion in culture, an interesting perspective is given by Merleau-Ponty: The task of religion seems to be to mark a place in our culture for what is foreign and enigmatic, a role that religion carries out ‘not insofar as it is dogma nor even belief, but as a cry’ (Merleau-Ponty :*La métaphysique dans l’homme* [1947] quoted in Bannan, J. 1967. *The Philosophy of Merleau-Ponty*. N.Y.: Harcourt, Brace and World: 175.
32. The turn to social movements such as those in the areas of animal rights, ecology/environment, green policies, peace and peace orientation, anti-nuclear, populism, feminism, children-as- soldiers, and a host of other issues are some of many born of postmodernism. Postmodernism has called for a greater awareness of marginalised people such as those disabled, handicapped, the elderly, and generally disadvantaged. In this approach, discussions ranging from formal to restorative to distributive justice are raised. New perspectives in bioethics and public policy concerning disability, difference, and discrimination are brought to the fore. Concern is no longer focused on the state, but calls for a return to the subject; small is beautiful, and autonomy is a prerequisite.
33. Struber (1994) as well as Singer (1993,1994,1996) argues against the ‘sanctity of life’ position both raise this point. Singer terms it the ‘Domination Theory’ (1993:290-293).
34. In Britain, it was not until the 19th century that the social status of doctors became elevated and concurrently the power of their guilds evolved. Up until that time, magistrates and midwives dealt with issues such as infanticide.

35. The complex role of medicine as a social construct and the multitude of roles played by agents in and out of this construct cannot be overemphasised. As van Niekerk (1998:6) writes, “ One of the important implications of the insights that the individual patient can and often has to be seen as a representation of a whole population is the need to recognise that **medicine is as much a social or human as a natural science**. The reason for that is not only that medicine is active within the confines and possibilities of human society. The reason also is that the real base of biomedical knowledge testifies to its social dimensions.”
36. The thought concerning making choices under duress is based on the following quotation: “It seems that one of the essential features of ethical life is that we run into situations where there is no clear right decision, and where we may not determine what to count even as the best decision, if we ever do, until we have to take some action in the midst of confusion” (Fleishacker: 1992: 1955).
37. Participating in an ethical dialogue requires self-discipline, self-evaluation, and introspection and in this way, strengthens the autonomy of the moral agent. Postmodern thought warns us that there may be no solution, which poses a problem for us as moral agents as well as ‘ liberation movements trying to identify principles on which to base their elaboration of new ethics’ (Foucault: 1982:231). Thus there are no guarantees, but there never were. As Schopenhauer puts it, “ I am of the opinion that there cannot be either privileged, useful, or even harmless errors, but that every error does infinitely more harm than good. On the other hand, if it were the intention to make prevailing prejudices the standards of truth or the boundary mark beyond which the expounding of truth may not go, then it would be more honest to abolish philosophical faculties and academies entirely; for that which does not exist should also not appear “ (Schopenhauer, trans. E.J.F. Payne: 1995: 198).
38. *On the Dock*. Pomerance’s (1979) play *The Elephant Man* recreates using particularly theatre and church (referring to Merrick’s construction of a model of St Phillip’s Cathedral) a space of interplay where polarities may be overcome. Evident in Act III, the form Pomerance uses is one of medical interrogation. Roles are switched and Treves takes Merrick’s place as medical case being

exhibited (referring to both his exhibition to the London Pathological Society and as a ‘freak’ exhibited by his past employers). The conclusion of the play calls attention to issues of control and authority and the abuse of power, particularly in the telling of our own stories and those of other people’s lives. I have adopted this interrogative form.

Some of the anatomical descriptions used by Treves in Merrick’s exhibition to the London Pathological Society (Montagu: 1971[appendix] 24-131) also evident in his *Reminiscences* (ibid: 17-46) are presented as metaphors and analogies. For example, describing the size of rounded exostoses of Merrick’s skull he compares them to the size larger than a “Tangerine Orange”, plus other descriptions such as.... “rudimentary trunk or tusk”... “appearance of a radish” (Graham and Oehlschlaeger: 1992: 42). In his case presentation, by emphasising Merrick’s unaffected body parts, Treves exaggerates differences. And in doing so identifies Merrick’s biological human kinship as well as distancing him from ‘normal’ humans. It seems that Treves, although finding the words to describe Merrick confidently enough, as Graham and Oehlschlaeger: (1992: 17) write he ‘almost totally sunders Merrick’s physical self from his existential condition’.

39. It was common practice in Europe and the US even up to the 1960’s to ‘exhibit’ patients in amphitheatres as ‘cases’ with little if any ‘informed consent’.
40. Under ideal circumstances, good medical and ethical practice are grounded in the mutual construction of a narrative that will have both explanatory power and a fully realised potential for healing (Hunter: 1994: xi). As Brody (1997:83) writes, “As the physician moves from the position of technician and information source to that of counselor, advisor and friend, the physician acquires relatively more power over that relationship and power could be abused. But if we respond to the threat of abuse by saying ‘physicians should not be counselors, advisors or friends,’ we deprive patients of relationships that they find supportive and helpful in most circumstances and that in many cases actually enhance the patients’ autonomy.”

What appears lacking in Brody’s argument rests on the language used, and the meaning of words in language. Doctor-Patient relationships are, like all social

relationships, complex. Certainly, the particular circumstance in which a patient consults a doctor in and of itself shifts the balance of power to that of the doctor. In ethical negotiations with a patient, it is necessary for the doctor to genuinely attempt to engage in a dialogue with her, one in which her autonomy is reinforced. In most cases, if this is held paramount, as Gillon (1986:166) writes, “Doctors will benefit their patients more if rationale of the proposed beneficial actions is understood and approved of by their patients.” It follows that the meaning of words used should be understood and defined much as possible, and raises some serious considerations: for instance, what constitutes a ‘friend’ to one person may not be the same as what ‘friend’ means to another. Language games are heterogeneous and consist in goals and values. While these are potentially realisable, they may also conflict. Agents learn to operate within the confinements of each relevant language game. Within the ‘game’ decisions concerning what is right conduct are identified. One language game may differ from another and vary according to changing circumstances. In addition, the rules of the language game must remain flexible enough to be revised should the need occur (Cilliers: 1998:135-140).

41. RE: Treves’ examples: The appendectomy performed by Treves on the Prince of Wales (Edward VII) and the death of his youngest daughter Hetty at the age of 18 years due to peritonitis from appendicitis are both documented facts (See: Trombley 1989:87, Montagu 1971:9, Graham and Oehlschlaeger 1992:33, Howell and Ford: 1980:167).
42. Treves, according to Graham and Oehlschlaeger (1992:65-66) had a persistent habit of referring to Merrick as ‘John’ rather than ‘Joseph’, even in his *Remembrances*. This raises such questions as: the meaning of giving him the name ‘John’ or an unfulfilled need on the part of Treves to re-name (thus placing himself in the role of a father). The questions remain unanswered:
43. A phenomenological approach to the relationship of consciousness and nature is discussed in detail by John Bannan in his chapter The Relationship of Consciousness and Nature. In, *The Philosophy of Merleau-Ponty* N.Y.: Harcourt Brace Publishers : 27-57.

44. In Wilde's story *The Happy Prince*, a swallow comforts the now commercially valueless Prince with tales of wonder and fantasy, "of the King of the Mountain of the Moon...of the Sphinx as old as the world itself...of pygmies, always at war with butterflies" (Wilde: 1880:96). I decided to end the pygmy-butterfly war.
45. Deformed or 'normal', the fact of being human requires that one be somehow embodied. Being embodied, however, is also contingent on *which* specific body parts (complete with their own particular anatomic- physiologic- bio-neurological make-up) turn out to be experienced as 'yours' or 'mine'. Being embodied, apart from a *conditio sine qua non*, is also inescapable; whatever one's particular ideal' body, wish or desire, their very expressions and stark limitations are defined within the very embodiment one has. For example, whether Merrick liked it or not (and he undoubtedly did not like it) there were some activities, sensory refinements, gestures not within his bodily scope. He wanted his body to do certain things, he probably willed his body to perform certain actions, but he remained subject to and at the mercy of, his body. He has two arms. Both are his. But the afflicted arm 'has' him as much as he 'has' it. The sense of 'having' and 'being had by' one's body is discussed by Plügge in *Man and His Body* (E. Eng, Trans.) In, *The Philosophy of the Body*. 1970. S.F. Spicker (Ed) Chicago: Quadrangle Books: 305-307.
46. As documented (Graham and Oehlschlaeger: 1992:22-23, 116-117, Montagu: 1971: 66 and Howell and Ford: 1980:156-157,209-210) Merrick had been overcome by the weight of his grossly deformed head, while taking a natural sleep, it had pressed against his windpipe, causing suffocation. There was, though, some discussion in both the *London Times* and the *British Medical Journal* concerning whether the suffocation was caused by the head falling frontward or backwards. According to all accounts, Merrick knew there was no cure for his disease. Perhaps, he chose to die.
47. Miller Williams (1997: 306) identifies in the following poem that, there appears to be a societal connotation that those differing from the 'normal' are somehow 'bad' and should ask for forgiveness for being born.

"The Ones that are Thrown Out

One has flippers. This one is like a seal.

One has gills. This one is like a fish.

One has webbed hands, is like a duck.

One has a little tail, is like a pig.

One is like a frog

With no dome above the eyes.

They call them bad babies.

They didn't mean to be bad

But who does."

48. From Lynch's screenplay (1979:112):

MERRICK:

"When will the stream be weary of flowing under my eye?

When will the wind be weary of blowing over the sky?

When will the clouds be weary of fleeting?

When will the heart be weary of beating... And nature die?

JOHN'S MUM:

Never, oh! Never, nothing will die;

The stream flows, the wind blows, the clouds fleet, the heart beats...

Nothing will die."

To this, I add the following quote from Derrida (1995: 115): "As often happens, the call of or for the question, and the request that echoes through it, takes us further than the response."

ADDENDUM I

Scanned images of Joseph Merrick from Montagu's book: *The Elephant Man: A Study in Human Dignity*, 1971, pages 85-86, 126-127 and 24-25.

Merrick's Skin and Bone Lesions

The illustrations showing Merrick's appearance (Figures 12 and 13) require few words. Figure 12 shows Merrick at the time when Treves first met him in November 1884. This illustration represents an engraving made from a photograph. It was published as part of Treves' report on Merrick in the *Transactions of the Pathological Society of London* in 1885. At the time the photos were made Merrick was 22 years and three months of age. As can be seen from this illustration, virtually every part of Merrick's body was affected by the disorder, with the exception of the left upper extremity and shoulder. The former was perfectly normal in every respect and remained so throughout his life. The skeletal elements forming the upper extremity were also perfectly normally formed.

Quite otherwise is the gross overgrowth and malformation of every part of the right upper extremity. In addition to the overgrowth of bone and soft tissue the greater apparent elongation of the arm was due to the extreme curvature of the spine to the right from which Merrick suffered, as may be seen in Figures 18 and 19.

Merrick's right hand was completely useless to him. The fingers were so deformed and the palm so overgrown with fibrous tissue and disordered elements of the subcutaneous tissues that it could at most have served only as a sort of anchor. For all practical purposes his left hand had to serve him for two. It was with this one left hand that Merrick wove his baskets and made his remarkable models.

All the bones of the right upper extremity were more or less affected by the disorder. The humerus was thickened, and at its jointure with the radius and ulna much deformed. The forearm bones showed the ulna to be badly affected while the radius (on the thumb side) was much less affected.

That the skin was involved wherever the underlying bones were also disordered presents an interesting and significant correlation. Sheathed (myelinated) and unsheathed (unmyelinated) nerves enter a bone along with the blood vessels that supply it. The nerve fibers can often be traced as far as the bone-forming cells. Wherever the connective tissue cells surrounding the nerve bundles, between the nerve fibers, and around the peripheral nerves (myelin sheaths) were pathologically affected the bone became disordered. It is this fact that presumably accounts for the close skeletal and skin association of the disorder that affected Merrick.

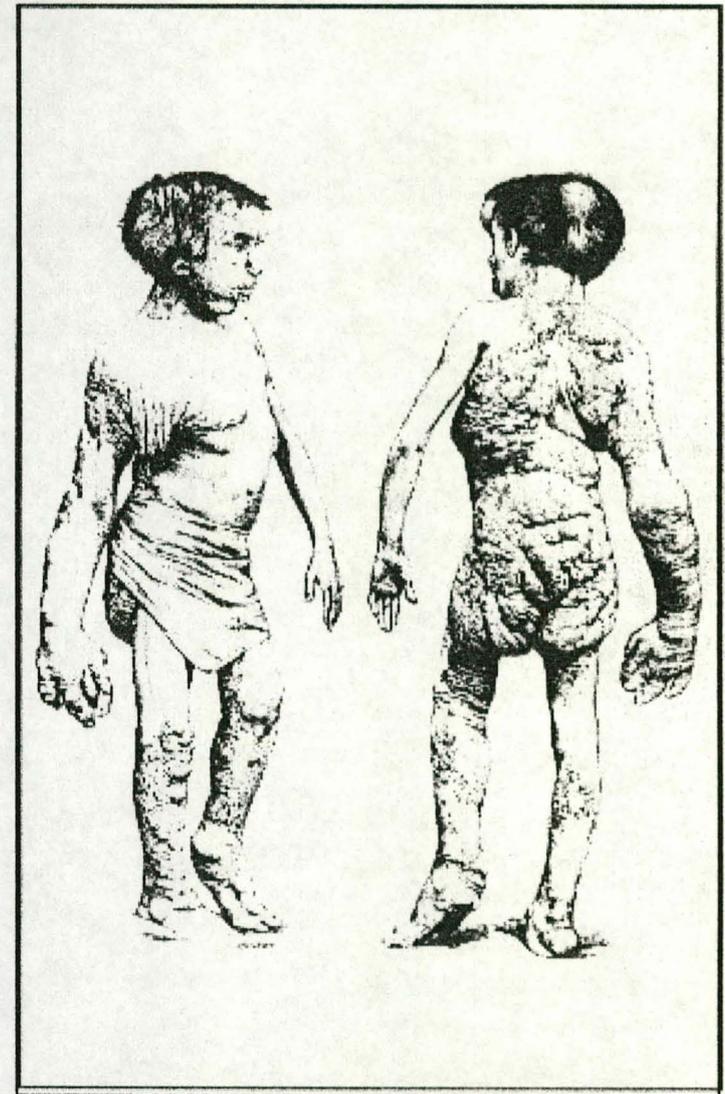


Figure 12. Merrick, as he appeared in 1884-85, shortly after being discovered by Sir Frederick Treves in a shop across the street from the London Hospital. These drawings from photographs are from *The Transactions of the Pathological Society of London*, Vol. 36, p. 494, 1885.

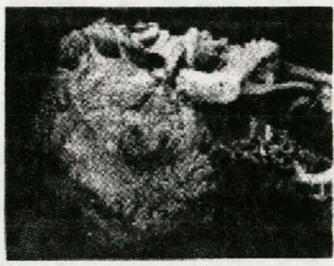


Figure 16. Right side view of the skull.



Figure 15. Left side view of the skull.

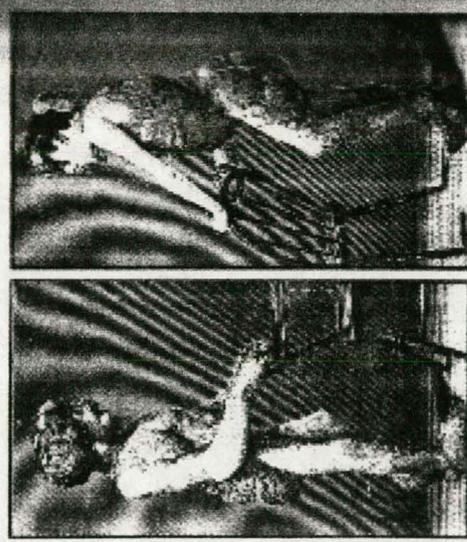


Figure 17. Front (top) and back (bottom) views of the skull. From *The Journal of the Royal Medical Society*, Vol. 1, pp. 168-81.

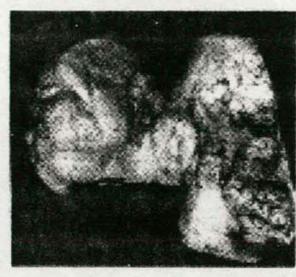


Figure 18. A front view of the skull, showing the bridge of the nose and the eye sockets.

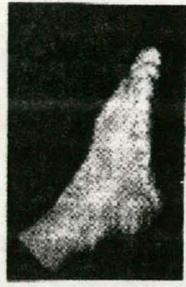


Figure 19. A view of the back of the skull.

Figure 19. A view of the back of the skull, showing the occipital condyles and the base of the skull.

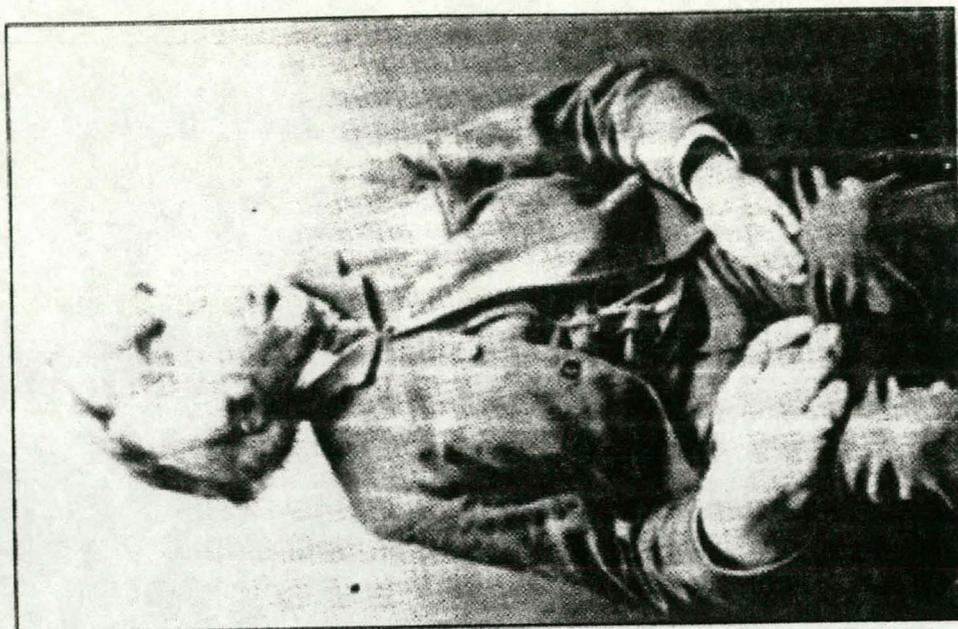


Figure 9 Merrick, dressed up, circa 1889, the year before his death

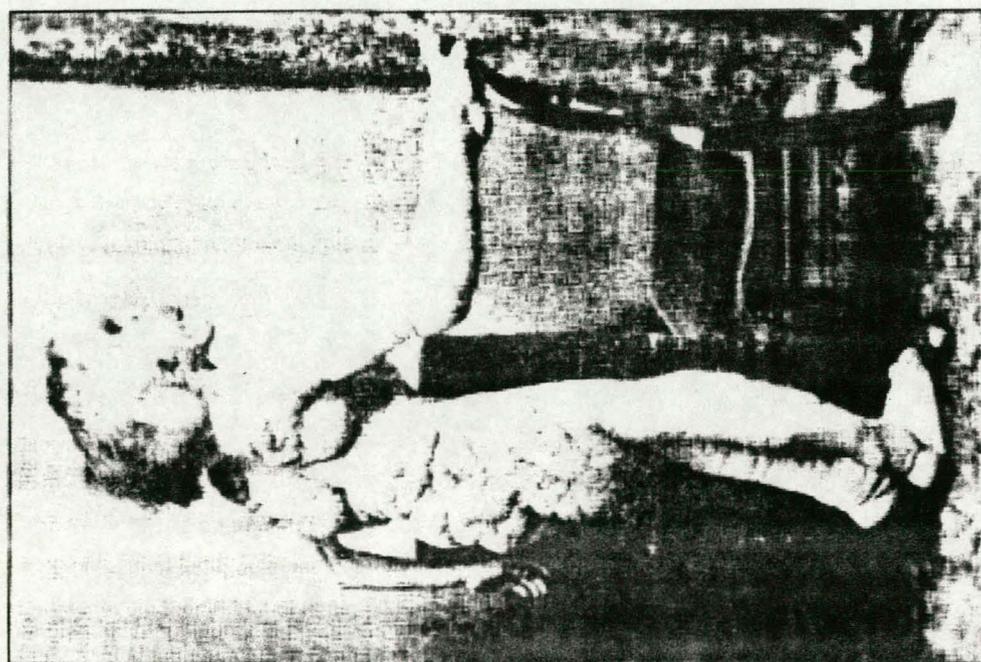


Figure 8 Merrick as he appeared some months before his death (From the British Medical Journal, Vol. 1, 1893, p. 916).

SECTION TWO

SINGER ON THE SLOPE

INTRODUCTION TO SECTION II

In current times the possibilities available to wealthy industrialised nations of actually repairing defects, rearranging genes and so on has made the unrestored face or body less socially acceptable, stubbornly *unhuman*. In many ways, ethical issues arising from ‘those different from us’ are culturally relative. At the same time, those born with, or who acquire ‘difference’ will always be a part of our world, as we will be of theirs.

In the industrialised West, those visibly different generally constitute a population in possession of differences that will not respond to available treatment. Yet all those different from us, be they in wealthy or poor countries, are resultantly stigmatised. Consequently, they are situated within a social structure of the “ ‘afflicted’- removed from normative conventions of social and scientific intervention”(Murphy: 1995:148).

While important inroads such as vocational training and easier transport have been made for those disabled (while having little bearing on those visibly different) they represent external aids only. They do not prevent or assuage the pain of looking ugly in a society obsessed with physical perfection, where just first impressions count to such an extent that they cloud all other aspects of human relationships.

What is essential for the quality of life of those disfigured or disabled, in Merrick’s time or ours, is the need for trained sensitivity and awareness on the part of society. For society, this means going beyond the body to the agent inhabiting it. For the disfigured, this means that, despite their understandable hypersensitivity, they too, can by their demeanour and expectations both consciously and unconsciously affect, in both positive and negative ways, the quality of human interaction with the non-disfigured (Macgregor: 1979:116).

In the previous section of this paper, I opened a conversation concerning those ‘visibly different’ using the example of Joseph Merrick *The Elephant Man*. From all accounts written concerning his life, I must say I found something endearing in his character. I liked him. I believe he enriched the lives of others, just as others enriched his life.

In adding to his story, I created a scene in which he, Treves, and Carr Gomm were making a model of a mountain. Let us return to look at it.

The uncompleted mountain sits on Joseph's table. On the right hand side it's slope is well-formed, gradual, rising and falling. The left-hand side remains unfinished. If we were perched on the top of the mountain, looking down we could see the frame: bits of cardboard and fragments of wood jutting out at irregular intervals like ledges. The glue, now dried, looks shiny, even slippery in appearance.

The rich metaphor of the *slippery slope* is one of the most powerful intuitional ideas in social science and ethics. In this image, some idea, situation or, as Pence (1995:30) writes, “even society as a whole” is imagined as standing perched on the top of a mountain slope. Lining the slope are moral principles and ethical tenets envisioned as chocks or checks- ledges that prevent the top of the mountain (usually presented as the *status-quo* situation or idea) from falling, capitulating into moral abandonment; for at the bottom of the slope waits Dante’s ‘*Inferno*’, the ‘*River Charon*’, in other words, moral chaos. The argument goes that if we remove one ledge, then we remove another, if we remove that chock, we will then remove another, and so on until the momentum is such that the slide to amorality is inevitable.

Slippery slope arguments presuppose a *status quo* position prohibiting a certain action or actions to take place (Den Hartough: 1994: 280). Merrick, deformed and disabled is the *status quo* position. We prohibit the killing of deformed or disabled members of our society. I perched him on the top of the unfinished mountain. But now, it is proposed that we move from the *status quo* position to a new one, which, as Den Hartough (ibid: 281) writes is “ the top of the slope, in which *A* will be considered acceptable or be permitted henceforth”.

The slippery slope argument in contemporary voice has been raised by many normal, disabled and handicapped people against the hiring (April 1999) of Professor Peter Singer to hold the chair of the Ira W. De Camp professorship of Bioethics at Princeton University’s Center for Human Values. The slippery slope argument and the basis for this dissension is the subject of Section II.

SCOPE OF SECTION II

Part I. THE SLIPPERY SLOPE ARGUMENT

In part one, I outline and discuss the slippery slope argument.

Part II. WHY ALL THE FUSS?

In part one of this section, I identify some of the arguments arising from the hiring of Singer by Princeton University. Considering the reactions to his appointment, I will argue with Singer (1993b:175) that “ the use of the Nazi analogy is utterly misleading.”¹ Yet, in order to understand the emotion behind Singer’s hiring, based mainly on fear, I felt it necessary to overview origins of the concept of eugenics. The history of the eugenics movement is valuable because it makes so dramatically visible cultural judgements that are inevitably part of defining any human difference as a disease or a disability subject to removal. In the eugenics overview, I conclude that public debates related to Singer’s hiring supply the necessary checks and balances needed to dissolve the slippery slope and suggest that eternal vigilance is the price society must pay not to fall into the abyss of amorality.

Part III. PETER SINGER’S STANCE AND ITS RELATIONSHIP TO THE SLIPPERY SLOPE

In part three, I overview Singer’s stance and identify many ethical issues he has opened in challenging the *status quo* position.

Part IV. THEORY AND PRACTICE

In this section, moving from theory to practice, I highlight a few considerations I feel should be included in ethical discussions particularly concerning matters of life and death.

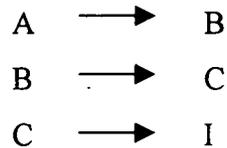
Conclusion: MERRICK AND OTHERS MEET SINGER

In the conclusion, I unite Merrick and other disabled people with Singer thus adding contemporary perspectives of some disabled persons to the questions arising from bodily difference. I identify that Singer’s position does not imply lack of respect for people with disabilities, quoting him (Singer :1993b:189) “ The principle of equal consideration of interests rejects any discounting of people on grounds of disability.”

PART I

THE SLIPPERY SLOPE ARGUMENT

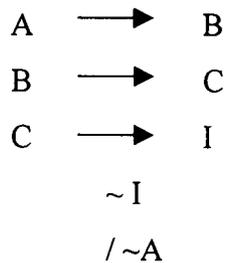
The most common of the two forms of the 'slippery slope' or 'wedge' (Beauchamp: 1997:39) argument used by protesters against principally Singer's argument is formulated in a valid deductive form (i.e. a string of "if-then" causal claims that lead to a conclusion). It would look like this:



"A" equals a particular group of actions usually questioned as to whether they should be legally accepted or morally permitted by society and presupposes a status quo position prohibiting "A" (Den Hartogh: 1994:280). Predictably, human behaviour suggests that once "A" is accepted as the norm, "B" will be accepted, and so on ending in "I". "I" in a slippery slope argument equals Dante's *Inferno*- or a result 'beyond the pale' (ibid) that no sane or rational human being could endorse. Implicitly, then:

$$\sim I$$

In an extended version of a deductively valid *modus tollens*, the argument implicitly or explicitly would conclude with the rejection of the opening premise:



However, while deductively valid, in its informal form, the slippery slope argument involves causal connections, which, in the case of deductive logic, are not certain. This is because the antecedent is not only a necessary but also a sufficient condition for the truth of the consequent (*IF A is true, THEN B must also be true*). Considering the inductive world referred to in slippery slope arguments, the actual consequences remain as unknowns. Slippery slope arguments rely, largely, on an appeal to emotions, particularly, fear (such as being cast into Dante's *Inferno*).

As mentioned, slippery slope arguments usually take two forms: an appeal to a prediction about empirical consequences if a moral stance is changed, or a causal linkage in reasoning should certain premises be accepted. As Den Hartogh (1994: 289) writes, “slippery slope arguments...should rather be taken as expressions of allegiance to the moral superiority of the status quo position and should be addressed as such”. In other words, the question actually concerns the boundaries between the status quo and the proposed new position. By addressing the language and meaning *per se* of the *status quo* position and through comparing that to the proposed one identification of the morality/immorality of a (proposed) action may better be defined. This is because the purported links of the causal chain may be identified as expressions of the grounds of condemnation, but do not add additional grounds for the condemnation of a proposed or actual practice (ibid: 290).

Supporting this, Beauchamp and Childress (1994:229) also present two versions of this argument: the conceptual (“the slope is slippery because the concepts and distinctions used in moral and legal rules are vague and may lead to unanticipated outcomes”) and the psycho-sociological (“the slope is slippery if making exceptions to a moral obligation result in permissivity and an erosion of respect for human life”). Khuse (1991:301) also makes the claim that the slippery slope, as a logical argument is unconvincing.

While we may easily sit-back and see that the argument is not logical, why is it that it keeps popping up like a *Punch and Judy* show? Probably the basis rests somewhere in the arena of, as Beauchamp (1997:39) writes, “judging acts as morally acceptable that one cannot support legalising.” According to him (ibid: 39-40) “Although particular acts of assistance in dying might be morally justified on some occasions, the social consequences of sanctioning practices of killing would involve serious risks of abuse and misuse and, on balance, would cause more harm than benefit to society.” In concluding his argument in support of the Oregon legislation ² as a “promising development”, he remarks that research should be carried out in coming years to determine the benefits and risks of such a trial programme that may or may not succeed (ibid: 40).

There is something undeniable in the fearful junction of morally justifying mercy killings on one level and the legislation of them on another. Proponents of the deductive model of the slippery slope claim that there appears a ready acceptance of “doctors to accept the ‘duty’ of judging the quality of an patient’s life, setting the parameters of an acceptable quality, and to act as an executioner when it fails to meet their professionally determined criteria and now it is sanctioned by law ” (Smith: 1997:268).

PART II

WHY ALL THE FUSS?

Professor Peter Singer has challenged a position held since the birth of Western philosophy, namely that *Homo sapiens* are the measure of all things. He provokes and confronts us writing (1996: 122)

“ Philosophy as practised in the university today does not challenge anyone’s preconceptions about our relationship with other species. By their writings these philosophers who tackle problems that touch upon the issue reveal that they make the same unquestioned assumptions as most other humans, and what they say tends to confirm the reader in his or her comfortable speciesist habits”.

This example, one of his many challenges, asks us to consider what it ethically means to be at the top of the pecking order, and he argues that we should re-think our place in the world. This of course gives rise to a multitude of other questions such as, what is it to be a ‘person’ or a ‘human being’. What constitutes our uniqueness, what gives us priority over other species? Is it language? Consciousness? Immortal souls? Domination-by right? Which animals, if any are people? These examples list only a few issues which subsequently give rise to more and enter into threads of numerous ethical debates such as: abortion, euthanasia, suicide, the world’s resources, animals and rights, *Homo sapiens* and rights, and world hunger, to name only a few. Singer had the audacity to challenge our comfortable world.

There have been numerous rally’s held against Singer’s appointment in the U.S. as well as before and during scheduled guest lectures in various countries (van Niekerk: 1999). The ‘fuss’ concerns certain statements, for the most part, taken out of context and made social-political platforms. While it is recognised that to feel something

emotionally is not the same as to logically and dispassionately argue pro or con an ethical point, the power of emotions in the case against Singer are strong. He has written, and the following examples are often included in reactions to his writings indicating why the debate is so intense:

“ Killing a defective infant is not morally equivalent to killing a person”(Singer: 1993a: 191). *“ Even an abortion late in pregnancy for the most trivial reasons is hard to condone unless we also condemn the slaughter of far more advanced forms of life for the taste of their flesh”*(ibid: 1976: 88). *“If killing the haemophiliac infant has no adverse effects on others, it would be... right to kill him”* (ibid: 1993b: 186).

In the protests, conclusions drawn from such statements are usually translated in somewhat different terms. For example, Singer advocates *murdering* (as opposed to the philosophically neutral term ‘killing’) *babies* (as opposed to severely handicapped new-borns). In these emotional responses, his advocating ‘murder’ also extends from ‘babies’ to handicapped adults.

An Associated Press report (April 1999) wrote that Singer had been given the nickname, “Dr. Death”. How would we react if Dr. Death sneaked the room of Joseph Merrick and injected him with a lethal dose of something- or- another just because he was deformed and disabled? Actually, if we follow the **emotional** responses, Singer wouldn’t even have to sneak into Merrick’s room. This is because, simply by association, Princeton University must also sanction such practices after all, they hired him. To identify this, the following is quoted from a protester (UPS April 17th 1999): *“This is getting close to Hitler’s politics...Hitler did the same thing in Nazi Germany to the deformed and disabled with the support of academics ... judging their lives not worth living.”* Since Princeton University, one of the ‘Top-ten’ U.S. Ivy-League Universities hired him, they must be in collusion with other universities or ‘academics’...and the ‘plot’ is so carried back to and *must* involve government intrigues, secret projects and so on. Certainly, while we may agree that logically this is not the case, the power of emotions cannot be denied.

Against Singer’s hiring, the example of the abyss of moral degradation to which we will all fall should his arguments be accepted is the archetype of Nazi Germany. For

example, Rachael Hurst (1999), Chair of the United Kingdom's *Disability Awareness in Action Group* in a letter to Princeton University wrote:

"In fact, both Singer and other supporters of 'quality adjusted life years' assessments are both satisfying their own prejudices and are in direct opposition to the basic premise of the Universal Declaration of Human Rights that states 'All human beings are born free and equal in dignity and rights'...written as an international response to the eugenics of Nazism- an effort to eradicate that attitude forever. The Declaration was written by a society who had witnessed massive killings of innocent people and the attempted eradication of ethnic minorities...What Singer and his supporters are advocating is eugenics- pure and simple."...

Echoed in writings on disability, Morris (1992:16) cites three examples of public policies that evidence the low-regard in which lives of the disabled are held. The first is the American court ruling that it is entirely rational for a person with serious impairment to choose to die.³ The second, British legislation excepting pregnancies diagnosed as likely to result in children with disabilities from a prohibition against terminating past twenty-four weeks. Lastly, the 1939 German decree authorising physicians to accord a mercy death to impaired persons who could not be cured. She concludes that, *"Implementation of this program corrupted the moral climate and facilitated subsequent stages of the Holocaust"* (ibid, my italics).

Even in the Kevorkian case, the lawyer for the prosecution was reported as saying, "There are eleven million souls buried in Europe that can tell you that when you make euthanasia a state policy, some catastrophic things evolve from that"(Grace: 1999:41).

Many disabled persons in wheel-chairs protested against Singer wearing black T-shirts that said, *'Not Dead... Yet'*.

OVER-VIEWING THE EUGENICS MOVEMENT

Concerning the hiring of Singer, proponents of the slippery slope argument would tend to reason something like this: Since abortion has been legalised, this has resulted in a consequential disvaluation of human life. So the next step is that we kill severely disabled new-borns, then having accepted this position, we will kill slightly disabled

new-borns (or blind or deaf or carriers of genetic diseases and so on) once that's accepted we will find it easy to kill babies of minorities (those our particular society considers racially inferior) and so on. Of course, the argument can be construed in many ways, from severely disabled new-borns directly to severely disabled adults.

The constructions of possible extensions are obvious. Although prejudices concerning 'those different from us' have been present for aeons, I will begin at the end of the 18th century in Britain and overview the genealogy of the eugenics movement from Britain to the U.S. and Nazi Germany, noting that they largely overlap. I will show that while appeals to emotions are strong, the basis of the Holocaust did not begin nor end with eugenics. Yet, while arguing that the basis for the Holocaust was not the eugenic movement, I will identify certain parallels in speeches and legislation that are present in contemporary times.

Doctors in society

Deformity, disfigurement, disease, and death were common in urban London during the Industrial revolution. In 1869, the average life span of an urban Londoner was 33 years. Hospitals, while numerous were regarded by the population in general as 'death houses'. According to McKeown and Brown (1994), all surgery done during this period was highly lethal, so the more surgery that was done, the higher the mortality rate; institutional confinement was associated with a higher maternal death rate based on acquired puerperal infection. Indeed, as we noted in Merrick's story, surgeons wore black coats, stiff with the blood of numerous surgical procedures, (the stiffer the more prestigious) rarely washed (Graham and Oehlschlager: 1992: 23). It follows that not until the basic principles of bacteriology were both understood (a development of the last quarter of the 19th Century) and applied in practice could any reduction of the death rate through the work of doctors and hospitals be expected.

The social prestige of doctors, which became established in the 19th century, did not extend to the official but inferior rank of health orderlies, and even less to the shady world of bonesetters and charlatans (Sournia: 1992: 363). Medicine in general, was evolving as a science, and a discipline in its own right. The principles of diagnosing diseases and actual disorders were slowly being identified. Yet, the scientific knowledge of medicine available at that time was not adequate to handle the

calamities of epidemics, war injuries, and a growing population. Ethics, as practised in medicine, was based generally on the Hippocratic oath. During this period, doctors were gaining a different and subsequently more powerful status in society (van Niekerk: 1998: 11). It was of course, white upper class males who held the position of doctors. As their power base grew, as well as quite rapidly the discoveries of science, the profession not only was enhanced, but also expanded. A theory which served to influence greatly these doctors and the times in which they lived (and often is still referred to in contemporary discussions) concerns population growth and food production; the writings of Thomas Malthus (1766-1834).

Malthusian Mixing

The population of Britain alone increased over three-fold between 1800 to 1900, despite much immigration (Quinton: 1997: 338). Problems with both increased industrialism and a rising population, particularly that of the urban, inflated numerous political problems, mainly how to provide for the needs of this new and growing urban population as well as how to control them.

Thomas Malthus (1766-1834) was an English political economist and historian who, in 1798 published a book called *An Essay on the Principles of Population*. This publication evoked a reaction against the earlier writings of Godwin, Condorcet, and others. They advocated the principles of emancipation and enlightenment which ensued after the French Revolution. Coleridge added his voice to the debate criticising urban industrialism and debasing the kind of work to which it condemned those caught up in it. His influence, reported by Quinton (1997:343), gave impetus to changes in political philosophical approaches, carried on by Ruskin and Morris. This 'humanistic' appeal, influenced by Romanticism resulted in much reflection in British thought during the Victorian age. Importantly, Coleridge influenced John Stuart Mill, moving him from "bleakly mechanical Benthamism in which he was brought up to larger conceptions of the true nature of human happiness and fulfilment"(ibid). Institutions such as the 'Poorhouses', 'Asylums', and 'Workhouses' were created, to some extent in good faith, only to later be condemned for existing.

Debates raged in the British Parliament such as that presented by Hansard (April 4, 1879) concerning *The Benefit of the Factory Legislation* (cited in Flynn: 1978: 130):

"What say you, then to children - children of the tenderest years? Why they become stunted, crippled, deformed, useless...I asked for a collection of cripples and deformities. In a short time, more than eighty were gathered in a large courtyard. They were mere examples of the entire mass. ...They stood or squatted before me in all shapes of the letters of the alphabet."

While Hansard made appeals for reform, Lord Chadwick (1803-1890) articulated the conditions of the working class in a somewhat different manner. While debating against the (now infamous) *Poor Laws*, Chadwick (cited in Del Col: 1996: 23) issued this report.

RE: *The Poor Law Commissioners Inquiry into the Sanitary Conditions of the Labouring Population of Great Britain*

"That the younger population, bred under noxious physical agencies, is inferior in physical organisation and general health...that the population so exposed is less susceptible of moral influences, and the effects of education are more transient than with a healthy population...these habits lead to the abandonment of all the conveniences and decencies of life, and especially lead to an overcrowding of their homes, which is destructive to the morality as well as health...these adverse circumstances tend to produce an adult population short-lived, improvident, reckless and intemperate, and with habitual avidity for sensual gratifications."

The influence of Malthus's argument in the writings of Lord Chadwick may be identified, although re-interpreted. Malthus proposed that poverty, and therefore by association, vice and misery, are unavoidable. They are unavoidable because population growth will always exceed food production. The checks and balances on population growth, according to his thesis, are wars, famine, and diseases. Malthus proposed that through 'sexual abstinence' (directed at the working class) population excesses could be diminished and a balance achieved. The atmosphere was such that the prevention of solutions to actual social problems were mixed with a often subtle leaning towards the idea that an individual was morally responsibility for being poor. The shift of moral responsibility for poverty was, then, directed from policy makers to the 'lower' social classes and promoted repressive legislation that worsened the

conditions of the poor in England (Kelly: 1969: 354). It was reasoned that better working conditions for the poor only encourage them to propagate.

Darwin's Influence

While the British Empire expanded (concurrently with enthusiasm and obsession at home for things, people and plants labelled 'exotic'), the British upper classes concerned themselves with 'total health'. *Mens sana in corpore sano* was a dominant concept for the Victorians, as important in shaping thought about human growth and conduct as nature was to the Romantics (Flynn: 1978: 44). The publication of Darwin's *Origin of the Species by Means of Natural Selection or The Preservation of Favoured Race In the Struggle for Life* in 1859 mixed, mingled, and influenced the culture of the times. His publication plus several other factors coincided giving the body a special conceptual prominence in 19th Century thought. In 1871, he published a second text, *The Descent of Man and Selection in Relation to Sex*, based on his original work but addressing only *Homo sapiens*. Darwin, a naturalist, concluded that in both physical and physiological behaviour there was no difference between man and other mammals. He also unfortunately attempted to explain that in social development, man struggled for existence and selection through natural means- and "attempted, although he was a humanist and well meaning, to apply a biological solution to philosophical social problems" (Nesbitt: 1982: 342).

It was also in the early 19th century that physiology, once incorporated into the broad discipline of anatomy, became a separate science and offered the promise that laws of life could be learned in their relationship to human beings. The emphasis was placed on the body whole, or what Charles Singer has called a 'synthetic study', organs viewed in relationship to other organs. The emergence of 'physiological psychology' together with the rise in interest in the actions of man based on psychological or psychiatric approaches also gained momentum.

Galton's Appropriation

At this juncture, Francis Galton (1822-1911), a half-cousin of Darwin, attempted to merge human mental abilities with heredity. Reportedly (Nesbitt: 1982: 48) 'an erratic thinker unable to complete research in any area over a sustained period of time', Galton extended Darwin's theory of natural selection into a concept of deliberate

social intervention, which he held to be the logical extension of evolution to the human race. He decided that an optimum human race could be best achieved through "selective breeding" (ibid: 67), accomplished through social intervention. This he called 'eugenics' the principle of which was that through encouraging better human stock to be bred (and conversely discouraging the breeding of less desirable stock) the whole 'race' of Englishmen would be improved. In England, this movement resulted in a pseudo-science called 'Social Darwinism'. Social Darwinism may be viewed as an odd-mixture of excerpts from Malthus' population theory fused with extrapolations from Darwin's evolutionary theory, mainly centred on Spencer's earlier phrase, "survival of the fittest", preferred, allegedly even by Darwin over his own term "natural selection" (ibid: 97).

To add to the movement, Britain, in its expansion of Empire, was caught up in the psychological- social appeal of things and people 'different'-'exotic'. Samples, objects, flora, fauna, as well as humans were exhibited as fascinating images of things not understood, alien and thus often deemed inferior; a mirror by which the English measured their own self-esteem. This amalgamation gained increasing momentum with demands for social legislation in accordance with the principle of 'the fittest must survive'. Together, those 'defective' (physically and socially) were being defined through eugenics, aesthetics and mass-culture- eugenics as a movement had begun (Kevles: 1995: 32). In Germany, Alfred Ploetz became the leader of this movement and drawing from various sources added the concept of racial hygiene into the already-becoming complex issue of eugenics.

The Concept of 'Racial Hygiene'

The modern development of the concept of 'racial hygiene' may be traced to a Frenchman, Count Arthur de Gobineau (1816-1882) who published a work titled "*Essay on the Inequality of Human Races*" in 1855 (Friedman: 1965: 32). Although he wrote in a romantic fashion, creating a fair-haired Aryan race superior to all others, his work did not claim for the superiority of any particular fair-haired race, nor did he denigrate other racial groups (ibid: 97). Influenced by Marx, the gist of his writings in fact reflected class differences, the aristocracy versus the proletariat. Yet, portions of his text were appropriated and distorted to fit a particular theory- that of racial

superiority. His work, reported by Simpson (1964: 341), went generally unnoticed in France but was quite popular in Germany.

In 1890, Gobineau's book was revised and translated. This met with such enthusiasm that in 1894 the Gobineau Association was founded in Munich Germany (ibid: 74). At this time, the Pan-Germans, an anti-Jewish group supporting strongly German nationalism rose in power. One of their members was an Englishman name Houston S. Chamberlain who held German citizenship. In 1899 he published a book in both German and English called "*The Foundations of the Nineteenth Century*". Departing from the style of Gobineau, he held the German race to be the purest form of Aryanism and damned as inferior Jews, Gypsies and Negroes. (Mosse: 1997:121). Aryans, he purported, were responsible for all great Western cultures of the past, which had declined because of racial mixing. Racial mixing was to be condemned by all means, racial hygienics maintained. Eugenics, Social Darwinism and Racial Hygiene now merged and from the 1900's various Eugenics societies rose up in Europe, Britain and the U.S.A. (Kevles: 1995: 4).

Sequencing eugenics: the rise of nationalism.

The strong nationalistic movement in Germany gave impetus to the eugenics movement. Lazare (1995: 45) gives an example of this: In 1900 a contest was held by one of its eugenic societies for the best essay on the subject 'What can we learn from the principles of Darwinism for application to inner political development and the laws of the state?' The winner interpreted culture, society, and morality in terms of the struggle for survival. Society, he claimed, must enforce laws to prevent the white races from degenerating to the level of "aborigines". This degeneration was unavoidable as long as society continued to pander to the physically and mentally weak. Among his other points was a "suggestion that a panel of doctors be present at the birth of each child to judge whether the child was fit enough to live, and, if not, kill it."

Hardly confined to Germany, the Eugenics movement not only took hold in Europe, Britain, and America, but also branched out to include other disciplines. Particularly important was the influence of 'Mental Hygiene' on the fledgling disciplines of psychiatry and psychology (Kevles: 1995:89). Well meaning, many of these societies

attempted to provide improved treatment for mental patients. It was, perhaps in their enthusiasm that a further role was perceived, the safeguarding of the public's mental health by weeding out the unfit. To the extent that these organisations and thoughts grew, contingent on their particular political, cultural and historical period, so grew their sphere of political influence (Lazare: 1995:56).

Legislating eugenics: Sterilisation.

Laws of a general nature provided for the establishment of institutions and colonies that served to isolate the mentally ill from the rest of the population, thus facilitating both control and prohibition of procreation. Examples of two such laws are Britain's Mental Deficiency Act of 1913 and the South African Mental Disorders Act of 1916 (Simpson: 1964: 81). Other laws were more definite and defined such as the Sterilisation Acts for the insane in the United States, passed by many States during the early 1900's. From sterilisation of the insane further writings indicate a movement towards social sterilisation on different grounds, often politically biased. Not to be outdone, similar statements were heard from other countries. Reported in 'Periodical Notes' in *The Birth Control Review* (1925), Volume IX, Number 6 (June) is the following quotation: "Far more conservative of the proposition to regulate the stream of life at its source is Birth Control. Sterilisation of the unfit is actually law in many places. And now Denmark proposes euthanasia and has introduced into its parliament, according to press dispatches, a bill which would provide that the attending physician shall have the power to put painlessly to death an infant who is hopelessly deformed or mentally." This proposed bill did not pass through Parliament. With the exception of Germany, in general, movements concerning legislation of sterilisation fell out of favour in most countries by the late 1920's.

Legislating eugenics: Euthanasia

Euthanasia, by definition 'easy death' in common understanding suggests its usage as a painless peaceful death for someone incurable and terminally ill.

As we earlier mentioned, Alfred Ploetz introduced Social Darwinism and founded in Germany, the Racial Hygiene movement. In his book, *Fundamental Outline of Racial Hygiene* he argues for the elimination of counter-selective processes, or processes such as war and legislation protecting the weak or ill (Simpson: 1964:88). As an

illustration, he gives the example of a couple who produced a malformed child. A Board of Doctors, he recommends, should give the child, an easy death with an overdose of morphine (ibid). Proposals were put forth in Germany for the legislation of euthanasia in 1921 and 1922, however they were rejected. In 1935, a French-American Nobel laureate, Dr. Alex Carrel published a book titled *Man the Unknown*. According to Simpson (Lazare: 1995: 95), within three years it was translated into nine different languages and appears to have been widely supported by eugenic societies operating in Britain, the U.S. and the Continent. In this book, euthanasia is directly linked to the eugenics movement. He writes (quoted in ibid: 96):

“Those who have murdered, robbed while armed with automatic pistol or machine gun, kidnapped children, despoiled the poor of their savings, mislead the public on important matters, should humanely and economically be disposed of in small euthansic institutions supplied with proper gases. A similar treatment could be advantageously applied to the insane, guilty of amoral acts...Philosophical systems and sentimental prejudices must give way before such a necessity. The development of the human personality is the ultimate purpose of civilisation.”

Hitler's Germany

We have so far in a broad outline sketched the eugenics movement noting that it was evidenced throughout the much of Western thought. Without a deep investigation into the social-economic and political climates of the countries in which eugenics as a movement peaked, suffice to say that the overview is incomplete, beyond the scope of this addendum. For those disabled, because the Nazi analogy is often used as final end of the slippery slope, we will now jump much time and events and focus on Hitler's Germany.

When Hitler left Vienna he was much influenced by the Pan-German movement, was a confirmed anti-Semite and a sworn enemy of Marxist ideology. Largely, his views reflected radical Social Darwinism, viewed as a situation in which individuals as well as groups were engaged in an endless struggle for superiority, and thus, power.

In *Mein Kampf*, familiar arguments appear such as the struggle of life forms for survival, the victory of the strong over the weak, ruthless disregard for the notion of

rights, the 'Jewish menace' to name only a few. Before Hitler assumed power it was illegal to perform sterilisation for 'eugenic' reasons. After gaining office in 1933, various laws were enacted which lent support to the eugenic and mental hygiene movements (Rathborne: 1999: 74). An important law passed only four months after Hitler assumed power was called the "Law for the Prevention of Hereditary Disease in Posterity" (Ehrhardt: 1965:115).

The categories of people under this law were:

1. "Anyone suffering from a hereditary disease could be sterilised by means of a surgical procedure if it could be expected with some certainty, according to the experience of medical science, that his posterity would suffer from a serious physical or mental hereditary disease.
2. Persons would be considered as hereditarily diseased in the sense of this law if they suffered from any one of the following disorders: innate mental deficiency, Schizophrenia, Manic-depressive insanity, Hereditary epilepsy, Hereditary Huntington's chorea, Hereditary blindness, Hereditary deafness, and /or Severe hereditary physical abnormality.
3. Further, persons could be sterilised who suffer from severe alcoholism" (ibid).

Further legal enactment's took place and in November 24th 1933, "habitual offenders against public morals" were added to the list of those to be castrated. Importantly, the Nazi definition of offenses against habitual offenders of public morals included those found guilty of "racial pollution" (ibid: 124).

Prior to 1933 anti-Jewish acts had no legal basis under the Constitution, although they occurred. However in 1935, the *Nuremberg Laws* came into effect and as the Reich their subjects were divided. Some were made citizens with full political rights, others were classified as subjects of the State. Based on 'racial' and ideological grounds, these laws placed the Jews beyond the boundaries of political rights (Mosse: 1997:99). In addition, in the same year a law was passed called the *Blood Protection Law*, based on protection of 'racial purity' (Hilberg: 1961:42). A claim is made by some writers (Simpson, Nesbitt) that the Nazis began their eugenics on small minority groups such as the Freemasons and Jehovah's Witness. Because of the relatively small movement of eugenics starting with essentially voiceless minorities, it is postulated (Mosse: 1997: 55) that the Jews, declared scapegoats, and the largest group not holding political rights, held onto a belief that it would never be their 'turn'. At this

time the momentum of the eugenics movement had not reached its full force and there was a possibility, should the Jews have been declared 'targets' in the first 'exercise' the outcry would have thwarted the Nazi's purpose (Hilberg: 1961: 67).

Hilberg asserts that sterilisation and euthanasia were not the original ideas of the Nazi's. They were ideas that were both supported and promoted throughout the world by numerous eugenic societies. Germany was the only country in which the social-political-economic climate was such that the materialisation of the final goals of eugenics was, most horrifically, realised.

The Fray and its Consequences

It was, of course, necessary in the political climate of Nazi Germany to have scapegoats. These were the Jews. Anti-Semitism however was not confined to Germany alone as I identify in the following summary.

The oldest theology of all – that of the ancient Greeks who invented the word, was based on the attempt to rationally reflect the cosmos, creation, and man's role in the world. This contrasted with the mythical expressions of belief held during that time.

Throughout history, cultures have risen and fallen in which their belief systems have been based on different things, such as God, witches, in spectral sightings, totems or trees. Societies have come and gone in which beliefs, such as a person's race determines moral and intellectual properties, that slaves and women have no rights, that three claps of the hands are required to summon the gods, and that Jews are evil were tenets. Beliefs such as these and many, many more were held as articles of faith. Many of these beliefs are now considered unreasonable and have vanished. Many remain.

Beliefs are necessary for people to define the social order and their role in it. Beliefs serve as guides and sources of inspiration, or as ways of reshaping, when necessary, the social order. Belief systems are part of the natural world, prescribed to by many as unquestioned articles of faith, traditionalised into the fabric of society (Cohn-Sherbok & Cohn-Sherbok: 1997: 4). Particular embedded beliefs served as axioms, unquestioned norms, no more likely to be doubted than fundamental notions. These

notions, so embedded, became essentially unnoticed, concealed from view, excluded as a part of society's conversation. With very few exceptions, individuals accept their society's cognitive beliefs and values, spoken as words or unarticulated as symbols as part of their own being. These cognitive models, of which people may be vaguely aware or totally unaware, effect all aspects of human relations. The orders and patterns of our culture and society, like our language, become imprinted in our minds as children- these patterns are all our developing minds have to draw upon. As we mature, these models often tend to guide our behaviour and they are territorial.

Anti-Semitism may be assumed to have both the status and properties of a cognitive model. However, the subject remains underdeveloped. This is a consequence of the mind's programming in setting apart the Jews as radically different from all other people, needing particular concepts to define and label them, and unique ways of treating them. This is so because the treatments and concepts used when dealing with other peoples or people would not apply and do not apply to Jews (ibid: 22). This leads us to ask why people were so influenced and/or to identify- the source of the malefic qualities assigned to the Jews. The reasoning behind the Jews' supposed perniciousness varies from the mundane to the imaginary. Is it based on religion, ethnic group, strange physical propensities, and special powers? For the roots and contents of this phenomena must be understood three fold: as an expression by a non-Jewish culture, as a permanent feature of Christian civilisation, and in socio-political conditions- which by their differing natures, dependent on the time, either saw an increase or a decrease in the expression of anti-Semitism (Lazare: 1995: 96).

Anti-Jewish agitation has existed for several thousand years. Jews were deported to Babylon twice, in 597 BC and again in 586 BC. During the time of the ancient Roman Empire, Jews were not regarded as citizens. But the timeline of the advent of Christianity is perhaps, the most significant point.

Jesus of Nazareth was born in Bethlehem, a city in Judea. He was a Jew. His followers were also Jews. His teachings diverged from the mainline Judaic teachings, one premise being that a Messiah would come and a prophecy would be fulfilled. Jesus' followers believed him to be the promised Messiah. Jews had an opportunity to join this school of thought. The majority rejected the claim. For his political and social activities, Jesus was called to trial.

Pontius Pilate, a Roman, convening the trial, chose to be politically expedient- he washed his hands of the matter. In doing so, the decision for life or death was left to the mob. The people composing the mob were Jews. Their decision prevailed. Jesus, in keeping with the common mode of execution of that era, was crucified. The Jews killed the Messiah. The Jews killed Christ.

During the first three centuries of this era, Christianity became increasingly powerful. The Edict of Milan, in 313 AD gave Christians rights under the Empire. After Constantine, Emperor of Rome converted self and empire to Christianity, antagonism, and later persecution of the Jews became commonplace (Cohn-Sherbok and Cohn-Sherbok: 1997: 34). St. Peter, one of Christ's original twelve disciples, keeper of the "Keys to the Kingdom of God", had earlier become the first Bishop of Rome. Each subsequent Roman Bishop was regarded as his successor in rights, duties, obligations and privileges- the theory of Apostolic Succession was established. Pope Adrian I, dying in 795 AD, formalised the temporal powers of the papacy. From the time of St. Peter (± 64 AD) the church was constructing an institution of power and authority.

Integrated in their theology, from the fourth century AD, and probably before, Jews were labelled as the killers of Christ. In addition, the thorough antipathy towards the Jews took on almost protean quality- beliefs about Jews became integral to the moral order of a Christian society (ibid: 77). All charges against them became both possible and plausible.

In Western Europe, imperial authority, ending with the fall of Rome in the 5th century, set the church on a path that supported a variety of relationships between church and state- both political and ecclesiastical. During the Dark Ages and Islamic conquest of Palestine, there was little threat to the Pauline church of Gnostic heresy affecting its doctrines. Jews specifically had been theologically addressed as early as in the third century and this continued throughout the church's history (ibid: 72).

During the medieval age, the church was successful in its "Gentilisation" of Jesus. According to Cohn-Sherbok and Cohn-Sherbok (1997:77). "He was no longer confused with the Jewish Messiah who would have followed the path of an Essene Gnostic, upholding, as he should, the Mosaic laws of his forefathers thus fulfilling the

prophecy. Jesus, was no longer a Jew- he was the Christ who had languished at the hands of the Romans, but whose destruction had been sealed by the duplicity of the Jews.” With a uniform and concise reconstruction of the life and passion of Jesus, the church texts and theology reigned supreme. With the increase in political control, the influence of the church on society was mighty.

Because the plebeians were generally ignorant and oppressed, it was expedient for the church to give them a source of evil on which to ventilate- something that could occupy their minds. In the middle of the 11th century, the English conducted anti-Jewish campaigns resulting in the fact that during 1290 – 1656 there were virtually no Jews in England (Lazare: 1995:43). Yet, even without the physical presence of Jews, their images remained akin to reality, because it was taught so. The Jews were Devil followers, if not the personification of the Devil itself. They were guilty of every imaginable horrible deed and act, guilty of every natural disaster that could be conceived. This became part of the belief system, then an axiom, handed down from generation to generation throughout Europe, with or without ever having seen or personally known a Jew.

In 1090, the church launched its First Crusade (De Villenardouin and De Joinville: 1963:55). The purpose was to free Jerusalem and concurrently, to expand the economic and political power of the church. One group suffered grievously from the mad enthusiasm that followed the call to arms by Pope Urban III. These were the original occupants of Jerusalem and Judea, now also dispersed throughout the Western kingdoms- the Jews. If heretics were accorded a trial, the Jews received none.

The history of the First Crusade, one of five launched by the church, encapsulated the influence of the church in its determination to expand its will – and to provide convenient scapegoats (ibid: 81). The position of the Jew and the Roman Catholic Church remained status quo for many years. Jews were put to the test under the Inquisition, pogroms took place in many cities, and towns and the activities of Jews were economically restricted. Jews were forced to wear identifying marks or garments, usually of a yellow colour. (These visual acts of intolerance had their roots historically in the Code of Omar I of Mesopotamia- 637 AD [Lazare: 1995:12]).

Under Roman Catholic monarchs in the 12th - 14th centuries, persecution of Jews was the rule. Mobs would unleash fury at those held responsible for the martyrdom of Jesus. During the Fourth Lateran Council, Pope Innocent III proclaimed an official policy of restrictions against the Jews. Throughout all Europe, Jews were despised, forced to live outside the confines of respectable society. The Black Death was solely the responsibility of the Jews who had poisoned wells, spread the plague- this was common knowledge. During the 16th century, Jews had found temporary refuge in Poland and Russia, both Christian countries. Later in that century, the brief reprieve was ended with renewed persecutions, chiefly instigated by the Cossacks of the Ukraine, but readily accepted by Russia and Poland as a whole. Jews were barred from craft guilds, agronomy, professions, and large mercantile enterprises- they lived by small commerce.

The Protestant Reformation, successful in challenging the tenets of the Roman Catholic Church, brought enlightenment to many- but by that time anti-Semitism was already such a common ingrained practice that the thought of questioning intolerance was never even conceived (Cohn-Sherbok and Cohn-Sherbok: 1997: 91). In the 18th and 19th centuries in Europe, as the rise of modern nation-states evolved, there was a gradual separation of church and state. The extent of the separation varied from country to country. The cycle of overt Jewish oppression was generally lessened during these centuries. However, until the time of Vatican II, in the “Great Intentions”, a prayer dutifully recited by Roman Catholics for centuries, there was only one group of people qualified as “*perfides*”- betrayers, traitors, apostates, conspirators, deceivers, renegades, tricksters- the Jews. By qualifying Jews as *perfides*, the church was inexorably spun in the perpetuation of anti-Semitism (ibid: 21). Jews were encouraged to migrate to England and the American Colonies. The French government enfranchised them in keeping with the democratic concepts of the French Revolution. This was the Age of Enlightenment.

With the formation of the German Empire in 1871, legal discrimination on the grounds of religious practice was adopted. However, persecution, not legally based on religion, could take place based on race. Therefore, the Jews became a race. While they were a ‘race’, they remained subjects of the State which gave them some privileges- abandoned when the Nazi’s came to power. During the years leading up to

the Second World War, no religious body, the Roman Catholic Church, the Protestant Churches, the Greek and Russian Orthodox churches, the Muslims or any others entered the arena shouting loudly against the prevalent theme of persecution of the Jews (ibid: 125).

IF's and THEN's - Any need to worry?

Protesters against Singer's hiring are say that he advocates eugenics. IF eugenics is accepted, THEN the final result will be another Holocaust. I have very briefly overviewed the eugenic movement. It has hopefully become clear that shifts and mixes, resulting in the Holocaust were dependent on many factors such as: the complex interactions of a twisted yet charismatic leader, a particular social-economic climate, an erosion of the principles of Justice within a political-legal system, deeply embedded assumptions of Jews as non-beings, and, fitting nicely into the whole, the particularly egoistic appeal of eugenics. The ethical question we are obliged to ask is if there is a need to be concerned. In other words, if Singer's stance is accepted, viz. the killing of disabled new-borns, then will societal devaluation of disabled or deformed adults become so pronounced that it will then sanction their killing as well?

If we only look at the surface, we may see threads in the history of eugenics echoed in contemporary times. An example that comes to mind is Singer's (1993a: 191) statement: "*Killing a defective infant is not morally equivalent to killing a person*" compared to America's Dr. Henry Haiseldon who, from 1915-1918 "electrified the nation by allowing the deaths of at least six infants he diagnosed as *defectives*" (Pernick: 1997: 89). Yet, threads echoed on the surface do not necessarily reflect reality. I suggest the bottom line lies in Foucault's admonition, of all things, regard them as dangerous- yet remain pessimistically optimistic. The loud outcries emanating from the hiring of Singer represents, I have argued, a fear articulated from those 'different from us'. And perhaps the fear concerning a supposed slippery slope fall to eugenics are captured in the words of Thomas Nagel (1970:146):

"To say that altruism and morality are possible in virtue of something basic to human nature is not to say that men are basically good. Men are basically complicated; how good they are depends on whether certain conceptions and ways of thinking have achieved dominance, a dominance that is precarious in any case. The manner in which

human beings have conducted themselves so far does not encourage optimism about the moral future of the species.”

The price to pay for the precariousness of dominance, of power, is eternal vigilance.

PART III

PETER SINGER’S STANCE AND ITS RELATIONSHIP TO THE SLIPPERY SLOPE

Peter Singer, a contemporary utilitarian, argues against two specific theses. The first is the simple Benthamite moral equating of humans and other sentient animals and what he calls a prejudice based on ‘speciesism’. *Speciesism* is a neologism attributed to Richard Ryder. Its intended usage is a pejorative, similar to racism and sexism (Gillon: 1996:47). Using the example of pain and suffering, Singer argues that “pains of the same intensity and duration are equally bad whether felt by humans and animals”(Singer: 1976:19). The grounding of different human moral rights and moral evaluations in Singer’s thesis are based on the human’s possession of differing interests. Such are: the capacity for self-awareness, ability to plan for the future, ability to have relationships with other humans, close family and personal ties, the importance to other affected human beings, plus other attributes such as the capacity for abstract thought and complex communication (1993a: 283-286). A member of a species possessing these qualities, claims Singer, may be considered more valuable than lives that do not possess such qualities. However, all sentient beings, while differing in sort of qualities, do possess moral qualities.

The possession of these qualities as befitting a utilitarian position, does not undermine the principle that in making moral decisions the interests of all sentient beings affected by the decision must be taken into equal account. Illustrating this point, Singer writes: “mere membership of our biological species cannot be a morally relevant criterion...A chimpanzee, dog or pig, for example, will have a higher degree of self-awareness and a greater capacity for meaningful relations with others than a severely retarded infant or someone in a state of advanced senility. So if we base the right to life on these characteristics we must grant these animals a right to life as good as, or better than, such retarded or senile humans.”(Ibid: 22).

This debate gives rise to others such as the concept of human fetal viability, personal identity, and 'personhood' among others: a lacuna in ethics as a whole and medical ethics in particular. Thus, Singer, by challenging the *status quo* position, is inexorably drawn into the slippery slope argument.

For example, continuing from this debate is the argument against the legalisation of voluntary euthanasia. This form asserts that, "although some acts of euthanasia may be morally permissible..., to allow them to occur will set a logical precedent for, or will causally result in, consequences that are morally repugnant" (Battin: 1994:n25: 115). The major point stressed in such arguments is that, for example, since abortion became legalised in many countries there has been a decline in the value and respect for human life. Now, if voluntary euthanasia were to be legally permitted, then it would lead to an even further decline in respect for human life. If voluntary euthanasia was to be permitted then involuntary euthanasia would be the norm and so on- no chocks, no checks, no balances: the *Inferno* of Dante waits. C. Everett Koop, once U.S. Surgeon General, wrote (1977: 538) that allowing brain- damaged infants to die would create a slippery slope. In his view, it would result in the killing of other impaired new-borns further resulting that killing would occur in cases such as, "all people with neurological defects after automobile accidents."

This well illustrates the slippery slope intuition that once handicapped infants are deprived of a right to life other infants and handicapped people are at risk, ultimately all of the human race or portions of the human race deemed 'unfit' for whatever reason. Such fears are currently articulated from a variety of 'undervalued' groups such as the disabled, disfigured, the elderly, minorities, and other groups traditionally discriminated against. Indeed, the role of aesthetic judgements in the definition of disease and disability remain controversial issues in applied ethics today. Should laws protecting the disabled against discrimination apply to those who are simply judged unattractive? Do aesthetic values create disability in the same way as stair-steps or other physical barriers do to a wheel chair confined person? I suggest that the history of eugenics identifies the futility of trying to open such questions by seeking to draw a sharp line between "objective ' physical cause and 'subjective' values. Anytime a culture defines disease or causation, it makes a partial subjective, value-based judgement" (Pernick: 1996: 56). Greater awareness, then, of the inevitability of the

value-based components in these ethical questions may or may not help in reaching more ethical judgements. However, by pretending that such judgements can ever be made without values only de-legitimizes and prevents the critical analysis of the implicit values at stake. This calls, then, for a continuous open and democratic society where issues are raised, no matter from what platform in a multitude of different voices. In doing so, the ethical debate becomes richer and the slippery slope in fact takes the form of an ethical watchdog.

PART IV

THEORY AND PRACTICE

As identified, there are numerous ethical issues arising from Singer's stance. Considering rising and revisited biomedical issues, I believe we may say that his views have served to increase ethical dialogues on a wealth of issues. Yet, thinking reflecting and writing theory does have a tendency to remove the philosopher from real world situations. A few of which are identified below.

A few problems between theory and practice

Theorists, mainly all removed from clinical practice, present to those in the medical field, (many working on the ground) arguments concerning matters of life and death. Ethical theories, it is argued, well may provide answers to questions clinicians face when faced with moral dilemmas concerning 'difficult choices'. While I personally subscribe on a theoretical level to Singer's position, I argue that *praxis* presents a different face: that those who agree with Singer's position ought to be able to actually perform the action they theoretically support. I wonder if they would be able to do so. To illustrate this, I offer the following examples for thought:

1. Theorists can not be held legally liable for the performance of actions they, for example argue as ethically correct: "*To summarise: passive ways of ending life result in a drawn-out death. They introduce irrelevant factors (a blockage in the intestine, or an easily curable infection) into the selection of those who shall die. If we are able to admit that our objective is a swift and painless death, we should not leave it up to chance to determine whether this objective is achieved. Having chosen death we should ensure that it comes in the best possible way*" (Singer: 1993b: 213).

“A year or so later, Dr. Kevorkian was first successfully prosecuted for assisting in the death of his seventeenth patient, Thomas Hyde, a 30 year old man in the last stages of Lou Gehrig’s disease (amyotrophic lateral sclerosis)”(Pence: 1997: 23). In this case, he was acquitted. Later, in 1999, assisting in another death, he was found guilty of second-degree murder (Grace: 1999:41). Could, would ethicists such as Singer and Tooley be willing to take on the legal network? The practice of medicine is a social construct, responsible to and created by society. The practice of ethics follows the same mandate. Ethicists, I suggest, ought to include in their scope of practice, greater consideration of the problems faced by agents when theory is practically applied.

2. In addition, the injunctions of law are contingent on cultural variables, for example: “...if children are dying, incurable, and in great pain, the Royal Dutch Medical Association has accepted that they have a right to die, even if their parents object”(Pence: 1985:146).

In the U.S., under the 1984 amendment to the Child Abuse Prevention and Treatment Act of 1974, non-treatment in Baby Doe cases constitutes child abuse. These amendments, signed into law by Ronald Regan in October of 1984, circumvented the injunction against the Baby Doe rules. This removed the federal government somewhat from the arena, and placed the responsibility on individual states. While different states have different laws regarding issues ranging from assisted suicide, choosing to die, and the treatment level extended to all but the most hopeless cases of severely impaired new-borns (Pence: 1994:198), perhaps the most controversial is the State of Oregon’s Death with Dignity legislation (see note 4). How many acts have in one historical period and culture been morally condemned as wrong, only in another time and space to be judged as right!

4. Nor are they actually placed in the position of being bodily present at the time of *euthanasing*, letting die, or killing: “...killings require that acts of persons be the causes of death. Accordingly, a natural death occurs when a respirator is removed, because natural conditions simply do what they would have done without the respirator”(Beauchamp: 1997:35).

Schiedermayer (1999:74) illustrates this in his personal clinical confrontations with patients requesting to die. Concerning his fourth example he writes:

" I consent on a ventilator-dependent quadriplegic man who refuses to be weaned so that he might die more easily when his ventilator is stopped. He is looking for a physician who is willing to stop his ventilator. The spinal cord unit physicians refuse to do this. In addition, the patient requests that he be not suctioned once the ventilator is removed. I offer to see him, but it is a mistake. The moment I see him I know I can't do what he wants. He doesn't have his talking trachea in but I don't have to hear what he says. He whispers, Help me, come back later...I can't accept him in transfer. But my friend does, without any real qualms. The patient dies two days after the withdrawal of the ventilator, with a high fever and aspiration pneumonia. It was all the noises in the dying I remember: the rasping, the bubbles, the whimpering-suffering." Well known to all, not all deaths, human or animal, are easy deaths. They may be even planned to be 'easy, gentle deaths' and all the equipment and humans necessary to 'make it gentle' may well be there, yet nature is capricious.

Conclusion

MERRICK AND OTHERS MEET SINGER

Complaints against ethical arguments raised by Singer and many others have been perceived and interpreted in a different manner by those disabled. For example, Silvers (1998:3) a disabled philosopher writes,

"The grounding of the question asking whether profoundly impaired neonates should live tests how much we value human life itself, as distinct from what individuals accomplish in their lives. And questioning why we favour severely compromised people over clever animals suggest where we place the value of being human."

Now, while we may sympathise with Silver's point: " The grounding of the question asking whether profoundly impaired neonates should live tests how much we value human life itself as distinct from what individuals accomplish in their lives." As Tooley (1997:41) writes, " Most people would prefer to raise children who do not suffer from gross deformities or from severe physical, emotional, or intellectual handicaps." I believe this to be correct. And to bridge the gap between being 'different' in a world 'normal' is no easy task, neither for the parents who, for

example, raise a handicapped child from birth nor for a person who later in life acquires disability or deformity. The emphasis on what an agent accomplishes in her life is certainly a worthy point. However, while no disrespect is meant to handicapped people, they (as a group) understandably tend to suffer, at minimum, a greater crises in self-identity (see: Pernick: 1997, Carey: 1989, Lefebvre: 1996, Strauss, 1988, Macgregor: 1974) than do those agents considered bodily 'normal'.

Singer (1993b: 188-189) while not addressing specifically the differential point concerning what individuals accomplish in their lives says, (re: The discovery that Thalidomide administered to pregnant women as an aid to sleep resulted in abnormal births. Causally numerous abortions were requested by such women and subsequently the drug was withdrawn from the market and compensation given to effected women by the manufacturer):

“ It still may be objected that to replace either a fetus or a new-born infant is wrong because it suggests to disabled people living today that their lives are less worthy than the lives of people who are not disabled. Yet it is surely flying in the face of reality to deny that, on the average this is so. If we really believed that there is no reason to think that the life of a disabled person is as likely to be any worse than that of a normal person we would not have regarded this (*Thalidomide*) as a tragedy. The children would merely have been 'different' ... To believe this implies no disrespect at all for those who are lacking limbs; it simply recognises the difficulties they face... Nor does this imply lack of respect or equal consideration for people with disabilities who are now living their lives in accordance with their own wishes.”

In writing this, Singer clearly identifies a real and stark reality; we do address those visibly normal, the handicapped, and the disabled in a different manner. We 'normal' do adore those 'normal' and thus become a part of the 'Tyranny of the Normal'.

In the story of Joseph Merrick, a man grossly deformed who lived in the 18th century; it is documented that he wrote an 'Autobiography' concerning his bodily 'difference.' Because of its detached style, it is contested whether he actually wrote it, or his exhibitor wrote it (Graham and Oehlschlaeger: 1992 12-15). In the introduction to the book *Disability, Difference, Discrimination*, (1998) written by Anita Silvers, David

Wassermann and Many B. Mahowald there is also a short narrative, written by Silvers, that concerns the attitudes of society towards 'difference'. While time and space separate the players, a common tie remains. To illustrate this, we need only compare quotes from Joseph Merrick's (1874) *'Autobiography'* (Howell and Ford: 1980:183) with that of Anita Silvers (1998:1):

Merrick:

"...I was sent about the town to see if I could procure work but being lame and deformed no one would employ me; when I went home for my meals, my step-mother used to say that I had not been to seek for work. I was taunted and sneered at...being deformed, people would not come to me to buy their wares. In consequence of my ill luck my life was again made misery to me...but my deformity had grown to such a large extent that I could not move about the town without having a large crowd of people gather around me..."

Silvers:

"...a faculty colleague and I sat soaked by rain outside the local grocery store, waiting until some pedestrian happening by, was willing to walk in, find the manager, and convince him to un-padlock the only entrance to the store wide enough to admit our wheelchairs. The manager's reason for closing it shut? Other shoppers were using it to push shopping carts out to the parking lot, and sometimes further...As you well know, we accept countless humiliations and repudiations daily and learn to ignore most of them, but then something like this happens.... What's wrong with these people?"

What is it then to be a *self* captured in a disabled or deformed body? Such a body appears to be *too* much a body, *too* real, *too* corporeal: a body that stands in its own way. Viewing it in another dimension, no less reductive, a disabled body appears to lack something essential, something necessary to make it less identifiable; it seems *too* little a body, *too* lacking in something essential, deficient, not real enough.

However, something remains lacking, for the 'body' itself seems to be in part a product of cultural construction. For example, as Donley and Buckley (1997:x) point out, mediasation of the 'ideal' body, the perfect body, has consequential results. The

rise in anorexics, the implied need for body reconstruction and perpetual 'youth' are particular contemporary, largely Western, cultural constructs.

If there is such emphasis on the 'ideal' body by those possessing 'normal' bodies, then what perceptions of self are present in agents possessing deformed or disabled bodies? A disabled body presents a very threat to the very idea of a 'normal' body. And, as Porter (1997: xiv) writes, a disabled body informs current theoretical views of the body normal. Such approaches shields theory from its objects, it protects us from confronting the body in any other way than comparison and fascination with the unknown difference.

In this section, I have shown that Singer does not argue for the killing of disabled humans who live their lives in accordance to their wishes. Did Merrick live his life in accordance to his wishes? Certainly, it appears that part of his life was lived as he wished. However, society, because of his deformity, largely defined the limits of his social interactions. Is it possible for deformed or disabled agents to have the opportunity to live their lives in accordance to their wishes? How precarious is the balance?

The supposed threat of extinction of disabled agents represents an emotional response to an envisioned 'slippery slope'. However, as I have identified, their claims, while emotive, ought not to be blithely dismissed. Those 'bodily different' call to us and we are obliged to heed their call. Their voices ask us to think about where we stand on issues such as bodily difference, of life and death, values, and theories of justice. They require us to ensure that the societies in which we live keep open and in public scrutiny, the myriad of moral issues surrounding those visibly different. It is a valid call to all of us as moral agents to listen with a different ear to the voices of those disabled and visibly different.

NOTES TO SECTION II

- 1 Supporting this, Godhagen (1996:23) writes: “The development in Germany well before the Nazi’s came to power of a virulent and violent ‘eliminationist’ variant of anti-Semitism, which called for the elimination of Jewish influence or Jews themselves from German society. When the Nazi’s did assume power, they found themselves the masters of a society already imbued with notions about Jews that were ready to be mobilised for the most extreme form of ‘elimination’ imaginable.”

- 2 The Oregon Legislation: Death with Dignity Act (1994). “Under this Act, terminally ill adults are allowed to obtain lethal drugs from physicians in order to hasten death and escape unbearable suffering (Beauchamp: 1997: 41,n4).”

3. “Choosing to Die” Morris refers to the case of Kenneth Bergstedt, one of four usually cited by disability activists to make this particular point. The other four cases concern David Rivlin, Larry McAfee, and Elizabeth Bouvia. All of these persons, quadriplegics, petitioned the courts for permission to remove life-sustaining equipment (respirators in the case of the three men and artificial feeding in the case of Ms. Bouvia). In all these cases, the courts adhered to the line of argument taken by the U.S. Supreme Court in *Cruzen* and *Casey*, namely that individuals have the right to refuse invasive treatment even if it is life sustaining. Bergstedt and Rivlin had their ventilators turned off and died. McAfee did not, and Bouvia initiated but then abandoned an attempt to die from starvation.

Legal and moral considerations of ‘competence’.

As Pence (1995: 29), points out, in legal and moral considerations concerning ‘competence’ it is important to distinguish between different types of cases. These he groups broadly as:

- Those of *competent adults* (considering the extent of their illnesses and defining their rights to refuse/ accept further treatment).
- The appointment of surrogates in *cases in which a patient was, but no longer is competent.*

- Surrogates for infants and child patients and judicial rulings on standards concerning those patients '*never competent*' (i.e. severely handicapped new-borns and adults).

The Bouvia case is of particular interest in that issues concerning the autonomy of competent adults requesting to die as well as social prejudices against disabled/disfigured people are particularly entwined. Let us unpack these briefly.

The Bouvia Case

Elizabeth Bouvia was twenty-five years old and almost totally paralysed by cerebral palsy. In addition, she suffered from degenerative arthritis. She never had use of her legs, although she had some control over movement in her right hand, and enough control over her facial muscles to chew, swallow and speak. In September 1983, her father drove her to a general hospital in the U.S., where she was diagnosed as suicidal. She stated that she wanted "just to be left alone and not bothered by friends or family or anyone else and to ultimately starve to death"(quoted in Pence: 1996: 41). Hospitalised, her psychiatrist refused to allow her to starve herself to death. Bouvia then contacted the American Civil Liberties Union (ACLU) and a reporter. Her case, the request to die, was accepted by a physician and lawyer as a *pro bono* (charity) case (ibid: 42).

Autonomy

To define or delimit actions considered 'self-regarding' John Stuart Mill in his essay *On Liberty* published in 1859 (1974:12) applied his principle of harm. Mill's aim is to centre these source of actions on the individual thus, 'self-regarding', as opposed to values imposed on an individual by the state. In other words, the state should not impose on an individual an action or actions for the public good or even in his or her best interest. Conceiving autonomy as an individual right, then, essentially affords it to serve as a limitation against government interference.

Question of competence

The theoretical question in the Bouvia's case was not whether she was 'competent' or 'incompetent'. Instead, as Pence (1994:55) identifies, the question would concern *if there was any reason to question* her competence. In other words, if there was no

room to doubt her competence, “then she would have a right to autonomy and she herself rather than anyone else could control the decision to die.” The application of the principle of autonomy, in the case of Bouvia, was challenged by some, saying that she appeared to want to commit suicide only when in hospital, was ‘unstable’ and appeared to have ‘some psychiatric problem’ (ibid).

Judicial Ruling: Bouvia Vs Superior Court (California Reporter, vol. 225, 1986: 296-308)

The judicial ruling in the case of Ms. Bouvia’s stated,

“...*(Moreover)* if the right of the patient to self-determination as to his own medical treatment is to have any meaning at all... *the right of a competent adult patient to refuse medical treatment is a constitutionally guaranteed right which must not be abridged....* In Elizabeth Bouvia’s view, the quality of her life had been diminished to the point of hopelessness, uselessness, unenjoyability, and frustration. She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless. She is not to be faulted for so concluding...As all matters, lines must be drawn at some point, somewhere, but that decision must ultimately belong to the one whose life is the issue.”

Complex conditions for autonomous choice.

This precedent was important in establishing a legal framework for competent adults to refuse medical treatment, thus affirming the value of autonomy. Yet, as Winkler (1993:358-359) identifies, in complex cases such as Bouvia’s, “Particularly when the stakes are high, it is not enough merely to be competent and rational in a legal sense. It can be also critical whether the choice is *authentic*, in the sense of being consistent with one’s own most important values and commitments.” In this way, Winkler suggests that moral interpretation of cases informs ‘the understanding of principles (such as autonomy) rather than principles determining the morality of cases.’(ibid). The question of autonomy was also raised although directed from a different source than one might have expected. Longmore (1987:158), a disabled lawyer, said:

“ *Given the lumping together of people with disabilities with those who are terminally ill, the blurring of voluntary assisted suicide and forced ‘mercy’ killing, and the oppressive conditions of social devaluation and isolation, blocked opportunities, economic deprivation, and enforced social powerlessness, talk of*

'rational' or 'voluntary' suicide is simply Orwellian newspeak. The advocates of assisted suicide assume a non-existent autonomy. They offer an illusory self-determination".

Longmore's claim is that the Bouvia case is exemplary of a deeper social problem. In the creation of a despised 'abnormal' minority, American society (obsessed with idealising youth, beauty, fitness, and wealth) allows the disabled only one option consistent with the concept of autonomy: the decision they may take to die. It is in Longmore's critique of American society, placing greater value on the idealised 'normal' to the sacrifice of values such as caring, erudition, and community that a question may be considered. Can the concept of 'autonomy', after all a social construct, be used prejudicially against, for example disabled minorities?

After-word

An 'after-word' concerning the Bouvia case is important to articulate. Quoting Pence (1995:47):

"After her victory in court, Elizabeth Bouvia did not kill herself. Some caring people had come forward and offered to help her die. These friends seem to have shown her that life could be worth living, and gradually she came to change her mind". This important point, present in many disability studies, was also raised in the story of Joseph Merrick, "*the eye of others is where we seek the validation of our existence, and this is the yardstick by which we judge our self-worth. But universal approval, or even acceptance is far less important than the consistent love and admiration of a few consistent others*" (Lefebvre: 1996: 63).

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