Good life in the balance: A cross-national study of Dutch and Australian disability perspectives on euthanasia and physician-assisted suicide.

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GOOD LIFE IN THE BALANCE: A CROSS-NATIONAL STUDY OF DUTCH AND AUSTRALIAN DISABILITY PERSPECTIVES ON EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE.

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Dr. Alan Tapper
ABSTRACT

This is a cross-national qualitative study with the purpose of obtaining perspectives held by people with quadriplegia and leading figures in disability movements in the Netherlands and Australia on the issues of euthanasia and physician-assisted suicide (EPAS). A disability voice is not prominent in public debate on EPAS in Australia or the Netherlands, even though people with disabilities are often thought to be vulnerable in relation to EPAS policies. Disability perspectives are potentially valuable in illuminating issues in relation to euthanasia and physician-assisted suicide, because issues of dependence, independence, and individual autonomy play important roles in relation to both EPAS and to living with disability. The study’s methodology uses a phenomenological approach and incorporates aspects of heuristics and grounded theory. Its conceptual framework incorporates MacIntyre’s (1999) theory of acknowledged dependency and vulnerability; Habermas’ (1989) theory of knowledge; and Festinger’s (1959) theory of cognitive dissonance. The main sample of twenty people with quadriplegia (the grassroots sample) was interviewed in the Netherlands and in Australia. Additionally, four leading figures (the leaders sample) in disability movements in each country were interviewed, a total of 28 informants. Informants were recruited by means of referral from organisations and snow-balling techniques. In-depth, semi-structured interviews and an inductive data analysis, based on Colaizzi (1978), were used. The main finding was that grassroots informants hold views on EPAS similar to those of mainstream public opinion. No substantial difference was found between countries but there was some difference between the responses of the grassroots and leader samples. The grassroots informants’ views on EPAS were characterised by a value system that used the socially dominant value of ‘individual autonomy’. These views were largely not based on personal experience. Additionally, informants did not appear to be well-informed on issues pertinent to EPAS. The study also found
that the informants’ disability experience was characterised by an opposing value system, that of interdependence. In the interdependence framework informants experienced wellbeing and outgrew fundamental issues of human suffering. In the individual autonomy framework such issues were referred to an individual’s right to choose to have EPAS. Informants felt little cognitive dissonance about this apparent difference between their views on EPAS and their experience of suffering, even though suffering is common to the experience of living with quadriplegia and to individuals’ motivations in desiring EPAS. The significance of this low cognitive dissonance in relation to the informants’ views on EPAS was explained using the study’s conceptual framework. Various factors may play a role in preventing the informants from using their private interdependence values in the way they conceptualise their views on the public policy issue of EPAS.
DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

(i) incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;

(ii) contain any material previously published or written by another person except where due reference is made in the text; or

(iii) contain any defamatory material

Signed: ……………………………..

Date: ……………………………..
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My supervisors have truly represented a guide and stimulus towards the best that I could produce and tried to steer me away from reefs and sheer cliffs. If any navigation errors are still evident they are of course entirely mine. I greatly appreciate their help but none so as much my Senior Supervisor Dr. Alan Tapper’s level of critique and assistance. His collegial approach, as that of Associate Supervisors Dr. Bob Jackson and Dr. Christopher Newell, was of great help. Dr. Judy Cockram has been very generous in giving her time and independent advice on several occasions throughout this study. Dr. Jan Gray provided valuable advice on the themes and categories that emerged from the interview transcripts. I am grateful to them all.

I am of course very thankful for the honesty and willingness of my informants to give so much personal and thoughtful detail about their lives and views on the complex, sometimes emotional, issues that participation may have raised for them. I don’t underestimate the value of their contribution and thank them for it.

A number of people made themselves available to discuss aspects of the study with me or to obtain insight in wider contexts such as of palliative care, euthanasia and disability policy and international aspects of ethics of the study. I sincerely thank Dr. Kevin Yuen, Dr. Ben Zylics, Prof. Hans Reinders, Jeroen Zomerplaag, Prof. Linda Kristjanson, Prof. Evert van Leeuwen, Dr. Arko Oderwald at the Vrije Universiteit at Amsterdam and Dr. James Kennedy.

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CHAPTER ONE

INTRODUCTION

1.1 Background to the study

In this study I present beliefs and assumptions that Dutch and Australian people with quadriplegia, as well as some leaders in disability movements, hold about euthanasia and physician-assisted suicide (EPAS). This study is concerned with their perspectives on the phenomenon, practice and legalisation of EPAS and their possible impacts, including upon people who have disabilities.

In this chapter I present the context to this study, including philosophical, historical and social aspects; its purpose and significance; my beliefs; and some attempts at clarifying key terms.

1.1.1 A note on disability terminology

As preferred in the APA Publications Manual (American Psychological Association, 2001) I have mostly used the person-first terminology, such as people with disabilities to indicate people who have a disability. This terminology reflects that the person, the human, is the prime identifying, or defining, subject rather than the disability. This way of addressing persons who have disability is also Edith Cowan University’s preferred terminology. Sometimes I have also used disabled people. I have done this for two reasons. Within the international disability movement both terminologies are used: persons with disabilities, for the same reason as given above, and disabled people or persons. The second is used in recognition of social forces such as physical, human-made barriers, as well as public practices, policies and attitudes that exacerbate the disabling experiences of one’s impairment.
1.1.2 The Netherlands and Australia

The Netherlands and Australia have a similar population size although with vastly different population densities. The Dutch population stood at almost 16 million in 2000 with 6.4 per cent growth in the 1990’s (ESWIN, 2002) and for Australia at 19.7 million in 2001 (Australian Bureau of Statistics, 2003) with a 1.4 per cent annual growth rate. Both countries are parliamentary democracies and are liberal welfare states. In the Netherlands EPAS has been discussed, tolerated and practised for some thirty years and has been enshrined in legislation since 2002. Euthanasia was briefly legal in Australia’s Northern Territory during 1996 and debate on EPAS has been ongoing to the present. Various Australian States have discussed EPAS-enabling Bills in their Parliaments. In neither country has a prominent disability voice has been heard about EPAS.

1.1.3 Euthanasia and physician-assisted suicide

The sick … they see to with great affection, and let nothing at all pass concerning either physic or good diet, whereby they may be restored again to their health. Such as the sick of incurable diseases they comfort with sitting by them, with talking with them, and, to be short, with all manner of helps that may be. But if the disease be not only incurable, but also full of continual pain and anguish, then the priests and the magistrates exhort the man seeing he is not able to do any duty of life, and by overliving his own death is noisome and irksome to other and grievous to himself, that he will determine with himself no longer to cherish that pestilent and painful disease; and, seeing his life is to him but a torment, that will not be unwilling to die, but rather, take a good hope to him, and either despatch himself out of that painful life, as out of a prison, or a rack of torment, or else suffer himself willingly to be rid out of it by other. And in so doing they tell him that he shall do so wisely, seeing by his death he shall lose no commodity, but end his pain. And because in that act he shall follow the counsel of the priests, that is to say, of the interpreters of God’s will and pleasure, they shew him that he shall do like a godly and a virtuous man. They that thus be persuaded that finish their lives willingly, either with hunger, or else die in their sleep without any feeling of death. But they cause non be such to die against his will, nor they use no less diligence and attendance about him, believing this to be an honourable death else he that killeth himself before that the priests and the council have allowed the cause of his death, him as unworthy either to be buried or with fire to be consumed, they cast unburied into some stinking marsh. (More, 1516, pp. 98–99)
It is quite striking how Saint (Sir) Thomas More (1516/n.d.), in his satire on
the ideal State of Utopia, anticipated many of the features of the contemporary EPAS
debate and of its practices. He highlighted such contemporary features as
unrelievably, unbearable, individual, subjective suffering as a sufficient rationale for a
voluntary EPAS and the *courage* required undergoing it. He also pointed to the
tension between care for an ill person and burden on society, raising the possibility of
subtle coercion. Indeed thoughts of *euthanasia* and its rationales are not new. What is
new is the widespread acceptance of it as a state policy.

This section discusses some of the historical background to the present public
demand for EPAS. Kennedy (2002) points out that euthanasia and the law has been
widely debated in Europe and America from the end of the 19th century. Norway,
among others, had by then amended her Criminal Law to reduce punishment for
doctors engaging in euthanasia, and euthanasia had been vigorously debated in
Germany from that time. The American states of Ohio and Iowa made early attempts
in the beginning of the 20th century to enact euthanasia legislation. England tried the
same in the 1930’s and pro-euthanasia societies arose during that time in England
and America. Eighty per cent of New York physicians were in favour of euthanasia
in 1939. Much of this effort was based on the pseudo-science of eugenics, first
formulated by Charles Darwin’s cousin Francis Galton in 1883. Eugenics became
state ideology which saw the legal toleration of countless people with intellectual
disability and mental illness being sterilised and support withheld from *defective*
newborns in many Western countries (Kliwer & Drake, 1998; Park & Radforth,
1998; Louter, 1997). In Australia and the Netherlands legally approved eugenic
practices seem to have been confined to segregating and congregating people with
disabilities (Louter, 1997; Gillgren, 1996).

It was in September 1939 that these eugenic developments culminated in a
secret order, signed by Adolf Hitler, against a background of the Nazi government’s
eugenic doctrine of a superior Aryan race. This order authorised *Aktion T-4*, a
program with a purpose of the killing of people with disabilities. By end 1945
between 200,000 and 300,000 of them had been killed. The killing had been done by
medical doctors and psychiatrists, deceptively under the cloak of the very institutions
that were in place to the supposed benefit of people with disabilities. The
terminology that was associated with this operation therefore used terms such as "final"
medical assistance and mercy killing (Gallagher, 1995). The grey buses that transported people with disabilities to their deaths carried the logo of the ‘Charitable Patient Transport Company’. Gallagher, himself using a wheelchair, believes that these German doctors acted on feelings that reside in all of us:

Such things as the profound fear of those who may be different; the loathing of the vulnerability of the sick and disabled; the demented drive for perfect health, perfect bodies, perfect happiness. (p. xiii)

Few parents of those who were killed actively objected to the killing of their children. In fact a survey in 1920 showed a majority support for mercy killing among them (Gallagher, 1995). Among Nazi propaganda was a film called Ich klage an (I accuse) where the husband of a woman with multiple sclerosis accused society of prolonging his wife’s suffering if euthanasia were not permissible in effecting her death with dignity (Gallagher, p. 61). Gallagher (2001) and others (Boyd, 1995; Wolfensberger, 1984, 1984a, 1987), including psychologist and WW2 concentration camp survivor Viktor Frankl (Hoffmann, 1995), have pointed out various parallels between the Nazi and Western societies and drew different conclusions about a possible repeat of the Nazi “euthanasia” practice in contemporary society. Gallagher (2001) believes that the safeguards provided by the American Constitution would prevent its repeat in the USA whereas Boyd, Frankl, and Wolfensberger warn against a possible repeat and oppose it. It is beyond this thesis to go into more detail on these points.

The killing of people with disabilities was the precursor to following mass genocide of Jews and others. In the late 1960’s and 1970’s euthanasia and physician-assisted suicide again became acceptable issues for public debate in a number of Western countries. International abhorrence of the Nazi eugenic “euthanasia” of people with disabilities, and genocide of six million Jews and other groups of people (Gallagher, 1995; Wolfensberger, 1984) had not produced a taboo on its discussion in England and America (Kennedy, 2002). However, in Germany euthanasia continues to find a majority public opposition because of the enormities carried out under the heading of “euthanasia”. In the later debate, this history was often invoked to raise a slippery slope objection to euthanasia, to which others responded that Hitler’s euthanasia program, unlike present motivations for EPAS, had nothing to do with compassion or mercy (Sneiderman, Irvine & Osborne, 1995). However
“compassion” and “mercy” were frequently and publicly used by the Nazis to justify their euthanasia campaign (Gallagher, 1995).

Contemporary moves to allow “euthanasia” occur against a background of a combination of a greater emphasis on individual (patient) rights, choice and self determination; growing secularisation, individualism and technological developments in medical practices, which acquired powers to extend life beyond points considered acceptable by patients (Callahan & Hanson, 1998; Callahan, 1994; Griffiths, Bood & Weyers, 1998; Mann, 1998). Nowadays people have greater expectations of medical technology’s ability to extend life (Cassell, 1975). Medicine has removed many straightforward causes of death but its success has also resulted in most remaining causes of death becoming more drawn out, unpleasant and undignified dying experiences (Griffith, Bood & Weyers, 1998; Mann, 1998).

The international pro-euthanasia movement’s profile was raised by a number of prominent legal cases about rights to refuse treatment, drawing the public’s attention to the paradox of impressive medical abilities on the one hand and the doubtful quality of life that could be enabled by it on the other. Two such high-profile legal cases in the USA were that of Karen Ann Quinlan in 1976 and Nancy Cruzan in 1987, who were both in persistent vegetative states, kept alive by feeding tube and respirator. In a number of other legal actions litigants sought to establish a disabled individual’s right to end one’s life for reason of unbearable suffering arising from their disability. In 1993, Canadian Sue Rodriguez, a woman with amyotrophic lateral sclerosis (ALS), was unsuccessful in establishing a right for her to operate a intravenous drip in order to kill herself when she judged the time had come that her life was no longer worth living. Stating the familiar theme of self-determination and choice in the EPAS debate, she said at her petition hearing at the British Columbia Supreme Court: “I want to be in charge of my life and my death. I feel it’s a choice that I’ve made for myself, and I would like to be the one that does, you know, the final deed” (Sneiderman, Irvine & Osborne, 1995, p. 565). Four months after the judgment she killed herself, apparently with the illegal assistance of a physician.

Countries, such as the United Kingdom, Canada and the United States, continue to witness a high public interest in euthanasia. Oregon narrowly accepted physician-assisted suicide in a public referendum in 1994. In the UK the House of Lords Select Committee on Medical Ethics (House of Lords, 1993–1994) rejected

1.1.4 The Dutch context

As in the international debate (Callahan & Hanson, 1998; Callahan, 1994), the Dutch euthanasia debate in the late 1960’s also largely came about as a result of techno-medical pressures within a climate of increasing patient rights and secularisation. The Dutch had their own version of the Cruzan and Quinlan cases about withdrawal of treatment in the case of Mia Versluis in 1967, who was unconscious, brain damaged and kept alive by a respirator. This prompted a public questioning of medical powers and the kind of life that should be maintained by it (Griffiths, Bood & Weyers, 1998). The Dutch Penal Code of 1881 prohibited euthanasia as a criminal offence, and still does. But there was also a Dutch feeling that in a time of rapid social changes, the 1960’s and 1970’s, it was an inherently good thing to break through taboos, euthanasia being one of them. Together with a distinctive Dutch pragmatism, which is built on discussion and consensus, the Dutch attach value to bespreekbaarheid, that is the ability to talk about an issue openly. But bespreekbaarheid means more than that. It implies, by discussing it, the break-through of a taboo, which ought to be allowed in practice (Kennedy, 2002). Ten Have (1998) has suggested that the Dutch talk much about EPAS, in contrast to other cultures, in order to overcome a cognitive dissonance. This cognitive dissonance is caused by a discrepancy between an ideal of overcoming suffering in the private act of medical killing and its practice which is less than ideal: “We try to overcome the gap between what we do in practice and what we say we do. … To do otherwise is to dissimilate” (p. 218). The Dutch discussion began in earnest in 1969 with the publication of an influential book by J.H. van den Berg, called “Medische macht en medische ethiek (“Medical power and medical ethics”), which highlighted the medical powers to keep people alive beyond points that were acceptable to them.
Reflecting trends across the Western world, two strong influences in “getting euthanasia onto the [Dutch] agenda” (p. 49) were present. The first was a cultural change characterised by secularization, individualization and democratisation, and the second the medical-technological change (Griffiths, et al., 1998). Dutch palliative doctors Zylics (Enklaar, 1999) and ten Have (1998) have also described such factors in debating EPAS.

The first Dutch Court case about euthanasia occurred in 1973. A physician, doctor Postma, killed her elderly, partially deaf, wheelchair-using mother by lethal injection, upon her mother’s repeated requests to do so. This roused much public sympathy and other doctors came forward to confess similar actions. The Court imposed a light sentence on the physician, one week suspended imprisonment and a year’s probation (Thomasma et al., 1998). This set in train a series of trials, with courts progressively defining euthanasia and developing guidelines for its practice. Landmark trials over the next decades gradually widened criteria under which EPAS could be conducted. The 1984 matters of Schoonheim and Pols brought legal acceptance of the defence of the Dutch medical doctrine of force majeure or necessity. This means that, in the doctor’s defence of her act of medical killing, there had not been any other alternative open to the doctor than to kill, given the patient’s overwhelming need for medical attention in circumstances of unbearable suffering and their request to die (Griffiths). In 1985 the Admiraal case resulted in legal acceptance of a defence of careful practice, meaning the doctor’s careful weighing up the decision to commit EPAS in consultation with colleagues. In this matter Admiraal performed euthanasia on a non-terminally ill woman who was suffering from her multiple sclerosis: “life was nothing but torture to her, mainly because of her complete dependency on others” (Griffiths, p. 66). In 1994 the Chabot case established the legality of euthanasia in the presence of non-somatic suffering. Psychiatrist Chabot was convicted of the offence of assisted suicide as a second, independent physician had not examined the patient, even though Chabot had consulted other colleagues. The case involved a woman who persistently requested assisted death. She was not terminally ill but was suffering as a result of multiple

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1 Pieter Admiraal, a Dutch anaesthetist, has been a leading figure in the Dutch pro-euthanasia movement for many years.
close family deaths and marital break-up and no longer wanted to live. She was susceptible to psychiatric treatment but consistently refused it. The Court observed that the physician’s defence of force-majeure, or necessity, in this matter was well founded but could not be proved for lack of a legally required, second consultant. It agreed with a lower Court’s judgement “that the wish to die of a person whose suffering is psychic can be based on a autonomous judgement”. The physician received no punishment from the Court (Griffiths, pp. 80–82; Klozko & Chabot, 1998). More recently the Sutorius case temporarily stretched the concept of unbearable suffering as a legitimation for EPAS. A Dutch District Court ruled in 2000 that the *tiredness of life*, which elderly senator Brongersma said had robbed him from enjoyment of life, was a sufficient reason for the act of physician-assisted suicide that killed him (Rechtspraak.nl, n.d.). The Dutch High Court rejected the ruling in 2002 but it remains unclear what the difference is between allowable non-somatic suffering and the disqualified tiredness of life. In view of the findings of one of the major Dutch evaluation studies on EPAS (van der Maas, van Delden, & Pijnenborg, 1991), which was that 23 per cent of people cited tiredness of life as a reason to have EPAS, this judgement is not likely to be the last word on this matter. The Prins and Kadijk cases, both heard in 1995, established the legality of euthanasia for “severely defective new-born babies” without an explicit request. This was permissible only in the face of unbearable and hopeless suffering in absence of the availability of other treatment; decision-making according to careful practice guidelines; the doctor having acted in a medically sound manner; and there having been a repeated request from the babies’ parents (Griffiths, p. 83).

These legally accepted processes and increasing public acceptance of EPAS, with significant involvement of the Dutch Medical Association KNMG, and Dutch Voluntary Euthanasia Society (NVVE), culminated in the “Wet toetsing levensbeeindiging op verzoek en hulp bij zelfdoding” of 2001 or “Termination of life on request and assisted suicide (Review Procedures) Act”. The central point of law upon which the Dutch EPAS approach rests is that of force majeure. If a physician committing EPAS reports the case as EPAS and has been found to have followed the guidelines laid down in the Act by a government EPAS monitoring committee she will not be prosecuted.
1.1.5 EPAS in practice

Until the advent of legalised EPAS, the Supreme Court guidelines, developed by the Dutch Medical Association, provided the criteria for whether an act of EPAS was legal. These guidelines have been adopted in the 2001 law and require the doctor to fulfil them so that the Penal Code is not breached. They are:

a.) to be convinced of a voluntary and well considered request from the patient,
b.) to be convinced of the presence of unbearable suffering without prospect of recovery,
c.) to have informed the patient about the situation they are in and their medical prospects,
d.) to have come to a joint conclusion with the patient that for this situation there is no reasonable alternative solution,
e.) to have consulted at least one independent doctor who has seen the patient and has given his written opinion about the doctor’s adherence to the guidelines a.) to d.), and
f.) to have medically carried out the ending of life or assisted suicide in a conscientious (medically careful) manner.

Notably the law allows for EPAS of children between the ages of twelve and sixteen, with parental consent. From sixteen years of age they do not need parental consent. The law contains provision for an advance directive about desired end-of-life actions in the event of future incompetence.

In the spirit of openness and bespreekbaarheid, the Dutch government commissioned various reports about the practice of its EPAS policy, the Remmelink Reports of 1990 and 1995 with a third report underway currently. The first report of 1990 found that 1.7 per cent (2300) of all deaths were by means of euthanasia and 0.3 per cent (400) through physician-assisted suicide. Thirty eight per cent of all deaths involved a medical decision, of which about 17.9 per cent involved withdrawal or withholding of treatment and in another 18 per cent treatment for pain contributed to death. Doctors reported 18 per cent (484 cases) of the deaths estimated to have been caused by EPAS in 1990. In the case of 0.8 per cent (1000 cases) of all
deaths EPAS occurred without a request from the patient, 53 per cent of whom were no longer able to indicate their wishes. These were described as mostly seriously ill and dying people whose lives were shortened by hours to a few days. Doctors refused two thirds of all requests for EPAS. In 1995 the percentages had gone up to 2.4 per cent (3200) for euthanasia and remained at 400 for physician-assisted suicide. Doctors now reported forty one per cent of EPAS deaths and two thirds of requests were still refused. Deaths by EPAS without request were now 0.7 per cent (900), and 79 per cent of these were now said to no longer be able to indicate their wishes.

Deaths from withdrawal or withholding of treatment had increased to 20.2 per cent. (van der Maas, van Delden & Pijnenborg, 1991).

In 1998, regional committees (Toetsingscommissies) were established to receive all reported deaths by EPAS from the involved physicians and to check the rigour of adherence to the guidelines. If dissatisfied the committee can refer the case for legal prosecution. These committees are made up of at least a lawyer, a medical practitioner and an ethicist. The new EPAS law of 2001 retained these committees and guidelines. The coroner reports to the regional Toetsings Committees who make a recommendation to the College of Public Prosecutors and the regional Inspector for Health. Physicians who have complied with all the guidelines and who have reported the act of EPAS to the coroner are not punishable. Where the guidelines have been breached the Prosecutor will undertake further investigation and eventual prosecution. The Committees deliver an annual Ministerial report of their activities. They report on the number of cases, their nature and the committees’ judgements (Wet Toetsing Levensbeeindiging op Verzoek, 2001).

Various authors have claimed that EPAS in practice is problematic. Equally so, others claim that these are not necessarily serious issues. It is beyond this thesis to debate these claims but it is relevant to understand the types of controversy that have accompanied EPAS and its practice. Arguments against EPAS in the Netherlands often involve an assertion of a slippery slope affecting the most vulnerable, the aged and disabled (Keown, 1995; Pollard 1994). Critics point to the fact that respectively only 18 per cent and 41 per cent of physicians reported their acts of EPAS in 1990 (Van der Maas, van Delden, & Pijnenborg, 1991) and 1995 (Van der Wal & van der Maas, 1996); there are a reported 1000 cases of non-voluntary euthanasia; and the use of EPAS where palliative care could have been used, all contravening the
guidelines (Jochemsen & Keown, 1999; 1999a). A slippery slope has also been detected in the widening of the criteria that constitute suffering as sufficient to allow EPAS. Hendin (1997) has argued that it is impossible to devise workable guidelines as safeguards for EPAS because “they fail to address the inter-active nature of the decision-making process that is at the heart of euthanasia and its abuse” (p. 1491).

This argument seems supported by the Australian findings of Waddell, Clarinette, Smith, Oldham & Kellehear (1996) who found that treatment decisions at end of life were more significantly determined by the doctor’s individual characteristics, their medical training and socio-demographic background, than by the nature of the medical problem. Others (DiPasquale and Gluck, 2001; Pool, 1996) reflect similar findings among American psychologists and psychiatrists and Dutch medical hospital professionals. A lack of palliative care predisposes people towards EPAS, Dutch physicians know little about palliative care practices (Enklaar, 1999). In the case of some 1000 patients whose lives are ended without their request, 21 per cent in 1995 and 37 per cent in 1990 were competent. In these cases consultants were who are legally required to give a second opinion in cases of proposed EPAS, were almost never involved (Hendin, 1999). Consultants have been found to be inexperienced in end of life issues. In 12 per cent of EPAS cases a consultant did not see the patient, they: “basically functioned in a pro forma way, asking questions to confirm that the patient wished to go forward with euthanasia”(Hendin. p. 351). This led Hendin to conclude that “this probably reflects the view frequently expressed to me by Dutch physicians that the consultations were for the purpose of meeting legal requirements (Hendin, 1999, p. 351). Many doctors consulted for each others, thus removing the independent nature of a second opinion (Onwuteaka-Philipsen, van der Wal, Kostense, & van der Maas, 1999). To overcome such problems the Dutch Medical Association (Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunde) started a program, named SCEN (Steun en Consultatie bij Euthanasie in Nederland) which trains doctors as independent euthanasia consultants in giving an assessment of a patient’s competence and nature of their suffering (“Landelijke dekking SCEN”, 2003). Some instances of clinical problems were found where intended PAS ended up as euthanasia because the patient could not complete the suicide for various reasons (Groenewoud, van der Heide, Onwuteaka-Philipsen, Willems, van der Maas, & van der Wal, 2000). These are obviously stressful situations, not conducive to a dignified death. Forty two per cent of physicians who
had performed EPAS reported feelings of discomfort but ninety-five per cent of respondents said that they were willing to perform EPAS again (Haverkate, van der Heide, Onwuteaka-Philipsen, van der Maas, & van der Wal, 2001). Some EPAS occurred outside medical purview. Psychiatrist Chabot, in researching his book “Sterfwerk” (“Dying work”), found that non-medical volunteers from the Dutch national euthanasia society, the Nederlandse Vereniging voor Vrijwillige Euthanasie (NVVE) and another, De Einder, sometimes directly assisted with suicide (“Cognac, een bakje vla”, 2001). Doctors have felt the reporting procedure to be burdensome.

Others have argued that the practice of EPAS has not led to abuse, noting only a slight increase in EPAS cases between the two major government evaluations of 1990 and 1995, most being cancer patients (van der Maas, van der Wal, Haverkate, de Carmen, Graaff, Kester, Onwuteaka-Philipsen, van der Heide, Bosma, and Willems, 1997). The Dutch have engaged in open discussion and monitoring of EPAS through government-sponsored reports and problems such as a low level of reporting EPAS will be overcome in time (Griffith, Bood & Weyers, 1998). The 1995 study concluded that “substantial progress” had been made in the “oversight of physician-assisted death in the Netherlands” (p. 1706) (van der Wal, van der Maas, Bosma, Onwuteaka-Philipsen, Willems, Haverkate & Kostense, 1996). Government-sponsored Dutch evaluation studies, held in 1990 (Van der Wal & van der Maas, 1996) and 1995 (Van der Maas, van Delden, & Pijnenborg, 1991) saw an increase in doctors’ reporting EPAS from 18 to 41 per cent. Griffith (1998a) suggests therefore that the Dutch may be “clambering up” a slippery slope (p. 94). More recent information appears to cast doubt upon this positive concept of the slippery slope. Since the passing of the Dutch euthanasia legislation in 2001 doctors’ reporting of euthanasia has dropped by 8 per cent. An anonymous survey among 355 Dutch lung specialists found that the reasons are that doctors do not like the official euthanasia procedure nor its reporting requirements which are experienced as too onerous. As a result “euthanasia” was more often performed by means of inducement of ‘terminal sedation’ and subsequent withdrawal of food and fluids (“Artsen: illegale euthanasie”, 2003). Further arguments for EPAS include that the procedure is voluntary for patients and for doctors, no-one is forced to have it or perform it and that the high public support of EPAS shows that the law is grounded in the moral norms and values in society, as it should (Griffith, Bood & Weyers; Kimsma & van
Leeuwen, 1998). Kimsma & van Leeuwen agree that, in 1998, several important matters were outstanding, deserving attention by the Dutch. These included firstly the relationship between terminal disease, depression and requests for EPAS because of emphasis on the voluntariness of EPAS; secondly not enough was known about the relationship between palliative care and requests for EPAS; and thirdly there was an absence of common procedures to implement living wills.

1.1.6 The Australian context

The Australian background to EPAS shares the underlying issues that drive the Dutch debate: “intense individualism” (Somerville, 2000, p. 121), secularisation and “technical determinism and bureaucratic processes which characterise modern medicine” (Magnusson, 2002, pp. 36–37). To these Somerville adds consumerism, individual and societal fears of death and a media which has contributed to the acceptance of euthanasia (pp. 122–128).

Euthanasia remains illegal in Australia. But various studies have claimed levels of its illegal practice. Between 12.3 per cent and 28 per cent of surveyed samples of physicians (Kuhse & Singer; Stevens & Hassan, 1994; Baume & O’Malley, cited in Magnusson, 2002, pp. 39–40) were found to have illegally ended patients’ lives. In one study of nurses’ practices 85 per cent of them had complied with requests from patients to end their lives (Kuhse & Singer, cited in Magnusson, 2002, p. 39). Paradoxically, Kuhse, Singer, Baume, Clark and Rickard (1997) identified a higher incidence of EPAS in Australia than is found in the Netherlands. They found a 1.8 per cent per cent Australian level of euthanasia, which included 0.1 per cent rate of physician-assisted suicide. In 30 per cent of all Australian deaths, doctors made end-of-life decisions “with the explicit intention of ending the patient's life, of which 4 per cent were in response to a direct request from the patient”. The authors concluded that Australia’s rate of intentional ending of life without the patient's request was higher than that in the Netherlands and that the law had not prevented this. Possible explanations for these results included the survey respondents’ inaccurate knowledge of the definition of euthanasia; and a still low level of medical knowledge of palliative care (Ashby, 1997; Report Constitutional Affairs Committee, 1998). Van der Weyden (1997) gives three possible reactions to Singer and Kuhse’s study. Firstly, EPAS proponents will say that regulation by law
and guidelines is the correct response and point to the Dutch studies to say that there is no justified fear of a slippery slope. Secondly, opponents will be alarmed at the existing slippery slope and call for more palliative care responses (Ashby) while pointing to the crudeness of law as a tool to alleviate suffering during the complex process of dying. A third, neutral position, would be to point to how little is known about dying in Australia and call for further studies and physician training. Magnusson (2002) also found a presence of illegal end of life practices among Australian physicians, other professionals and paramedical staff.

Parliamentary inquiries into legalisation of euthanasia have been held in most Australian States and Territories. These include the Australian Capital Territory, Tasmania, Victoria, Western Australia, the Northern Territory, New South Wales and South Australia. The issue of EPAS is currently before the South Australian government for the second time and a voluntary euthanasia Bill has been introduced in the Western Australian Parliament. Only in the Northern Territory has euthanasia been legislated, be it briefly, between July 1996 and March 1997. This legislation was the Rights of the Terminally Ill Act (ROTI) of 1995. It was over-ridden by the Commonwealth Government’s Euthanasia Laws Act 1997. The ROTI Act allowed a terminally ill (in absence of medical treatment acceptable to the patient), competent adult to be killed by a medical practitioner after examination by at least two doctors (Parliament of South Australia, 1999). Under the Act’s provisions seven people died, all of whom had cancer and all but one of whom were terminally ill (Kissane, Street, Nitschke, 1998). Meanwhile, despite absence of high profile legal cases that propelled euthanasia and assisted suicide issues to the forefront in other countries, these issues do remain much in the news. A number of recent, publicised suicides have occurred, such as those of Mrs. Nancy Crick and others, in which Dr. Philip Nitschke was involved (“Nitschke’s absence deliberate”, 2002). Dr. Philip Nitschke, a high profile supporter of the Rights of the Terminally Ill Act (1995), facilitated the deaths of four patients by prescribing them lethal drugs, during the period of existence of the ROTI Act (Kissane, Street, Nitschke). In 1999 he was reportedly claiming to have helped 60 people to die (Euthanasia Clinic (News), 1999). He continues to be the single most visible pro-EPAS activist in Australia. He conducts regular workshops for those who want to explore ending their lives (Leipoldt, 2002). He has more recently, through his “EXIT Australia” organisation promoted suicide
aids such as plastic bags (“Exit bag”, 2002) and de-breathing devices (“Nitschke suicide device out”, 2002) as part of a civil disobedience campaign (“Nitschke: Right-to-die civil disobedience”, 2002) towards achieving legal EPAS. The popularity of the EPAS issue in Australia is perhaps reflected in Dr. Nitschke’s winning of 9 per cent of the vote in the 1998 Federal election, when he stood as a candidate, against the Minister who was responsible for successfully challenging the ROTI Act (“Nitschke gains 9 per cent”).

In conclusion, the Australian EPAS debate contains three driving forces of liberal individualism, secularisation and the effects of an overly techno-medical approach to care. EPAS remains illegal in Australia even though it has been reported to be practiced at levels comparable to the Dutch legal practice. Continuing efforts to see it legalised are substantial despite controversy surrounding the Dutch record of legally tolerated EPAS.

1.1.7 Public support for EPAS

Arguments in support of legal EPAS often claim high levels of public support. Public support for the principle and practice of EPAS is high in the Netherlands, with percentages as high as 92 per cent of the Dutch public in favour (“Overgrote meerderheid”, 1998) having risen from 52 per cent in 1966 (Griffiths, Bood & Weyers, 1998). In Australia public support for legalised EPAS stood at 78 per cent in 1995 (Morgan Gallup, 1995), whereas this was 47 per cent in 1962 (Walsh, 1996). This matches growing support in the USA (Benson, 1999; DeCesare, 2000), Germany (Glass, 2000), Canada (Edwards & Mazzuca, 1999) and Britain (O’Neill Feenan, Hughes, & McAlister, 2002).

Many surveys have been conducted to ascertain physicians’ support for EPAS as well as that of nurses and allied health care workers. For example, Portenoy, Coyle, Kash, Brescia, Scanlon, O’Hare, Misbin, Holland, et al., (1997) found a variance from five per cent to 70 per cent support in various surveys among physicians about their support for E or PAS whereas they saw a “near-even split” in support of EPAS among physicians and oncology nurses in “the most credible” surveys (p. 278). Definitional issues, types of questions asked and closeness to the dying experience influence survey results and their interpretation. In addition, factors such as the doctors’ medical training, socio-demographics and patients’ wishes
affected end of life decision-making. Generally such details are not present in attitudinal surveys (Waddell, Clarnette, Smith, Oldham & Kellehear, 1996).

Hassan (1996) reported on consistent medical professionals’ support for EPAS, in surveys conducted in Australia and overseas. As Braun and Kayashima (2001) also found in reviewing such surveys, the majority of them appear to reflect a lower level of support of euthanasia and physician-assisted suicide. However the level of their support appears generally lower than that of the general public. For example, in a survey of American oncologists, patients and the public, less than half of the oncologists were found to support euthanasia and only 23 per cent supported physician-assisted suicide in case of intractable pain. However two-thirds of patients and the public supported both (Ezekiel, Emanuel, Fairclough, Daniels, & Clarridge, 1996). In another survey thirty-six per cent of American physicians said that they would prescribe medications for suicide if it were legal to do so (Meier, Emmons, Wallenstein, Quill, Morrison, & Cassel, 1998). In 1988, 60 per cent of surveyed Australian physicians believed that EPAS should be legalised (Kuhse, & Singer, 1988). But Waddell, Clarnette, Smith, Oldham & Kellehear, (1996) reported only a small proportion of Australian doctors in favour, if the questions asked involved palliative care options. Indeed, an analysis of the determinants of willingness to endorse assisted suicide among 1, 137 US physicians, nurses and social workers found that the greater the experience with people with advanced medical illness, the less willingness there is to endorse assisted suicide. Doctors were less inclined to endorse it than social workers and those doctors who worked with terminally ill people were less willing to endorse PAS than doctors who were not. Professional burn-out and a lower knowledge of pain management was associated with a higher willingness to endorse PAS (Portenoy, et al., 1997). Furthermore, based on a review of diminished distance to death (the closer one moves to one’s end of life or the physician in possibly giving assistance to die, the less support for EPAS) and lack of knowledge of circumstances of dying have been identified as factors in decreasing support for euthanasia and physician-assisted suicide (Braun & Kayashima, 2001). Religious adherence is an additional factor and is associated with physicians’ reduced willingness to endorse EPAS (Bachman, Alcser, Doukas, Lichtenstein, Corning, & Brody, 1996; Portenoy, et al., 1997; van der Maas, van Delden, Pijnenborg, 1991; Shapiro, R.S., Derse, A.R., Gottlieb, M., Schiedermayer, D., &
Olson, M., 1994). If active participation in EPAS can be seen as an indicator of support for the practice and legalisation of it, the following figures are of interest. Fifty three per cent of Dutch physicians have performed EPAS (Douglas, Kerridge, Rainbird, McPhee, Hancock, & Spigelman, 2001). Douglas et al., also report on other studies in countries where EPAS is prohibited. In response to specific requests for EPAS doctors have performed medically assisted deaths at consistent levels of between 3 and 6 per cent in the US, 7 per cent in Denmark, 8 per cent in the UK and between 2.2 and twelve per cent in Australia.

Polls and surveys are often quoted in support of EPAS but have been found to be a poor indicator of true levels of informed support (Annas, 1994; Shertz & Blendon, 1993). Issues such as uncertainty of definitional aspects (Aranda and O’Connor, 1995; Emanuel, Fairclough, Daniels, & Clarridge, 1996; Meier, Emmons, Wallenstein, Quill, Morrison, & Cassell, 1998) and biased phrasing of questions (Bachman et al., 1996; Jansz, 1996; Morgan, 1996) play a role. Additionally, an identified low public awareness of the nature and practice of palliative care in Australia (Webster & Kristjanson, 2002) and in the Netherlands (Enklaar, 1999) could be expected to influence survey outcomes that inquire into public support for EPAS. Likewise, the Dutch public is said to have a low understanding of, and to hold a certain indifference towards, their country’s regulatory policies and practices on EPAS (Kennedy, 2002, p. 10; Gomez, 1991). This literature appears to confirm the complexity of EPAS issues and unreliability of interpreting survey figures into unqualified support for EPAS. Further complications in interpreting survey data are represented by McNamara’s (2001) findings that people are more likely to agree with the principle of euthanasia than to envisage themselves asking for assistance in ending their own lives (p. 21). Responses may also depend upon the respondent’s closeness to a situation of dying. In response to the statement: “the law should allow doctors to comply with the wishes of a dying patient in severe distress who asks to have his or her life ended” regular US Harris Polls show that most adults support a right to euthanasia and physician-assisted suicide. A 61 to 34 per cent majority of Oregonians would support a law that covered physician-assisted suicide and euthanasia (Harris Poll, 2002). Such support has to be qualified by Chochinov et al’s (1997) finding that less than ten per cent of terminally ill patients ask for death.
1.1.8 Summary

This brief survey of the history of the EPAS debate shows that much of the contemporary EPAS debate and practice has its origin in international debate and eugenic developments dating from the early nineteenth century. Modern rationales for EPAS occur in a secular social context and include high emphasis on individual rights for choice; and a highly technical medical environment, which can facilitate prolonged life but which may not be considered bearable. These circumstances have contributed to a call for a legalised *death with dignity* through EPAS. Internationally and in the Netherlands public cases involving withdrawal of life-support enlivened the EPAS discussion. In the nineteen sixties and seventies the Dutch climate of social change, involving greater individual expressiveness and tolerance, and a drive to publicly discuss formally taboo social issues (bespreekbaarheid), contributed to greater acceptance of EPAS. A Dutch governmental policy of tolerance towards the practice of EPAS, within an evolving framework of guidelines, and monitored with two evaluations, led to legalisation of the practice in 2002. Australia briefly experienced legal EPAS in its Northern Territory in 1995. It has seen numerous efforts in State and Territory legislatures to make EPAS legal. Such efforts as well as acts of public activism are ongoing. An Australian public debate on EPAS is continually stimulated by these efforts although it does not appear to be driven by the Dutch bespreekbaarheid. The Australian and Dutch debates share the underlying issues of secularisation, individual rights to choice and dual impacts of technomedical practice. Many authors have criticised the Dutch EPAS practice and many have defended it, providing an ongoing controversial environment in which practice and debate occur. A consistent and growing public majority support for EPAS exists in many countries. The support of health care workers is generally lower than the public’s. Responses to such surveys are dependent on a number of factors, including personal religious orientation, training, and the level of knowledge of the issues and closeness to the experience of dying. Whereas such polls are often used to defend EPAS a closer examination reveals that the issue is more complex than often portrayed.
1.1.9 The social position of people with disabilities and EPAS.

It is important to know something about the social position of people with disabilities to understand the importance of their perspectives on EPAS. Among today’s people who have disabilities many are known to have a heightened vulnerability to abuse, neglect, isolation and discrimination and are disadvantaged, oppressed, stigmatised and devalued (Cocks, 1994; Cocks & Duffy, 1993; Cross & Zeni, 1993; Goffmann, 1963; Kliwer & Drake, 1998; Sobsey, 1994, 1994a; Wolfensberger, 1987, 1998). They are frequently seen and treated as devalued people (Wolfensberger, 1987, 1992, 1994, 1998).

Society’s responses to vulnerable people with disabilities have varied through the ages. They were included in community, sometimes marginalised and sometimes killed. For instance, Braddock & Parish (2001) tell of evidence of some Neanderthal people with disabilities having been part of their society. Ancient Greek people with disability “were integral to the society” (Edwards, cited in Braddock and Parish, p. 16) and were offered some public support when they could not earn a living due to their impairment. Hospices for blind persons existed in the fourth to sixth centuries AD in Turkey, Syria and France. A Belgian town in the 13th century organised the care of people with mental illness within their family settings. On the other hand ancient Greeks and Romans practised some infanticide for economic reasons. The Spartans killed all disabled newborns regardless of economics. During the Middle Ages intellectual and mental disability as well as epilepsy were seen as caused by demonic possession and many such people were killed as witches. The Enlightenment, beginning in the seventeenth century, begat the first educational and psychological approaches towards people with disability, based on the beliefs the experience and reason could be employed to improve humans and society. This development included the emergence of charitable hospitals and asylums, which began a Western history of institutionalisation of people with disabilities. Later, the Enlightenment’s beliefs about improvement combined with the emergence of social Darwinism were also expressed in the German eugenics movement as elsewhere and remain current (Gallagher, 1995).

… as prevalent as ever – are the beliefs that the pursuit of “progress” (Gallagher’s quotation marks) can serve as justification of mass killings (p. xvii).
This eugenics movement resulted in widespread refusal by physicians to treat newly born infants with disabilities. They thereby facilitated their deaths and the sterilisation of many thousands of people with intellectual and mental disabilities. Such sterilisation for eugenic reasons was performed in many Western countries. Nazi Germany used the Californian sterilisation program as a model for its own eugenic sterilisation law, with eugenics culminating the Nazi German euthanasia program for people with disabilities (Braddock & Parish, p. 40; Gallagher).

Abuse of people with disabilities is pervasive and persistent as Sobsey (1994), who leads the world’s leading international research centre on violence and abuse of people with disabilities, describes.

In spite of the United Nation’s noble objectives, violence, sexual abuse and neglect of children and adults with disabilities continues throughout the world. For example, in Malaysia, adolescents with disability are spending their lives tied down to beds. In Africa, Eastern Europe and Latin America, children with mental retardation are being kidnapped to sell their vital organs to affluent buyers. People who commit offences against people with mental retardation in Germany and Spain are receiving reduced penalties because their victims are viewed as incapable of suffering…. The US and UK report cases of people with disabilities being denied proper legal representation and convicted of crimes that they did not commit. Institutional abuse and neglect continues to be reported from Albania, Australia, Belgium, the Commonwealth of Independent States, Greece, Jamaica and many others. Studies from many countries (eg, US, UK, Australia\(^2\)) suggest that child abuse, beatings and rape are common occurrences in the lives of many, probably most, people with developmental disabilities. (Sobsey, 1994, p. 3)

The Dutch found it necessary to introduce two Bills in their Parliament in 2001 to safeguard the position of citizens with disabilities. One makes it illegal to insult people with disabilities or incite hatred or violence for reasons of disability or chronic illness. The other attempts to ensure equal treatment of people with disabilities in terms of employment, training and sports (CG Raad, 2001). The Australian Disability Discrimination Act was proclaimed in 1993 in recognition of many disadvantages to people with disabilities, now reflected in its standards applying to access, education, employment, telecommunications, insurance and

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\(^2\) Sobsey (p. 39-41) cites 27 studies, dated between 1967 and 1992. Two of these are Australian.
sports. The US and United Kingdom also have protective disability legislation in place.

In Australia many people with disabilities are still among the poorest of citizens, live friendless and isolated lives within the community, are over represented in prison populations, and may receive inadequate support with the meeting of their basic needs. (Meekosha, 1999). Dutch people with disabilities still encounter insufficient access to education, employment, public buildings and one’s own home, to public transport and care. Many people with intellectual disabilities have moved from institutions to living independently in the community, reportedly giving them more choice and autonomy. But many are not included in local community as they lack social networks and have a low income (de Klerk, 2002).

People with disabilities are vulnerable also as a result of developments in medical, genetic screening of unborn babies for defects, which is commonplace in the Netherlands as it is in Australia. In the Netherlands “adults with congenital disabilities who wish to have children, face the judgement of geneticists about what they think is ‘healthy’. (…). Doctors decide by refusing to co-operate doctors. In this way passive [eugenic] selection has become a fact in the Netherlands” (Vreeswijk, n.d.). The medical world’s emphasis on genetic “cure” ignores the social and cultural dimensions of disability. This emphasis leads towards a socially devaluing view of disability and devaluing practices towards persons who have disabilities (Reinders, 1999). Newell (1999) believes that globally “there is already evidence of threats to the rights of people with disabilities and already stories of oppression and discrimination based upon genetic knowledge” (p. 35). Indeed a peak disability group’s submission linked genetic screening to the Dutch Parliamentary debate about amendment to its abortion legislation.

The law with regard to abortion, with reference to the late termination of pregnancy [in the case of unborn babies with disabilities], in absence of evaluative norms applicable to physicians and prenatal screening can have the unintentional result that eugenics in the Netherlands will become an implicit rule. ("Biotechnologie", 2001)

An Australian report on unlawful sterilization of girls with intellectual disability concluded that “there is good reason … to believe that girls continue to be sterilised,
and sterilised in numbers which far exceed those that have been lawfully authorised“ (Brady, Britton & Grover, 2001, p. 57).

Besides such overt expressions of abuse, discrimination and neglect, Wolfensberger (1984; 1984a; 1990) has identified other practices that may lead to the eventual deaths of people with disability who are subject to them. He has called these practices deathmaking. For example, he referred to infanticide of handicapped new-borns in hospitals, prescribing psychotropic drugs in excess and people with disabilities dying as a result of neglect and abuse in human services. He estimated annual deaths in the US from such practices to be “hardly less than 100, 000” (Wolfensberger, 1990, p. 64). Abuse and death-making practices are often covert and cloaked in euphemisms where killing might be called a mercy-killing, merciful release, a blessing for the suffering (Wolfensberger, 1990, p. 69), and where “murder” can be called “euthanasia, neglect, assisted suicide, allowing to die” (Sobsey, 1994, p. xix). Nazi euphemisms which “re-define, essentially de-define, human life” (Sobsey, p. 2) were similar including “life without value for itself or society, a life whose continuation is of no interest to any reasonably thinking person, empty shells, and life devoid of value”. Nazi euphemisms for euthanasia included death with dignity and final release (Wolfensberger, 1981). EPAS of people with disabilities can become an extension of other deathmaking practices based on the widespread devaluation of people with disabilities (Wolfensberger, 1987, 1984a, 1990). A slippery slope effect from legalised EPAS adds to further abuse of people with disabilities (Keown, 1995; Pollard, 1994; Wolfensberger, 1987).

1.1.10 Disability and EPAS

Vulnerability is part of the human condition (MacIntyre, 1999) but many people with disabilities experience a heightened vulnerability (Cocks & Duffy, 1993). It has been argued that a person’s vulnerability is heightened when “the person has more than one characteristic which then places that person in more than one group”, such as being poor, having few skills, and having a disability (Cocks & Duffy, p. 19; Wolfensberger, 1998). But even without such multiple group membership the direct effects of impairment itself, due to an absence of some functions, can lead to a heightened level of vulnerability in itself. Much of this heightened vulnerability arises from the socially constructed devaluation of people.
who have a disability (Wolfensberger, 1998) and disempowerment (Oliver, 1996), inherent in negative social ideologies about disability, combined with dominant social values of individualism, hedonism and materialism (Wolfensberger, 1990). People with disabilities are particularly vulnerable when social and health-related consequences of disability and a terminally ill state converge (Cocks & Duffy, 1993; Rock, 1996; Wolfensberger, 1987, 1992, 1998). Indeed people with disabilities are included as eligible for assisted suicide by virtue of their disability by various prominent euthanasia proponents (Gill, 2000). In the US, the disability group “Not Dead Yet” conducts a high-profile opposition to such assumptions. Yet a stance against EPAS by a majority of people with disabilities cannot be taken for granted. Though criticised as unrepresentative for its one-shot, small sample (Gill, 2000), an American 1994 Harris poll for instance found 66 per cent of people with disabilities in favour of physician-assisted suicide, compared with the general public’s response of 70 per cent (Batavia, 2000). Also, I am not aware of any organised disability opposition to EPAS in the Netherlands, Australia or in countries other than the US.

Many people with disabilities, including those with quadriplegia, live long lives with conditions affecting their continence, mobility, dignity, appearance, independence, autonomy and so forth. Some may live with constant or regular pain and disability is often characterised by a higher dependence on others than most people experience. This can mean dependence on others for highly personal tasks, such as assistance with showering, toilet or dressing. Issues of pain and dignity are often stated as reasons for euthanasia for people who are at the end of their lives (Dworkin, 1995; Keown, 1995; Kuhse, 1994; Pollard, 1994). Reasons for acting on assisted suicide requests, as given by Dutch physicians, include pain (46 per cent of patients) the loss of dignity (57 per cent) and a state of dependence (33 per cent) (Van der Maas and Emanuel, 1998). Reasons for euthanasia are often addressed in terms of a declining quality of life (Kuhse, 1994; Pollard, 1994) which is often thought of as determined by such perceptions of pain, dependency and loss of dignity. Quality of life assessments are pervasive and are controversial tools to indicate human wellbeing, particularly for people with disability. For example, the World Health Organization uses the DALY (Disability Adjusted Life Year) in calculating the global burden due to premature death and of that caused by non-fatal health outcomes. The rating was developed by asking able-bodied people how they
value a year of life with disability, pain and immobility (Bach & Tilton, 1994). Such measurements of quality of life, and ranking of people by degree of disability, valorises the normal body (Rock, 2000) and puts people with disabilities at risk, including risk of their lives being seen as worse than death (Bach & Tilton, 1994). It is clear that quality of life assessments are highly controversial. This is because an individual person’s quality of life depends on their subjective attitudes, beliefs and values (Somerville, 2000) and assessments use another’s subjective criteria, which may be used to attach more worth to one life than another (Dennis, Williams, Giangreco, & Cloninger, 1993; Wolfensberger, 1994). Underlining these concerns, people with disabilities have rated the experience of their lives as far more positive than others, such as medical doctors, have (Albrecht & Devlieger, 1999; Gill, 2000; Rothwell, McDowell, Wong, & Dorman, 1997).

A medical doctor and prominent Australian EPAS campaigner, Dr. Philip Nitschke highlighted the relevance of concerns about using quality of life assessments for people with disability in terms of their eligibility for EPAS in his evidence to the South Australian Inquiry by the Community Development Committee into Voluntary Euthanasia, 1996 (Parliament of South Australia, 1999). He portrays the use of EPAS in a way that would legitimise the ending of life under conditions of a perceived low quality of life experienced by people with disabilities. For them the choice then seems to be between “quality of life” or life while the social and other causes of their supposed “abysmal” life of “chronic suffering” are ignored.

The term ‘terminal illness’…is encompassed in that [definition of euthanasia], but a person’s definition of what I would describe as chronic and unremitting suffering is the definition. If a person can establish that – and it is not hard to establish – then certainly that would involve people who were, for example, not technically terminally-ill, such as people with problems associated with, say, quadriplegia, where they may have long life expectancies but, to the patient’s assessment the quality of their life is so abysmal that they wish to end it. (Nitschke, oral evidence, p 136)

1.1.11 Summary

The heightened vulnerability of many people with disabilities arises from their impairment, from social values and attitudes, and from societal (service) responses towards them. Their lives are vulnerable in a world that often celebrates
the opposite values to those represented by their embodiment of physical imperfection. Their lives are also more vulnerable as a result of the inadequate socio-economic circumstances in which many people with disabilities find themselves. Assessment of quality of life of such disadvantaged and vulnerable people with disabilities therefore seems problematic in a world context of widespread abuse. Yet people with disabilities most often rate their own lives as good as anyone else’s. Quality of life is obviously measured or experienced differently by those with and without disability. When medical doctors assess quality of life and weigh it in their treatment decisions, including at end of life, the odds can then often be stacked against people with disabilities. Under the weight of their social position and negative societal assumptions about their lives people with disabilities are especially vulnerable to any implementation of EPAS.

1.1.12 People with quadriplegia

The main sample for this study is made up of people who have quadriplegia. Quadriplegia in this study is limited to being caused by a traumatic event, an accident, which results in paralysis in body trunk and four (quad is four) limbs. This involves injury to the spinal cord, effecting various levels of paralysis, corresponding with the site of injury. The higher up on the spinal cord the more global the paralysis. So $C3/4$, for instance, is shorthand for injury to the spinal cord between the 3rd and 4th cervical vertebrae. Some or all of continence, breathing, sexual function, temperature control, balance are usually impaired. People with spinal cord injury today can expect to survive their injury as a result of technological advances made in medicine after the Second World War. These advances allowed prevention of death from urinary tract and kidney infections and sepsis from pressure sores. These were major causes of death before that time (Eisenberg & Salz, 1991) often within a period of weeks to a few months. Rehabilitation efforts first began in 1994 in England (van Asbeck, 1998).

Quadriplegia is often seen as a condition that is intolerable to live with. Indeed, the social consequences of quadriplegia include vulnerability to certain health problems, psychological and social challenges (Post, 1997). For many years the condition of quadriplegia has been the subject of much research in order to find a cure (Finkel, 1996; Read, 1996; Young, 1996). Forty four per cent of nurses in a
survey in the Australian Capital Territory said they would support a change in the law to allow voluntary active euthanasia for persons with quadriplegia (Kitchener & Jorm, 1999). Vignettes of people with spinal injury have been used in arguing for legal access to EPAS (Kuhse, 1994) or to explore arguments for and against (Parsons & Newell, 1996). They have been proposed as eligible for EPAS on the basis of the individual’s negative assessment of life with quadriplegia (Nitschke, 1996).

People with disabilities have been the subject of legal proceedings where they sought access to assisted suicide, for instance Rodriguez vs. British Columbia in 1993 and the cases of McAfee, Rivlin, Bergstedt, and Bouvia in America, all people with quadriplegia (Silvers, 1998a). There is a striking example of a man with quadriplegia in Spain who held to his wish for suicide for 29 years who finally, with assistance killed himself, despite reportedly living a full life amidst friends. His struggle has been labelled “autonomatasia”, a neologism for the right to die in a pursuit of one’s individual autonomy. Paradoxically he was “filled with a new sense of life” in the pursuit of this right (Guerra, 1999, p. 432). But the American cases of Bouvia, MacAfee, Rivlin and Bergstedt have revealed a society that is more ready to have their Courts allow them death than provide proper support to live a good life. People with disabilities live in a world that does not allow them equal autonomy (Bickenbach, J. 1998; Gill, 1992; Longmore, 1992; Silvers, 1998a).

Despite this unequal situation there is much evidence of people with quadriplegia having an equal or better sense of wellbeing, sense of life-satisfaction or quality of life, compared to their pre-injury days and compared to the general population. These findings are inclusive of respirator dependent and ageing people with quadriplegia, some of which are longitudinal studies covering 15 to 20 years of measurements (Bach & Tilton, 1994; Crewe, 1996; Dijkers, 1997, 1999; Eisenberg & Salz, 1991; Post, 1997; Ville & Ravaud, 2001).

1.1.13 Summary

People with quadriplegia are often singled out as living a life of unbearable suffering, and viewed as eligible for EPAS for such reasons. Their life experience differs from such perceptions. As disability perspectives are not often heard in the EPAS debate, they are, along with others who have disability, especially vulnerable to EPAS policy and practice.
1.2. Definitional approaches

Euthanasia and physician-assisted suicide are the key term in this study and others, such as quadriplegia have been explained in the above Background section.

1.2.1 Euthanasia and physician-assisted suicide

This section gives a brief overview of the various positions taken towards defining euthanasia and physician-assisted suicide and concludes by adopting one definition for purpose of this study.

*Euthanasia* and *assisted suicide* and *physician-assisted suicide* are sometimes ascribed distinct meanings but are also used interchangeably (Griffiths, Bood & Weyers, 1998). In physician-assisted suicide medical doctors provide suffering patients with the means to kill themselves. Euthanasia, in its commonly used context, usually means an act by someone, usually a physician, to deliberately end the life of a person in order to avoid suffering. Euthanasia is not always defined in this same way and various authors identify several sub categories of euthanasia (Griffith, 1996; Parsons & Newell, 1996; Pollard, 1989; Zdenkowski, 1997). These include:

- **Voluntary euthanasia**, where euthanasia is carried out on request of the patient.
- **Non-voluntary euthanasia**, where consent to perform euthanasia can not be obtained as the person is non-communicative, for instance because they are in a coma.
- **Involuntary euthanasia**, where euthanasia is performed in spite of the wishes of the person to the contrary.
- **Active euthanasia**, where a third party administers a substance in order to end life.
- **Passive euthanasia**, where withdrawal of treatment causes death.

Furthermore, EPAS is usually thought of as provided by a physician but some illegal *mercy-killing* by family or other health professionals has been described also as *euthanasia* or *physician-assisted suicide* (Magnusson, 2002).

Thus one could have active or inactive, voluntary, involuntary or non-voluntary euthanasia, usually, but not necessarily carried out by a physician, whether
one is or is not terminally ill. In practice of course there are attempts to circumscribe EPAS when it is made a legal or legally tolerated practice.

Euthanasia in the Netherlands was defined in guidelines laid down by the “Staats Commissie Euthanasie”, Ministries of Health, Environment and Justice (1985). It states: “Euthanasia is the deliberate life-terminating act by a person other than the person whose life is to be terminated, and which is done on the request of this person”. In the Netherlands euthanasia and physician-assisted suicide are generally treated together (Griffiths, Bood & Weyers, 1998). And in the newly adopted “Termination of life on request and assisted suicide (Review Procedures) Act” of 2001 euthanasia and physician-assisted suicide have indeed been treated as one concept called self-killing (zelf doding). The Act, Division 1, S.1 (b.), describes them as follows: “Help with self-killing: the deliberate aid to another’s self-killing or to give him the means thereto…” (Wet levensbeeindiging, 2001). There is no requirement in this legislation for someone to be terminally ill in order to be eligible for euthanasia but there is a requirement for an explicit request from the patient, as discussed above. So the Dutch view of legally permitted euthanasia can be described as active, voluntary euthanasia and does not encompass other life ending procedures such as withdrawal or withholding of treatment. Nor does it include involuntary or non-voluntary life ending. (Jochemsen & Keown, 1999).

In Australia the only euthanasia legislation that has ever existed was the short-lived Northern Territory of Australia Rights of the Terminally Ill Act, 1995. It defined under what circumstances euthanasia could be performed as follows:

A patient who, in the course of a terminal illness, is experiencing pain, suffering and/or distress to an extent unacceptable to the patient, may request the patient's medical practitioner to assist the patient to terminate the patient's life.

However, terminal illness was defined loosely, without a timeline, and the patient’s degree of suffering was accepted on the subjective report of the patient.

The intent of the doctor is held by some to be the determining factor in deciding whether a life-ending act is euthanasia or not (Somerville, 1993). If the intention is to kill the patient it is euthanasia. On this view, if the primary intention of medical attention is to relieve suffering but in doing so shortens life it is not euthanasia. This is called double effect. Beauchamp & Childress (2001, p. 129) list
four conditions of double effect, which must all be met for it to be justified as such. The act must be morally good or neutral in nature; the agent’s intention is for good effect on the patient; a bad effect on the patient should not be the means to a good effect; and the good effect must outweigh the bad effect. Others (Kuhse, 1998) do not see intent as relevant in making a moral distinction between letting someone die and taking active steps to kill out of compassion for someone’s unbearable suffering. The moral distinction between withdrawing or withholding treatment and EPAS thus vanishes.

One definition that covers both euthanasia and physician-assisted suicide and takes account of the issues of intent and active/inactive distinctions, is Margaret Somerville’s (1993, p. 4.). I adopt it as the definition of EPAS in this study.

An intervention or non-intervention by one person, to end the life of another person, who is terminally ill, for the purpose of relieving suffering, with the intent of causing the death of the other person, except where the primary intent is either to provide treatment necessary for the relief of pain or other symptoms of serious physical distress, or non-provision or withdrawal of treatment is justified, in particular, because there is a valid refusal of treatment or the treatment is futile.

1.2.2 Palliative care

Palliative care is directly relevant to any consideration of end-of-life-options, such as euthanasia or physician-assisted suicide may be. The World Health Organisation has defined palliative care in terms of physical, social, psychological and spiritual dimensions involved in dying, including the needs of the dying person, family and community.

Palliative care is the active, total care of patients at a time when their disease is no longer responsive to curative treatment and when control of pain, of other symptoms and of social, psychological and spiritual problems is paramount.

And,

Palliative care affirms life and regards dying as a natural process; it neither hastens nor postpones death. It offers a support system to help the patient live as actively as possible until death and help the family
cope during the patient's illness and in bereavement. Palliative care is multidisciplinary in its approach and encompasses the patient, the family and the community in its scope. (World Health Organisation, 1990)

1.3. My personal background

The researcher’s personal background is an important factor in qualitative research where the researcher is the primary instrument through which the data are collected. The researcher’s attitudes towards a study’s informants affects every aspect of the study (Rew, Bechtel & Sapp, 1993) and their qualifications, experience and perspectives influence the study’s credibility (Patton, 1990). It is also appropriate to articulate one’s background in the pursuit of an ethical problem as “one’s personal history, one’s experience, and one’s reflection on one’s history and experience are critical to the way one chooses, envisions and then deals with problems” (Loewy, 1993, p. xxii).

I was born in the Netherlands and am the only one in my family to have migrated to Australia, which I did at age 23. I sustained a spinal injury the following year and at the commencement of this study had experienced quadriplegia for some 23 years. I have been involved in Australia with disability issues in advocacy, advocacy development, government advisory bodies, guardianship and human service, at local, statewide and national levels. What the nature of community is and, later, how this relates to the issue of euthanasia have been growing interests over the years, which became practically explorable through the opportunity of this doctoral study.

This is a particularly sensitive research topic. It involves deeply personal and emotional issues such as end-of-life-decision making and accounts of vulnerability and dependence. Bracketing (Patton, 1990) against researcher bias is in part made visible here by putting up front my own beliefs and assumptions. At commencement of the study these were:

1. Human beings will always be imperfect and live in an imperfect world. Consequently, imperfection is the norm for the world and the human condition. Vulnerability and disability will always be with us.
2. People who have disabilities are more vulnerable than others to illness, exploitation, poverty, abuse and neglect arising from the nature of their disability, their social situation and service system,

3. People with disabilities, because of their heightened vulnerability, may experience an increased vulnerability to effects of euthanasia policies,

4. The life experiences of people who have disabilities may be highly instructive in how questions of euthanasia, and underlying issues of reasons for requesting euthanasia, may be approached,

5. Their specific perspectives are instructive as all humans face at least periods of heightened vulnerability and dependence in their lives and struggle between those issues and their needs for levels of personal autonomy and independence,

6. The risk of adding to the existing vulnerability of groups such as people with disabilities and its possible effect on the nature of society, may be powerful reasons for the application of caution in considering any legalisation of euthanasia and for the conceptualisation of strong safeguards to protect their interests whether euthanasia is legalised or not.

These have not changed. Now, at the end of this study, I sense how much the processes that I describe in my informants have also played a role in shaping my views and values. Undoubtedly they have influenced the idea, conceptualisation and design of this study.

1.4. Significance of the study

In this study a contribution arises from exploring the roles that vulnerability, independence, interdependence, dependence and personal autonomy play in the daily lives of people with disabilities. It examines how the universality of vulnerability, autonomy and dependency in human lives (Kittay, 1995; MacIntyre, 1999; Silvers, 1998; Wendell, 1996) may illuminate the euthanasia debate.

However, this study is of both specific interest to vulnerable people with disability and of universal significance. Four factors suggest the significance of this study. The first is that a disability voice on issues connected with EPAS is not much heard. The apparent absence of a previous study like this one adds to an impression
that a disability voice in this area is presently marginal. As people with disabilities are extra-vulnerable to decisions about their lives and deaths, it may be in their interests for their voice to be heard. Secondly, it appears that experience from living with disability may add fresh perspectives to the EPAS debate. This could be so as, unlike most people, many people with disabilities daily confront inevitable issues of dependence, vulnerability and personal autonomy, issues of the human condition and human nature that are central also to the EPAS debate. People with disabilities have obviously found their own approaches to these issues because many of them live long lives. In a public debate, which often appears to be stalled at polarised positions while majority support for EPAS continues to push for change in our laws, their contribution may be welcome and timely. Thirdly, reflection on any disability approaches to living under these circumstances in relation to attitudes, beliefs and practices with regard to EPAS may lead to new insights. Fourthly, such insights would be of disability-specific and universal interest. Disability is highly characterised by vulnerability, dependency and a struggle for individual autonomy. These are issues that touch on any human’s experience and are particularly, but not exclusively, felt when disabled or dying. Few of us are exempted from the first condition, none from the last. This fourth factor is interwoven throughout a brief explanation of the first three.

1.4.1 A marginal voice

Disability perspectives on EPAS are seldom heard publicly. The literature shows that some researchers, some known to have disabilities themselves, have investigated disability perspectives on euthanasia. But no studies were found that were derived wholly from interviewing people who have disabilities or disability movement leaders, although some works included some individual disability perspectives in a wider context (Kuhse, 1994; Parsons & Newell, 1996). The wider, public EPAS debate seldom includes disability perspectives or issues. Even more rarely are the voices of people with disabilities themselves heard on this issue (Council on Disability, 1999). There is, for instance, only one Australian disability advocacy group, Queensland Advocacy Inc., (out of more than 70 Commonwealth-funded disability advocacy groups) that is conducting research and advocacy on end-of-life matters concerning people with disability. However, I am not aware of a
public disability voice on EPAS by this group as yet. There is little evidence of a Dutch public disability perspective either. The peak Dutch disability group, the Gehandicaptenraad, supports the Dutch euthanasia law though it also says that it has fundamental doubts. It has pointed to a polarisation of opinion with a lack of social consent, insufficient enshrinement in law of a patient’s right to protection and to palliative care, and to a lack of sufficient legal codification of the requirements for careful practice (“Euthanasie, brief aan de leden”, 2001).

It is important that public debate on euthanasia includes the possible consequences upon various groups and individuals of its implementation or otherwise (Ewin, 2002). Legalising euthanasia or physician-assisted suicide may have an influence upon the social relations within a society, beyond those directly intended, including upon how we care for people who are ill, disabled and vulnerable (Mann, 1998; Somerville, 1993). And there may be direct adverse impacts from euthanasia practice on vulnerable people with disabilities arising from their devalued status, social exclusion and lack of personal autonomy (Fitzgerald, 1996; Wolfensberger, 1987; Sobsey; 1994). But, unlike in the USA, disability perspectives on EPAS are seldom raised in Australian or Dutch public debates.

1.4.2 A contribution from disability perspective

The potential contribution to this debate from disability perspective is of disability-specific and wider relevance. The experiences of both those who have disabilities and of those who are in close contact with disability, force those people to confront rarely addressed assumptions about life and our place in it (Goldin & Scheer, 1995). And not to inquire into the lives of people with disabilities may be knowledge lost about our fears about “the body, our weaknesses and imperfections and of our inevitable deterioration and death” (Wendell, 1996, p. 110). It is a contribution from a rich disability context and of insights on how we may best face up to our universal human condition (Goldin & Scheer, 1995). For instance, people with disabilities and those who are involved in their lives, including those in carer roles, have found enduring sources of moral values in living life lived with disability (Reinders, 2000). In a world that appears to lack common values and a guiding story (Hugh Mackay, in Eckersley, 1998, p.11) such insights may be welcome. An acknowledged shared human condition, and how we use any resources found in our
human nature will have impacts on how we view human fragility and deal with it, personally and publicly, whether disabled or not.

Specifically, the experience of people with disabilities in relation to dependence, vulnerability and autonomy is an obvious area to look for a contribution to the EPAS debate as central issues that the two have in common. Goldin & Scheer (1995) identified an ongoing struggle between issues of autonomy and dependency within individuals with disabilities. The available literature does also show differing approaches by people with disabilities themselves towards euthanasia. Some lean towards an emphasis on concepts of personal autonomy and independence in deciding questions of euthanasia and assisted suicide (Batavia, 1991, 1997; Hwang, 1995; Kuhse, 1994). Others show the existence of opposing views (Gill, 2000; Parsons & Newell, 1996). In the USA the disability activist group Not Dead Yet (Not Dead Yet, 2000) opposes legalisation of euthanasia while another “Autonomy Now” supports it. In Canada the B.C. Coalition of People with Disabilities submitted to a Senate enquiry that people with disabilities must have the same rights and choices as anyone else in ending their lives (B.C. Coalition of People With Disabilities, 1995, cited in Wendell, 1996). This tension is also reflected in the wider EPAS debate. It is that struggle, common to both disability issues and EPAS, which this study is inquiring into. In this study people with acquired quadriplegia all have experience of life with a wholly functioning body that allows a maximum independence and expression of individual autonomy, as well as experience of the opposite of that situation. This dual experience, and an ongoing personal engagement between issues of dependency, vulnerability and autonomy, which are shared core issues with the EPAS debate, are other reasons why they may be expected to bring universally relevant perspectives to the EPAS debate.

Disability experience and the experience of dying share common factors that affect the nature and quality of these experiences. Kastenbaum (2000), for instance, describes intra- and inter-personal, social and medical factors that influence the experience of dying. They include the quality of the dying person’s interpersonal relationships; the type of disease causing terminality, its medical treatment and the environment in which it occurs; a decline of personal control over one’s life and in one’s “social instrumentality”; how one is perceived and treated by others and; a decline in volunteer carers (pp. 111–114). Similar factors have been associated with
the quality of the disability experience, such as the nature of one’s impairment; socio-cultural factors, including human service responses; and dominant social values (Cocks, 1993; Wendell, 1997; Wolfensberger, 1998). Further, dying people may experience physical restrictions, a “distorted or altered body image”, disempowerment, restrictions in available time to get things done in a fast-paced world and a “transition from a world they have known” to another (Kastenbaum, pp. 120–121). Many people with disabilities must live with these realities in their daily lives. Thus the lessons from their experience are likely to be a relevant contribution to how one may live through dying, as well as to questions of hastening death.

1.4.3 Critical knowledge from the perspectives of devalued people

This research is founded on the belief that the perspectives of people with disabilities may be able to contribute new, or thus far at least insufficiently considered, aspects to the euthanasia debate. Major physical, social, and psychological changes and challenges arise for a person who acquires a significant disability like quadriplegia. Many such people learn to deal with these realities arising from the immediate crisis and live fulfilling lives. This may constitute useful knowledge, which may shed new light on end-of-life issues such as EPAS, for reasons just discussed. However, because people with disabilities embody socially devalued characteristics of difference, dependence and vulnerability any such emancipatory knowledge is devalued too and cannot easily emerge.

Habermas (1989) described three kinds of knowledge. The first is analytical/empirical knowledge. This knowledge is that of the Age of Reason, or Enlightenment, still dominant today. It involves empirical investigation of natural phenomena under controlled, objective conditions, based on reductionism, in order to develop a theory of causal relationships. In this study it sheds light on aspects of the social environment in which the informants live and on the kind of society in which the Enlightenment project is still dominant, and in which a demand for EPAS has arisen. Historical–hermeneutical knowledge is concerned with the phenomenology of people’s shared experiences, culture and (his)stories, in this case of people with disabilities. The third is emancipatory, or critical knowledge, being concerned with analyses of any differences between dominant ideologies and how people experience their lives. Any difference between knowledge from experience and of the wider
reality may dispel false consciousness about societal realities. Such emancipatory knowledge, synthesised from reflection on any differences between the first two kinds of knowledge might arise from this study that compares the experience of people with disabilities with their views on EPAS. I suggest that such new knowledge may be important, occurring as it does during a globally turbulent society, which appears to lack a common value base, or a guiding story.

At the same time, it was always held possible that no such new disability perspectives would emerge from this study. After all, people with disabilities live within the same social value culture that we all do, and are influenced by it. Any unique disability perspective on EPAS could therefore not be assumed.

1.5.0 Purpose of the study

People who have quadriplegia are the main subject of this qualitative study. A small sample of leading people in the disability movements in both the Netherlands and Australia was also interviewed for purposes of triangulation and indicators of issues which might need to be followed up with the primary sample.

The purposes of this study are:

- to discover Dutch and Australian disability perspectives towards euthanasia and physician-assisted suicide; and
- to find how the life experiences of the informants, within a cross-national context, may illuminate their perspectives.

1.5.1 Research objective

- To find how vulnerability, autonomy, dependency, interdependence and independence may be experienced in the daily lives of people with quadriplegia in the Netherlands and Australia, and how these may relate to their views on euthanasia and assisted suicide in a cross-national context.
1.5.2 Research questions

- What is the knowledge, including the beliefs and assumptions, of Dutch and Australian people with quadriplegia and leaders in Dutch and Australian disability movements, on issues of euthanasia and assisted suicide?

- What are the life experiences and views of Dutch and Australian people with quadriplegia and leaders in Dutch and Australian disability movements, with regard to issues of vulnerability, autonomy, dependency, interdependence and independence?

- What relationships may exist between the experiences of, and views on, these issues and the informants’ views on issues of euthanasia and assisted suicide?

- Do cross-national disability perspectives on the above issues lead to deeper understanding of and insight into the issues of euthanasia and physician-assisted suicide and their practical applications?
CHAPTER TWO

LITERATURE REVIEW

In giving a general context, Chapter two reviews literature on disability in relation to EPAS involving the roles of individual autonomy, dependence, independence and interdependence. Parts of the Chapter’s review of literature are in response to themes that arose from this study. These include personal value change and personal wellbeing; distance to dying and death; and dominant social values as an influential context to issues under examination in this study.

2.1 Disability, euthanasia and physician-assisted suicide

This section of the chapter reviews literature on the views of people with disability on EPAS and looks at literature about any vulnerability of this category of people to its practice.

No research was found which specifically sought the views of people with disabilities on euthanasia or physician-assisted suicide. In the context of an ongoing public debate on the vital issue of EPAS, this fact may well underscore the socially devalued status of disabled people.

Nevertheless, some work that includes the views of individual people with disabilities and the views of researchers known to have a disability provides some insight. Most of this literature is about the views of people with disability on the effects of EPAS on them as a group. Some, such as Dutch columnist and author Spaink (2002) and Australian researcher Newell (Parsons & Newell, 1996; Newell, 1996), mostly consider EPAS issues in general. Public debates about EPAS,

3 Of course it is often not known whether any particular researcher or author has a disability or not.
involving people with disabilities, have largely been American. Only two Australian studies were found that included views of some individuals with disabilities. Kuhse (1994), a non-disabled Australian ethicist who argues from respect for individual autonomy and a principle of the focal person’s best interests, edited the commentary of some people, including two disabled, who were represented as favourable towards euthanasia. Parsons & Newell (1996), the latter of whom has a disability himself, disagree about the merits of legalising euthanasia in Australia. The differing positions reached by the co-authors are reflected in the wider literature. Parsons (Parsons & Newell, 1996), a disability advocate, supports legal euthanasia on the basis of individual rights to choose one’s own assisted death. He acknowledges a devaluing social context for people with disabilities, including attitudes of doctors towards this group, but favours the legalisation of euthanasia. His support for EPAS is based on respect for individual autonomy and a person’s best interests where legal EPAS is thought safer than unregulated practice. In doing so he separates morality from protecting individual autonomy and dignity and public from private morality:

…neither autonomy nor dignity are threatened but rather, protected by laws that allow for active euthanasia. The moral dimensions of the issue are another matter. But like all issues of morality, these are the domain of individuals, and of ethicists, not of governments or the writers of law. (Parsons & Newell, 1996, p. 168)

Newell (1996, Parsons & Newell, 1996) concludes differently. Like others (Gill, 1992; Morris, 1991, 1992; Rock, 1996; Rock, 2000) he sees a threat to people with disabilities in legalising euthanasia because of the already existing devalued position of that group and the social valuing of the normal body. Exercising one’s autonomy to effect one’s euthanasia is a serious and irrevocable act. An effort to address the causes of the distress that leads some to request euthanasia is needed, rather than killing. Both co-authors, Parsons and Newell, agree that the euthanasia debate is far more complex than being either for or against EPAS.

Individual autonomy plays a prominent role in the EPAS debate. The Australian dialogue between Parsons and Newell is mirrored in an exchange on physician-assisted suicide (PAS) between two American authors who have quadriplegia: Batavia and Gill. Batavia (2000), who headed a pro-assisted suicide
group called “Autonomy” (Autonomy, 2002), held a similar view to philosophers such as Dworkin (1993) and others (Dworkin, Nagel, Nozick, Rawls, Scanlon, & Thomson, 1999). His view was that it is the dominant values of his society, self-determination and individual autonomy, which are the real issues in arguing for a right to PAS for both terminally ill and non-terminally ill people with disabilities. He acknowledged the presence of empirical evidence about disabled people’s devaluation and vulnerability, through their generally low social position, and the negative attitudes of the medical profession. He does not however see that as a barrier to insisting on the individual right to PAS. For him that is a matter of personal choice and self-determination (Batavia, 1991, 1997, 2000). Gill (2000) claims that negative attitudes from the medical and allied professions do present a threat to people with disabilities in the event of PAS being legalised, within a context of the wider devaluation of people with disability.

The Dutch columnist and author Karin Spaink (2001), who has multiple sclerosis, also supports individual autonomy as a guiding principle in ending one’s life. But her focus on personal autonomy leads her to reject euthanasia or physician-assisted suicide. She observes that the necessary involvement of doctors in a regulated process for EPAS brings with it a compromised and bureaucratised individual autonomy. Therefore she favours the self-administration of lethal drugs. She has written about how to obtain these via the internet, fraud or illegal drug dealers. She sees this lethal possession as an insurance against a time that the effects of her progressive condition are so disabling that she would soon not be able to kill herself and supports this strategy for those who are “finished with their lives” (Spaink, 2001, p. 93).4

Without suggesting that this is necessarily Spaink’s position, in the case of people with disabilities, the call for one’s autonomy to be respected in dying is often

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4 The public availability of suicide pills to elderly people has been part of the Dutch debate since 1991 when retired Vice President of the Dutch High Court Mr. Drion, publicly advocated the legal availability of suicide pills to the elderly. He saw this as a solution for people who “saw the moment arrive when [they] could no longer care for [themselves] (…) in a nursing home where [they] would feel dependent on others and where he would have to live his last years exclusively among elderly people” (Drion, cited in: Spaink, 2002, p. 93). Henceforth this proposal has been known as Drion’s Pill. The then Minister for Health, Mrs. Borst, remarked immediately upon passage of the Dutch Euthanasia Act that she was not against such a pill and since then legalisation of EPAS in the Netherlands has now been taken up by the Dutch Voluntary Euthanasia as their next aim (Dikkers, 2002).
taken at face value by those who lack an informed perspective and harbour a fear of
disability (Gill, 1992). But this call can, rather, be one for a more general respect for
one’s person. When American respirator-dependent quadriplegic Larry MacAfee
obtained court permission to be killed by shutting off his respirator he was finally
offered the independent living option that the nursing home had denied him. He
obtained legal standing and a right to die from the courts where he could not get the
standing to improve his living arrangements in the care system. He then no longer
wanted to die and is now living in the community. Australian, Anne McDonald,
herself a person with severe disabilities with personal experience of the ill effects of
institutionalisation, agrees that the lives of many people with disabilities are awful.
She holds that only when we improve the quality of the lives of those people will we
be able to ascertain whether they want euthanasia because “they think life with a
disability is worthless or because they think it is awful” (Parsons & Newell, 1996, p.
54). The cases of quadriplegics Bouvia, Bergstedt, Rodas and Rivlin are further
examples of (American) society’s willingness to give people with disabilities their
autonomy to die where it was less willing to give autonomy to them in life (Gill,
try to dissuade suicidal persons from their death wish. However, these people were
encouraged by doctors, judges and family members who called their determination to
die rational, courageous and the solution (Gill, 1992). In Australia there is no legal
history of individual people with disability’s quests for assisted death. But it has been
suggested that the autonomous choices that are involved in living full lives are often
non-existent for people with disabilities (Wareing & Newell, 2002). Such restricted
individual autonomy is reflected in the lives of such Australian institutional
“escapees” as McDonald (Crossley & McDonald, 1984) who experienced great
difficulties in unfolding her human potential in the restrictive institutional setting that
she lived in. EPAS in relation to disability is clearly an issue that cannot be isolated
from its social context. It is “interrelated with … general issues of rights,
opportunities and status … and of the services, programs, policies and services for
people with disabilities” (National Council on Disability, 1999).

The literature on disability generally views people with disabilities as
experiencing a generally devalued, segregated, stigmatised, excluded position in
society (Cocks & Duffy, 1993; Cross & Zeni, 1993; Goffman, 1963; Kliwer & Drake, 1998, Wolfensberger, 1987, 1992). They are seen as belonging to a category at high risk of violence and abuse (Sobsey, 1994a). Cocks (1998) points to some key dominant values in modernist Western societies as impacting on the situation of people with (intellectual) disabilities. Like Wolfensberger (1998), he identifies these as materialism, utilitarianism, individualism and choice, hedonism and immediacy. A high social value accorded to youth and physical beauty is part of this value system. The expression of these values in media, political processes, social policies and institutions is reflected in “social dislocation, dysfunctional social institutions, worsening social indicators and a weakening of commitments to vulnerable people” (p. 13). Western society devalues those who, like many people with disabilities, do not meet its valued human attributes of intelligence, independence and competence. It will withhold such goods as supportive relationships, respect and autonomy from them in what often is an unconscious process of social devaluation (Wolfensberger, 1998). Braddock & Parish (2001) contend that a growing stigmatisation and segregation of disabled people began in seventeenth and eighteenth century perspectives on poverty and a “medicalised interpretation of disability in the following two centuries” (p. 11).

Various conceptions of a social model of disability exist. For instance, Oliver (1983, 1990) and Bickenbach (in Braddock & Parish, p. 44) see handicaps as socially created disadvantages arising from the social response to impairments and disabilities. Wendell’s (1996) disability theory adds subtle social influences as contributing to disability, such as the fast pace of life and the disabled individual’s perception of life with disability. Murphy (1990), an anthropologist who examined his own experience of quadriplegia, holds that disability still creates fears “in the able-bodied … that impairment could happen to them … and … guilt that it hasn’t” (p. 117). Silvers (1998a) on the other hand says that portraying people with disabilities as weak and vulnerable is paternalistic and that they would be better served with a public policy that protects them from being assigned the sick role, as this role begs physician-assisted suicide. In saying this she may make the assumption that a sick role is the main, or only, issue that increases the person with disability’s vulnerability to misuse of assisted suicide. Others who, like Silvers, have direct experience of disability themselves (Coleman, 2002; Gill, 2000; Sobsey, 1994,
1994a; Wendell, 1996) contradict this view and want to acknowledge vulnerabilities experienced by people with disabilities. But Batavia and Gallagher (2002) have stated their outright disbelief that there is oppression and vulnerability of people with disabilities in contemporary US society, including vulnerability arising from physicians’ attitudes, even though they insisted on strong safeguards against abuse of any PAS legislation. The latter is a person with paraplegia who has described the extermination of people with disabilities in Nazi Germany (Gallagher, 1990). His disbelief in contemporary disabled people’s oppression and vulnerability contrasts remarkably with his belief expressed in that book.

How they treated their insane, handicapped and retarded during the Third Reich was certainly extreme behaviour (…) but it was not inconsistent with patterns of social behaviour that can be traced throughout the history of the disabled over the centuries. The German physicians actually acted on the basis of feelings, which are common (…) to most men and women in most societies (Gallagher, 1990, p. 239).

Wendell (1996) appears to be in agreement with Gallagher’s observation on an endemic negative public attitude to disability when she says that a public notion that disabled lives are not worth living …

lies at the heart of much theorising about abortion, euthanasia and health care reform, putting the welfare and security, and the social acceptance, of people with disabilities in jeopardy (p. 151).

Wendell (1996) adds that, on the other hand, people with disabilities, with their extensive experiences of the limitations of medical treatment, “are unlikely to support an ethic of life at any cost, or a reduction of individuals’ rights to choose death” (p. 151). Anne McDonald, herself a person with significant disabilities and who escaped the life-wasting and killing effects of Australian institutionalisation (Crossley & McDonald, 1984), agrees that the lives of many people with disabilities are awful. She holds that only when we improve the quality of the lives of those people will we be able to ascertain whether they want euthanasia because “they think life with a disability is worthless or because they think it is awful” (Parsons & Newell, 1996, p. 54). US disability activist and researcher Paul Longmore, points to the need for social acceptance of disability and the risks involved to people with disabilities of a socially negative view of dependency. He asks whether society has
come to a point where people prefer death and will receive assistance to die because “people cannot wipe their own behinds”? (cited in Smith, 2000, p. 115).

Clearly the available literature shows differing approaches by people with disabilities themselves towards euthanasia and assisted suicide. Their views vary between valuing the primacy of individual autonomy to seeing the social context as contributing to requests for EPAS and a need for society to accept disability. Not all people with disabilities accept their vulnerability as a given or that it might render them at risk if euthanasia were legalised. However these views are not based on studies of disabled persons’ attitudes towards EPAS.

Literature about the actual consequences for disabled people of a legalised public policy that allows EPAS is of course based on the Dutch and Oregon experiences and more recently on the Belgium experience. One of the deaths by assisted suicide in Oregon in 2000 was that of a woman who had ALS (amyotrophic lateral sclerosis). Her assessment of the depression that led to the approval of her assisted suicide was done without seeing a psychologist but through a written test that her psychologist sent her (International Task Force, 2001). One week after legalisation of EPAS in Belgium, the first man who received euthanasia also represented the first violation of this Act’s provisions. This man had multiple sclerosis. It happened despite a lawfully required one month cooling off period (“Belgian outcry”, 2002). The four patients who died under the Australian Northern Territory’s Rights for the Terminally Ill Act all had cancer, not a disability (Kissane, Street & Nitschke, 1998). However, any impacts of illegal EPAS in Australia (Magnusson, 2002; Kuhse, Singer, Baume, Clark & Rickard, 1997) on people with disabilities cannot be ignored. In relation to people who have AIDS, a disease that involves eventually disabling conditions, Magnusson has revealed disturbing illegal medical killing by doctors, nursing staff, other professionals, community workers and even a funeral director. Some of these deaths increased suffering and led to death with little or no dignity. Some killing acts were botched and extra medication, even smothering with a pillow was used. Obviously depressed people were medically killed and at very short notice by doctors and others who did not know them.

It is noteworthy that in the Netherlands no comprehensive disability-related data were collected in two major government-sponsored reports on the national practice of EPAS (van der Maas, van Delden & Pijnenborg, 1991; van der Wal &
van der Maas, 1996). This absence of data could be regarded as remarkable as standard objections to EPAS often involve a *slippery slope* which affects vulnerable people such as the aged and people with disabilities (Keown, 1995; Pollard, 1994).

Pijnenburg (1998), a Dutch physician, stated that the one-dimensional focus on autonomous choice has led to growing attention being paid to the “entitlement” of those who are not competent and autonomous to “receive an end to their life because of the presence – in the view of others – of unbearable and hopeless suffering” (p. 246). Like Newell (Parsons & Newell, 1996), Pijnenburg sees a logical extension of “autonomy” to choose assisted death to other categories, such as those with Alzheimer’s disease or severe handicap, who might be presumed to suffer unbearably. They cannot choose but ought to be *entitled* to the same right to end their lives as anyone else. Indeed Gomez (1991, p. 137) felt that in the Dutch practice of EPAS something more than “an argument from autonomy was at work”. He felt that there was a sentiment that certain patients were better off dead and it was humane to kill them. Callahan (1993), like Newell (Parsons & Newell, 1996), argued that such outcomes were inevitable, arising from the combination of the two main arguments for EPAS, as he sees them: self-determination and compassion in the face of suffering. In his view it is not possible to quarantine EPAS for competent people from EPAS for non-competent people, or from those who insisted that they were suffering unbearably for a range of reasons, including losses of meaning and dignity. This inevitability was particularly so in the Netherlands, where his first-hand observations included those of doctors’ indifference to their country’s low EPAS reporting rates, and thus to the policy’s safeguards. Kennedy (2002) and Gomez (1991) have also reported on such ambivalence in the Netherlands. Prominent Dutch historian van der Horst (1996) has described how a physician-assisted suicide death in his family went unreported, apparently with everyone’s tacit agreement.

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5 Van der Horst described a woman of under 40 dying of lung cancer who obtained lethal pills from her doctor and used them. This had, and still has, a great effect on me. For everyone who was close to her, including myself, it was a great comfort that a humane doctor had given her the choice. We were grateful for this form of tolerance. The same doctor who had given her the pills certified that she had died a natural death, so there was no need for an autopsy. Otherwise the pathologist would almost certainly have established death by poisoning and the doctor would have been prosecuted. But no-one saw any reason to request an autopsy, including the specialists at the Roman Catholic Hospital that had discharged the woman a few weeks before her death in the conviction that, with radiation and chemotherapy, she could live another year. In her case tolerance allowed her suffering to come to an end” (p. 125).
There are perhaps some empirically supported indicators of Pijnenburg’s and Gomez’s assertions. People with disabilities seem over-represented in the Netherlands in actual acts of EPAS and in making inquiries about it. Compared to all reported Dutch deaths by EPAS (0.82 per cent) between 1984 and 1993, higher rates of death by EPAS have been reported for people with AIDS (13.41 per cent), multiple sclerosis (5.35 per cent) and amyotrophic lateral sclerosis (ALS) (4.08 per cent) (van der Wal & Onwuteaka-Philipsen, 1996). Ganzini & Block (2002) found that 20 per cent of Dutch patients with ALS requested EPAS, which they saw as excessively high and suggestive of inadequate palliative care. No data are available for people with spinal cord injury in relation to EPAS but in 1995 one fifth of euthanasia inquiries to the Dutch national euthanasia association, the NVVE, came from people with chronic illness or disability. The remainder included psychiatric patients (Molenwijk, 1995). One per cent of all EPAS involves people with a diagnosis of mental illness with an estimated two to five assisted suicides per year (Griffith, Bood & Weyers, 1998).

As mentioned in Chapter One, the 1994 Chabot euthanasia case of a non-terminally ill person, Mrs. Hilly Bosscher, who was said to experience intense and long-term psychic suffering set a new benchmark for suffering as a valid reason for EPAS. The Court decided that “that the wish to die of a person whose suffering is psychic can be based on a autonomous judgement” (Griffiths, pp. 80–82; Klozko & Chabot, 1998). This Court’s decision considered the degree of suffering rather than its causes (Gevers & Leegemate, 1998), which in this case involved suffering from terminated relationships with her sons and husband through terminal disease, suicide and divorce. Other EPAS cases involving psychiatric illness (van der Meer, De Veen, Noorthoorn & Kraan, 1999), fear of dementia at an early stage of it (“Als goede zorg ontbreekt”, 1999) and tiredness of life (Rechtspraak.nl, undated) have focused attention on a Dutch widening of the concept of unbearable suffering. Arguably, people with disabilities, who might request EPAS for suffering arising from effects of bad care, could receive it on such grounds as accepted in the Chabot case. They might not even have to raise their request themselves, as in 50 per cent of cases Dutch doctors initiated the subject of euthanasia with their patients (Hendin, 1997). The Dutch government’s report on the practice of EPAS during 2002 touches on the difficulties of determining unbearable suffering, including for those with disabilities.
Unbearability depends on the “patient’s perspective, his personality and values. Besides the experience of suffering of each patient is different. For one patient it is unbearable to … become completely dependent on others, for another it is the ongoing loss of dignity” (p. 23). Such conditions include ALS, multiple sclerosis, spinal cord injury and cerebral vascular accidents. “In [the latter two] it is more difficult to determine that suffering is unbearable. There is no doubt however that the suffering of such patients is without prospect of recovery [a criterion for implementation of EPAS]” (Regionale Toetsings Commissies Euthanasie, 2002, p. 23). Under such vague approaches to unbearable suffering prominent Dutch physicians, such as EPAS pioneer Pieter Admiraal (Hendin, 1998, p. 193) and emeritus professor psychiatrist van Dantzig appear to confirm the reality of vulnerability of people with disabilities such as McDonald, MacAfee and others, who need good care and support but might receive permission to die upon their default. They think that EPAS for older dementing patients may be unavoidable, because of an ageing population and “steadily worsening circumstances: lack of community care and overfull nursing homes (…): “When nobody can care for you anymore and you’re no longer welcome anywhere, then some people would rather be dead” (“Als goede zorg ontbreekt”, 1999).

Over a five year period, within a sample of 89 physicians, four Dutch cases of intentional medical life-ending of institutionalised people with intellectual disability were found, all of which were reported as natural deaths (Van Thiel, Huibers & de Haan, 1997). End-of-life decision-making for this population reflects similar types and percentages as for the general population (Van Thiel, van Delden, de Haan & Huibers, 2001). There is a lack of openness among the medical profession with regard to end-of-life decision-making about people with intellectual disability (Van Thiel, et al.). This appears reflected in a zero per cent reporting of EPAS in this population, compared with 18 per cent in 1990 (van der Maas, van Delden & Pijnenborg, 1991) and 41 per cent in 1995 (van der Wal & van der Maas, 1996) for the general Dutch population. The Dutch peak parent group for people with intellectual disability, the “Federatie van Ouder Verenigingen” objects to EPAS of people with intellectual disability in a context of generally negative views from doctors of the quality of life of such people (van der Wijngaard & Quast, 1997). A changing notion of personhood from “intrinsic dignity of the individual entity to a set
of social characteristics that qualify one as a member of society”, brought about by the EPAS debate (Ten Have (1998, p. 209), together with an increased and misplaced emphasis on individual autonomy (Pijnenburg, 1998), may put people with cognitive impairments at risk.

2.1.1 Summary

The preceding literature shows differing approaches towards EPAS by people with direct experience of disability. However there is no literature of any examination of the attitudes that people with disabilities have towards this topic. Individual autonomy and the degree to which people with disabilities are able to exercise it play an important role in the EPAS debate. I am unaware of any relevant statistical information on the incidence of EPAS concerning people with disabilities. The best available evidence indicates however that the legal Dutch practice of EPAS appears to pose risks to people who have disabilities and there are some tenuous indicators from the Oregon and Belgium practice that may confirm such risk. The condition of disability may be seen as unbearable suffering. Some people, especially those who are incompetent, may receive EPAS under a misplaced proxy application of autonomy under circumstances of perceived unbearable suffering. In the Netherlands there appear to be some indicators of an increasing acceptance of wider criteria of suffering that may entitle one to EPAS. Social pressures arising from rising numbers of those who need care may see them receive EPAS instead. Such developments may also increase the vulnerability of people with physical disabilities who are seen to need a high level of care but who do not receive it. The illegal EPAS practice in Australia, mainly concerning people with AIDS, suggests that keeping EPAS illegal also poses problems.

2.2 Autonomy

In this section I pay closer attention to literature that refers to individual autonomy as it relates to people with disability and how autonomy relates to issues of EPAS more generally.

The same struggle between respect for one’s individual autonomy and one’s inevitable times of dependency and vulnerability as experienced by people with disabilities is present in the general EPAS debate. Many people seek respect for their
individual autonomy to choose their time of death in the face of their fears of an unworthy, undignified death, dependency on others and of being in pain (van der Maas, van Delden & Pijnenborg, 1991). A report about the first three years of operation of the Oregon Act found that burden on family, friends and care givers; losing autonomy; decreasing ability to participate in activities that make life enjoyable; and losing control of bodily functions, all rated much higher as motivations for PAS than inadequate pain control (“Oregon’s Death With Dignity Act”, 2000).

The word autonomy is derived from the Greek auto, or self, and nomos, meaning governance, law or rule. Issues and meanings of self-determination, authority, control, independence, rational choice, individual choice, liberty rights, privacy, freedom of will and self-governance have all been connected with the modern understanding of the term autonomy (Beauchamp & Childress, 2001; Dworkin, Frey & Bok, 1998; Ells, 2001; Fitzgerald, 1996). Autonomy as a theory has various constructions. Beauchamp & Childress (2001, p. 59) analyse autonomous action as that of “normal choosers who act intentionally, with understanding and without controlling influences that determine their action” (Beauchamp & Childress, 2001, pp. 58–59). They hold that almost all theories of autonomy agree that two conditions are essential. These are liberty, or independence from controlling influences, and agency, a capacity for intentional action. Modern conceptions of autonomy owe a lot to the work of philosophers Immanuel Kant and John Stuart Mill. Kant holds that each person has unconditional worth by virtue of having the capacity to decide one’s moral destiny. This makes them independent moral agents (Beauchamp & Childress, 2001). Kant is the architect of the concept of the autonomous agent who makes moral choices based on reason. Good reasons are those that do not contain internal inconsistencies. And good choices are those that are universalisable (Kerner, 1990). Kant (cited in Callahan, 1993, p.112) also said that the use of free will to destroy one’s own life is internally inconsistent. John Stuart Mill was particularly concerned with the individuality of moral agents’ actions in advancing their preferences, as long as they do not harm others (Beauchamp & Childress). Others have criticised the individualistic view of the independent normal chooser as not accounting for the relational context in which we all find ourselves and is at odds with the disability experience (Ells, 2001; Donchin, 2000; Fitzgerald,
1996; Wendell, 1999). It also increases the vulnerability of those who do not meet the standards for rational normal choosers, as Reinders (2000) argues:

... the prevalent idea [is] ... that creating meaning is an individual activity has serious implications for human beings to whom the notion of agency does not apply. Where there is no agent there must be a deficit in meaning. Where there is a deficit of meaning it is difficult not to perceive human existence as the cause of grave suffering. If it is merely a cause of great suffering, the question of why these people are kept alive becomes hard to avoid indeed. Not only is it hard to avoid, it also appears to have a definite answer. (Reinders, p. 205)

Arising from a situation of high dependency on segregative and restrictive service models, people with disabilities first called for rights to autonomy and self-determination in the 1960’s. This culminated in the emergence of the influential “Independent Living Movement” in the USA in the 1970’s, and which has spread worldwide. Self-determination, self-image and public education, advocacy and service to all, were formulated as the core principles of this movement (Braddock & Parish, 2001). Despite what its name suggests, this disability movement recognised the social factors in contributing to disablement, besides a focus on individual independence. It sought greater independence for disabled individuals within the social context. This is different from the pursuit of the greatest possible physical independence from others. People with disabilities’ struggle for autonomy is most often manifest in their struggle for independence (Ells, 2001). This is a struggle between the dependence arising from impairments and social and cultural factors (Wendell, 1996) and individual autonomy expressed in grappling with barriers to such goods as work, housing, education, transport, and the physical environment. Grappling with these inevitably involves connection with others, not separateness from them (Ells, 2001). But the dominant “paradigm of humanity” that has been constructed around an identity of the healthy, able-bodied, “ideally shaped” person, over-emphasises respect for individual autonomy. This idea of autonomy, as used in the bio-ethical debate, is about the concept of the individual in isolation, rather than in community (Fitzgerald, 1999). Indeed Martin, Emanuel & Singer (2000) view individual autonomy as the socially dominant principle applied in health-care, rather than as one in balance with other principles of nonmaleficence, beneficence and justice as advanced by Beauchamp & Childress (2001). Pellegrino (1993) criticises Beauchamp and Childress’ principles, which include autonomy, as being too
abstract, rationalistic and too removed from the context in which moral choices are made. They ignore the person’s character, life story, cultural background and gender.

In arguments in favour of euthanasia and physician-assisted suicide (EPAS) individual autonomy, self-determination, control over the circumstances and timing of one’s death in order to find relief from suffering are dominant ideas (Bickenbach, 1998; Donchin, 2000; Dworkin, 1993; Dworkin, Frey & Bok, 1998; Dworkin, Nagel, Nozick, Rawls, Scanlon, & Thomson, 1999; Griffiths, Bood & Weyers, 1998; Mann, 1998; Kuhse, 1994; Somerville, 2000). In the debate about physician-assisted suicide, this concept of individual autonomy was advocated by six prominent philosophers (Dworkin, et al., 1999) in their Amici Curae Brief to the US Supreme Court in defence of the right of terminally ill patients who experienced unbearable suffering. These patients, they said, have a right to demonstrate that their “decision to die is indeed informed, stable, and fully free”. It was based on a right of liberty to make one’s own decisions "involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy" (Planned Parenthood v. Casey, 505 U.S. 833, 851, 1992, cited in Dworkin et al., 1999). Speaking of euthanasia, Ronald Dworkin (1993) supports the individual freedom to choose one’s death, in accordance with the way we have lived our lives, that is in possession of the important human characteristics of self-determination and individual autonomy. He claims that as people fear the impacts of pain, excessive medical treatment and dependence on others, when dying, euthanasia can accord dignity to death. But as Battin (1998) has pointed out, his analysis focuses on the person’s agency at the end of life, and the agency of others is only taken into account in so far as it may impinge on the dying person’s agency. For most people the reality is one of a more complicated interpersonal life.

Just as individual autonomy is often present more in name than in actuality in the disability experience (Donchin, 2000; Ells, 2001; Fitzgerald, 1996; Gill, 2000; Pijnenburg, 1998; Sobsey, 1994; Wendell, 1999), there are indications of a similar situation with regard to the practice of EPAS and other end-of-life decision making in general. Physicians and other professionals have been found to make end-of-life decisions that were significantly determined by the doctor’s individual characteristics such as their medical training and socio-demographic background (Braun & Kayashima, 2001; DiPasquale and Gluck, 2001; Waddell, Clarnette, Smith, Oldham
& Kellehear, 1996). Pool (1996), an anthropologist who conducted a study in a Dutch hospital found that whether or not an act of EPAS was performed depended on individual doctors’ ability to communicate and willingness to perform it as well as difficulties in interpreting patients’ wishes. Some patients appeared to receive EPAS without a clear request and others not despite their request. In the US, physicians, while valuing patient autonomy, were found to place end-of-life decisions in a wider context and did not always accept that decisions ought to be made from this principle. Physicians who would not comply with patients requests still cited patient autonomy as the most important principle that they used in their decision making (Fried, Stein, O’Sullivan, Brock & Novack, 1993). Blaas (1998) found that Dutch physicians did often not honour advance directions about euthanasia once individuals became incompetent. Bach (1992) also found that the attitudes that patients have towards their disability and their treatment options was less influenced by them making informed rational decisions than by the attitudes of their doctors.

2.2.1 Public and private morality

Besides saying that individual autonomy is inevitably relational in nature but is often used as non-relational and that its dominant use as non-relational adds to the vulnerability of people with disabilities as it appears to do for those who are the subject of end-of-life decisions, there is another dimension of autonomy relevant to EPAS. That is the role of individual autonomy with regard to public and private morality. Individual autonomy in EPAS involves two interpretations. The first is the idea that autonomy is a matter of individual rights about whether one lives or dies. The second involves the individual’s capacity to make reasonable choices. Rights are derived from social agreements. Thus the limits of a right to autonomy are socially decided (Ewin, 2002). But according to Reinders (2000), our liberal, pluralistic society is unable to engage values that go further than the level of rights to individual choice and self-determination.

This idea of neutrality of government with regard to private morals and the values that they are based on is called by Griffith, Bood & Weyers (1998) the principle of tolerance. The neutrality that guides governmental positions they term neutrality of justification (p. 187). A public morality that operates at that level accords people individual rights to choice and self-determination by which they then
make their own moral decisions. Public morality in liberal society does not concern itself with the morality of individual choices as long as their consequences remain in that person’s private sphere. Public morality then can only operate at a consensus level of, what Reinders (2000) calls narrow morality, leaving the remainder to private choices. And public policy is limited in what it can resolve about EPAS controversies because the public/private liberal paradigm cannot accommodate moral values that appear to restrict private individual freedom (Clor, 1996; Griffith, Bood & Weyers, 1998, p.185). For example, some people with disabilities themselves use this public/private dichotomy as a way to justifying a right to EPAS:

You do not need to be pro-abortion to support the rights of a woman to determine what happens to her own body. Nor do you need to be in favour of suicide to support physician-assisted suicide. You simply must recognise that these are personal issues. (Kohout, cited in Corbett, 1999)

According to Griffiths, Bood & Weyers (1998), a public/private separation principle, as recognised in legal philosophy, has two basic views. The liberal view is one of state power being restricted in principle, with a presumption of individual liberty that is reflected in any state regulations. Any restriction of individual freedom must be justified by considerations of greater weight, where those who argue for the restriction carry the burden of proof. The conservative view, by contrast, holds that there are only practical reasons for limited state power where communitarian and individual concerns of moral goods are held as important.

While taking different positions as to the role of individual autonomy in ethical decision-making, Griffith, Bood & Weyers (1998) and Reinders (2000) both conclude that a sensitive ethical question, such as EPAS represents, cannot be satisfactorily resolved by public policy. In the view of the first, there is a problem because of the compromises that need to be made, such as “restrictions on individual freedom [to exercise one’s autonomy to choose EPAS] which do not correspond with that [liberal] paradigm” (p. 185). In the view of the second, the problem is that the question can only be approached at a superficial level because of the compromise level at which debate in a pluralistic, liberal society stalls, requiring a cultural change, rather than a political solution (MacIntyre, 1999; Reinders, 2000). Reinders argues that the presumed divide between the first view (or procedural morality) and the second (or content-full morality) collapses. This is because the justification of
morality in the private/public paradigm cannot succeed without reference to the morals and values that individuals bring with them. The public and private spheres are intimately connected. His strategy is then to use the values found in care for, and living with, people with intellectual disability to point out that our society’s “moral fabric is much richer than liberal morality allows us to acknowledge” (p. 33). Ells (2001) concurs but includes disability, from the experience of the person who has the disability, in re-conceptualising individual autonomy.

In relation to attitudes towards EPAS there appears to be empirical evidence of the private/public divide, as Reinders (2000) described it, where individuals draw on different moral levels in each sphere. Some studies have shown a discrepancy between people’s approval for a public policy and what they do themselves. For example, positive private attitudes are often expressed about advance directives about medical treatment but few people complete them (Emanuel, Barry, Stoeckle, Ettelson & Emanuel, 1991; Kastenbaum, 2001). Chochinov et al., (1995) drew on a number of surveys of physicians’ attitudes towards EPAS (Fried, Stein, O’Sullivan, Brock & Novack, 1993; Kuhse & Singer, 1988; Kinsella & Verhoeff, 1993) to show that 35–60 per cent of doctors thought these practices should be legalised but only 28–40 per cent said that, if legal, they would be willing to practice them. Similarly, 60 per cent of doctors supported the legalisation of assisted suicide in Oregon but only 46 per cent were willing to prescribe the lethal drugs to effect it (Lee, Nelson, Tilden, Ganzini, Schmidt & Tolle, 1996). It has been suggested that a decrease in support for PAS among Oregon oncologists, between 1994 and 1998, was related to their increased training in and knowledge of palliative care. Portenoy, et al. (1997), in surveying doctors, nurses and social workers, confirmed this suggestion. One-and-a-half per cent of these oncologists had performed EPAS where they were able to provide all necessary care. However 6.2 per cent had performed EPAS where “administrative, fiscal and structural barriers allowed them to provide their dying patient with only some of the care they needed…” (p. 530) (Ezekiel, et al., 2000). Another study showed that of 988 terminally ill patients, 60 per cent supported a hypothetical EPAS situation. Only 10.6 per cent would consider it seriously for

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6 In 1998, from the time of enactment of Oregon’s Death With Dignity Act in 1994, Ezekiel, et al found that support for physician-assisted suicide among Oregon oncologists, declined by half and for euthanasia by two-thirds. Besides issues of training and knowledge of palliative care, spirituality also seemed to play some role.
themselves (Emanuel, Fairclough & Emanuel, 2000). The latter could perhaps also be explained as a distantiation between their own immediate, and future, circumstances. This seemed to be so in the case of people in the earlier stages of terminal illness of whom about one third would consider EPAS (Chochinov et al, 1995). As Chochinov et al. (1995) have pointed out, only 8.5 per cent of patients receiving palliative care for terminal cancer reported a strong desire for death (Chochinov et al., 1995); 3.6 per cent of dying people had discussed with family a wish to have euthanasia (Seale & Addington-Hall, 1994); and 9.9 per cent of Dutch patients who are nearing death from non-acute causes requested euthanasia (Olde Scheper & Duursma, 1994). Only 39.9 per cent of American terminally ill elderly patients with psychiatric and medical conditions preferred PAS, compared to 59.3 per cent of their relatives supporting their PAS. In cases of chronic illness patient support for PAS was respectively 18.2 per cent compared to 25.3 per cent of support by their relatives and in cases of mental incompetence patient and relatives’ support compared as 13.5 to 15.4 per cent (Koenig, Wildman-Hanlon, & Schmader, 1996). In other words, these studies show that the closer one’s experience with dying, the less support for EPAS there is. Public support for EPAS stands at 92 per cent in the Netherlands (Griffiths, Bood & Weyers, 1998) and at 78 per cent in Australia (Morgan Gallup, 1995). These large differences between public support for EPAS and private support by people who are terminally ill, or are otherwise closely involved in others’ dying, may be connected to Reinders’ public/private divide and may include an element of personal distantiation. A mechanism of distantiation may be the application of different values to each scenario, influenced by levels of personal knowledge of dying and palliative care. As phronesis (MacIntyre, 1999), or first-hand practical knowledge, develops, private values may change.

2.2.2 Summary

Regard for individual autonomy is a dominant argument in the general EPAS debate as it is in the EPAS debate with regard to disability. Scholars hold differing views. It is often used as a non-relational, free-standing principle but is inevitably bound up in inter-relational dynamics and is not free from controlling influences. These dynamics involve patients and medical and other professionals as decision-makers where the potential implementers of EPAS have the greater power. Just as in
the disability experience, patient autonomy may at times not be honoured and may be misplaced in justifying end-of-life decisions in general. Non-relational individual autonomy may be an insufficient principle to resolve end-of-life issues, which require additional, relational values in resolving underlying questions involving adequate care and support. The dominance of the non-relational autonomy paradigm involves a public/private divide as a means to address end-of-life issues by individual choice.

### 2.3 Interdependence

This section briefly discusses MacIntyre’s theory of *interdependence*, in relation to some of the disability literature on the subject. This theory is also described in Chapter Three, this study’s conceptual framework. It then goes on to review literature that seems related to MacIntyre’s concepts of *flourishing* and *phronesis*. These involve literature on wellbeing within the experiences of disability and personal value change and touch also on similar studies in relation to ageing and dying in suggesting a universal application of MacIntyre’s views. Themes involving wellbeing, value change and personal growth are manifest in this study’s findings.

MacIntyre argues that human dependency and vulnerability are insufficiently acknowledged in Western society. However, he explains that dependency on others, along with vulnerability, is a key human experience. Dependency and vulnerability are experienced by all of us at various times over the course of our lives: when newborn, a child, when ill, disabled or frail-aged. Not acknowledging these important aspects of our human nature leaves an unbalanced and incomplete account of ourselves and of our human nature. In turn this non-acknowledgement leaves us insufficiently open to using our emotional intelligence, that is, our ability to use both our emotional and rational capacities in conducting our lives. According to MacIntyre, for human beings to *flourish* a balance between the virtues of rational independence and acknowledged dependence and vulnerability is necessary. Flourishing involves entering into the full experience of engagement with the unacknowledged aspects of the human condition as well as concepts of ourselves as independent. It is within this engagement with “life as a whole” (p. 113), necessarily involving unconditional relationships with others, that private, relational values are expressed in the development of virtues such as kindness, generosity, patience and
persistence. A human being’s life flourishes “as a whole”, when an individual learns through “experience about the places both of independence and of dependence on others in the different stages of a flourishing life” (p. 113). The learning of a practical reasoner is that of “find[ing] one’s place within a network of givers and receivers in which the achievement of one’s individual good is understood to be inseparable from the achievement of the common good” (p. 113). Having thus acknowledged one’s vulnerability and dependence, and consequently having entered into an ongoing process of development of such virtues, or the practical knowledge called phronesis, in relationship with others, one may become a practical independent reasoner and experience human flourishing. Flourishing thus constitutes an ongoing developmental process involving both the individual and community.

Others have also described human dependency and vulnerability as unacknowledged in Western society but as inevitable parts of the human experience. These realities are felt most keenly when our survival, or wellbeing, such as under conditions of disability or illness, are threatened (Ells, 2001; Held, 1990; Loewy, 1993; Kittay, 1995; Reinders, 2000; Tronto, cited in Wendell; Wendell, 1996; Sontag, 1978).

… no culture that endures beyond one generation can secure itself against the claims of human dependency. While we are all dependent on some form of care or support, at least minimally, and although dependencies vary in degree, those that involve the survival or thriving of a person cut most deeply through the fiction of a social order presumably constituted by independent equal persons. (Kittay, 1995, p. 8)

The dependency of disability, needing others for very basic personal tasks, in a society which values individual independence, is often seen as humiliating (Wendell, 1996). Even within the disability movement there is a shame about the need for others, something rather kept in the realm of privacy. Therefore the disability movement tends to spend a lot more energy on issues like accessible transport than on ensuring basic care is available (Wade, cited in Wendell, p. 147). An example of the difficulty of acknowledging dependency appears reflected in medical staff’s more negative perception of suffering and levels of depression that spinal cord injury patients experience than the latter did themselves (Cushman & Dijkers, 1990; Patterson, Miller-Perrin, McCormick & Hudson, 1993). Also, some people would
rather be dead than dependent on others in their hour of need and in pain (van der Maas, van Delden & Pijnenborg, 1991; Oregon’s Death With Dignity Act, 2000).

Often we will not notice our bodies until something goes wrong with them and then have to adapt our lives to a different reality where the limited body becomes part of our identity (Leder and Zola, cited in Ells, 2001, p. 560). The literature contains many examples of an apparently good personal accommodation of the realities of increased dependence and vulnerability under conditions of acquired chronic disability, of old age and when dying. Parts of this literature indicate the presence of aspects of MacIntyre’s flourishing when it shows personal wellbeing and value changes towards greater emphasis on social aspects of life and a sense of personal growth. Relational factors are very important to the wellbeing in these categories of people and involve intra-personal attitudes and changes towards one’s changed circumstances and towards others.

Gill (2000) has pointed to the many studies showing high levels of wellbeing under conditions of severe disability, as an important part of her argument against PAS. Despite the presence of heightened dependency and vulnerability for many disabled people, most studies indicate that they rate their own lives as good or better than those of others (Crewe, 1996; Eisenberg & Salz, 1991; Stensman, 1985). In a sample of 1668 people with quadriplegia 74 per cent rated their lives from fairly good to very good and 26 per cent from fairly bad to very bad (Ville, Ravaud & Tetrafigap Group, 2001). Under conditions of ageing with quadriplegia, combining two concepts that are usually assumed to imply negative wellbeing, people felt “pretty good”. They were “happy with their lives and … glad to be alive”. This was so despite many “potential problems and health complications” (Gerhart, Charlifue, Menter, Weitzenkamp & Whiteneck, 1997). Dijkers (1999), Woodrich & Patterson (1983) also found no impact of ageing upon quality of life or levels of wellbeing among people with spinal cord injury, nor was level of injury related to acceptance of disability. This was also true in comparing those whose onset of spinal cord injury arose between the ages of 1–25 and 16–39, showing age and level of injury do not predict long-term psychological adjustment (Kennedy, Gorsuch & Marsh, 1995). Ventilator-assisted people with quadriplegia rated their lives as better than those without ventilation and the majority of both groups of people with quadriplegia, ventilated and non-ventilated, reported positive life satisfaction and wellbeing (Bach
Brooks, Tonack, King, Simson, Gould & Goldstein (2002), in a qualitative study, confirmed the perception of high quality of life among 26 respirator-dependent people who did have conditions other than quadriplegia. Such findings are contrary to public beliefs about the experience of disability (Patterson, Miller-Perron, McCormick & Hudson, 1993). Medical staff interprets the experiences of spinal cord injured more negatively than how the latter experience life themselves. Hospital staff, for instance, have been found to overestimate the suffering and levels of depression that spinal cord injury patients experience (Cushman & Dijkers, 1990; Patterson, Miller-Perrin, McCormick, & Hudson, 1993).

Some studies suggest that there is no significant difference between the quality of life of non-disabled and that of disabled people (Cameron, Titus, Kostin, & Kostin, 1973; Eisenberg & Salz, 1991; Fine & Asch, 1988; Stensman, 1985; Titley, 1996; Wacker, Harper, Powell & Healey, 1983; Weinberg, 1984; Yerxa & Baum 1968). Some people with disabilities may view their lives as better post injury than before it (Ray & West, 1984; Weinberg, 1984). Somewhat lower rating of the quality of their lives by people with disabilities compared to non-disabled control groups has also been shown (Decker & Schultz, 1985; Fuhrer, Rintala, Hart, Clearman & Young, 1992). Where studies show lower ratings of life satisfaction, these are due to negative correlation of quality of life to social dimensions (Gill, 2000). These include inadequate social support or control over life choices (Fuhrer et al., 1992; Viemero & Krause, 1998) rather than physical factors, such as severity of impairment (Decker & Schultz, 1985) or items related to independent functioning (Ville, Ravaud & Tetrafigap Group, 2001). As discussed by Ville et al., and Gill (2000), a number of studies have nevertheless shown that life satisfaction is not influenced by either severity of impairment or level of independence (Craig et al., 1994; Cushman & Hassett, 1992; Dijkers, 1997; Dunnum, 1990; Fuhrer, et al., 1992; Viemero & Krause, 1992). Instead life satisfaction is often related to social factors. Loss of autonomy was found to affect wellbeing to the degree it limited social activity, relational or occupational (Ville, et al., 2001), suggesting the primacy of importance of social relationships over other benefits derived from occupational activity. Social support was found to be important in adjustment to disability (Brooks, et al., 2002; McColl & Skinner, 1995). Support from family and friends ranked higher in
importance in adjusting to disability than disability conditions, psycho-social or
demographic factors (Li & Moore, 1998).

Life satisfaction, quality of life and wellbeing rises with the richness,
frequency and quality of social contacts, confiding relationships and social
interaction (Bach & Tilton, 1994; Coyle, Shank, Kinney & Hutchins, 1993; Schultz
& Decker, 1985; Crisp, 1992; Clayton & Chubon, 1994). Physical survival of people
with quadriplegia has been linked to better personal adjustment and being socially
Bracken & Shepard (1980) found that the kind of person one was before spinal
injury, and the influence of significant others, play a significant role in coping with
injury. They discussed studies showing that those with a more stable personality and
high ego strength with an ability to delay gratification, cope better with disability
than those who were ambitious and showed intense personal effort.

There is evidence that people who are faced with disability adjust to the new
situation by changing their values and worldview (Bach & McDaniel, 1993; Keaney
& Glueckauf, 1993). This is true for people with spinal cord injury (Crewe, 1996)
and has been found in people with many types of disabilities, whether congenital or
traumatic in origin (Keaney & Glueckauf). These studies do not directly refer to
acknowledgement of the respondents increased dependency and vulnerability but
appear to suggest an acceptance of that reality attended by value changes that would
assist flourishing. Wright (cited in Crewe, 1996) suggests that the key to good
psychological adjustment to onset of disability is a personal change in values. Four
areas of values change have been identified (Keaney & Glueckauf). Enlargement of
the scope of values occurs when the disabled person recognises other values as
important compared to those lost. This process is initiated by a number of factors,
including the need to attend to manage daily life and relief from grief over losses.
The enlargement is said to occur when the person perceives meaning in “[traumatic]
events [that have happened to them], abilities and goals” (Keaney & Glueckauf, p.
200). A seemingly closely related second avenue of values change opens when one’s
scope of values broadens, away from the socially admired values of physical
perfection, beauty and ability towards others such as friendship, intelligence, work
and creativity. This change is a compensation for the loss of one’s own physique.
Stensman (1985), for instance, showed people with mobility impairments redirect
their valuation of walking and getting dressed independently towards communicating, relating socially and thinking. The third area of values change occurs when the person sees their disability as but one of their characteristics, rather than as a condition that defines them. Watson, Cunningham-Burley, Watson & Milburn (1996) found that people with physical disabilities adopted criteria for judging health different from the dominant view. Their adopted criteria were independent of physical appearance or level of functioning. The fourth area of values change occurs when self worth is judged not by comparison with the social standard but as an expression of one’s intrinsic worth. A sense of personal growth may arise as the person becomes aware of their changed values (Crewe, 1996). In looking at gains and losses of 50 people with quadriplegia over a 20-year time span, Crewe found that the most frequently reported gains were in the areas of personal growth, reflecting changes in values, priorities and self-understanding. Deeper relationships were also often mentioned as perceived gains from the disability experience.

These phenomena of wellbeing, value change and personal growth are not restricted to the disability experience. They have been studied also in ageing people and in those who are dying. The world’s longest study of ageing, the Harvard Study of Adult Development, followed 824 people in three cohorts. Key findings on wellbeing included: the relationships with good people in overcoming negative events is a significant factor: that the capacities for gratitude, forgiveness and loving people facilitate healing relationships; that objective physical good health is less important than subjective good health, showing that is there is a difference between being ill and suffering from it. Further, graceful ageing involved being caring towards others, having trust and hope in life, “sensible autonomy”, initiative, a sense of humour and capacity to accept “indignities of old age, [being] graceful about dependency issues, [taking] care of self, and when ill [being] a patient a doctor would want to care for” (Vaillant, 2002, p. 346). Dignity was found in an integrity that was an acceptance of the “next best to what you want” (Vaillant, p. 159).

Vaillant concludes that wisdom is that which one needs to know to live life well and its acquisition depends on “the toleration of ambiguity and paradox” (p. 256). It is about engaging with one’s emotions, rather than ignoring them and involves the integrated use of cognitive and emotional intelligence (pp. 252–256).
Like in the disability and aged experiences, a *wellbeing* in dying is also associated with social support and intra-personal dimensions. Although the phrase *dying with dignity* is often heard in the EPAS debate, including from my informants, its meaning is seldom clarified. This is despite data, such in the Netherlands, which showed *loss of dignity* and associated issues to be highly relevant to the EPAS debate. In the Netherlands loss of dignity (57 per cent), dying in an ‘unworthy way’ (46 per cent), dependency on others (33 per cent), being tired of life (23 per cent) and physical pain and suffering (46 per cent) were reported as reasons underlying requests for EPAS (van der Maas, et al., 1991). Kass & Land (1996) hold that “death with dignity is solely dependent on social support” (p. 17). Chochinov, Hack, McClement, Kristjanson & Harlos (2002) clarified the meaning of loss of dignity in terminally ill people, capturing many of the issues that are also involved in wellbeing. They found three categories: firstly, *illness-related concerns*, including symptom management and preservation of independence; secondly, a *dignity-conserving repertoire*, involving the way one looks at one’s own situation and personal actions that bolster one’s dignity; and thirdly, a *social dignity inventory*, referring to “social concerns or relationship dynamics that enhance or detract from a patient’s sense of dignity” (p. 439). Chochinov et al.(2002) have proposed this as a new model for palliative care where the dignity of the dying person stands central. In this model the dignity conserving repertoire appears to incorporate the phenomenon of personal value change and growth, affecting the way one views one’s own situation and acts accordingly. The first and third categories appear to fit with the positive roles of good social support and care, and social relations in wellbeing, also found to be so for dying people by many others (Chochinov, et al., 1995; Lavery, Boyle, Dickens, Maclean, & Singer, 2001; Muskin, 1998; Breitbart, Rosenfeld, & Passik, 1996).

Akin to MacIntyre’s *flourishing*, *wellbeing* in dying has also been observed as part of a developmental process which, akin to phronesis offers opportunities for personal growth towards “feelings of mastery, expansion, a sense of wellbeing ..” (Byock, 1997, pp. 33–34) Imara (1993), Byock, (1994, 1996) and Thomas (2001) have also described dying as a developmental process containing opportunities for fulfilment and wellbeing.
2.3.1 Suffering and transformation

*Interdependence* and its manifestation under severe threats to human wellbeing or survival can be understood as responses to suffering found within the resources of human nature. It appears to be a successful approach because it acknowledges that a “whole of life” experience must involve engagement with all aspects of the human condition. This has a dual, inter-related outcome of flourishing, or wellbeing, as individuals within community and of overcoming suffering by accepting the full reality of the human condition. This second aspect of flourishing is the outgrowing of suffering by seeing it in a different light.

Suffering, including much physical pain, has been said to be always “socially informed” (Csordas, cited in Paterson & Hughes, 1999). Viktor Frankl described suffering as a loss of purpose and meaning rather than as the extreme deprivation of the German concentration camp that he endured (Frankl, 1985). According to Frankl and Achterhuis (1995), meaning seems to arise when life is not perfectly controlled. Because of findings of personal interpretations of pain in such dimensions as malfunction, as spiritual and self-growth, coping and control, abuse and power, pain is necessarily “permeated” with meaning (Paterson & Hughes, p. 602). Suffering is essentially caused by events that threaten one’s physical and psychological integrity, or intactness, as a person (Cassell, 1991). Because of the intra-personal and social nature of suffering it can be overcome by using these as resources to transform its experience, as MacIntyre’s interdependence framework does. Wendell (1996), who says that she is speaking from personal experience, speaks of transcendence of pain through acceptance:

… we must also talk about how to live with the suffering body, with that which cannot be noticed without pain, and that which cannot be celebrated without ambivalence. We may find then that there is a place in our discussion of the body for some concept of transcendence (p. 179).

The relevance of *suffering* to the disability experience and dying and end-of-life decision making such as EPAS, is apparent when considering its universal causes, arising from external circumstances, intra-personal dynamics and social relations as reflected in Wendell’s (1996) social theory of disability and in Cocks & Duffy’s (1993) concept of vulnerability.
Just as the enlargement of the scope of values held by people with quadriplegia allowed them to overcome suffering from their disability (Keaney & Glueckauf, 1993), Cassell (1991) sees patients as enlarging themselves as they grew in their suffering. They transcended their suffering by re-arranging their beliefs in new ways, leading to a self-perception as another “intactness” in a new dimension” (p. 44). Carl Jung (Wilhelm, 1962) believed that life’s most important and greatest problems are in essence insoluble and that they can only be outgrown. Outgrowing suffering in this sense means that the actual observable condition causing the suffering, like dependency, might not change but by perceiving it differently it may no longer be experienced as suffering. Jung held that these problems are unsolvable because such problems contain the polarities, like dependence and independence, inherent in any self-regulating system, or in MacIntyre’s life as a whole. When one part of such a system is denied, not acknowledged, or is attempted to be controlled, the system may become dys-functional. Meaning, a cause of suffering, may then disappear.

Reinders (2000) contends that there often is a conscious personal choice involved in accepting life as a whole. He uses the example of the personal growth, or “transformation experience” (pp. 175–187) of parents involved in the daily care and support of their children who had intellectual disability. Reinders points to a paradox of ‘subjective’ and ‘objective’ perception of one’s life. On the one hand these parents find their caring role enriching and rewarding in the sense of a ‘fulfilment’ that can only come in the pursuit of demanding, difficult tasks. On the other, they might think to themselves that they might choose a life without this task, if they had a choice – Reinders calls this the objective ‘view from the outside’. These subjective and objective views within the one person produce a tension because it is difficult to integrate the objective view into the subjective view grounded in one’s own experience. It is difficult to hold both views at the same time without the detached objective view undermining the commitment, which enables the care in one’s lived, subjective experience to occur. From the objective view their life may seem of a negative quality as a result of “the hardships we endure, the emotions we invest, the passions that absorb us into making an effort – all of which make our commitments seem important to us appear as simply a waste of energy” (p. 181). Thus the objective view may lead to alienation. The objective and subjective views are parts in
each of us and both have their value. But parents, in a study by Scorgie (in Reinders, pp. 184–185), transcended this inner conflict by making a choice of *embracement*, or acceptance, of their lives. They made a commitment of continual care for their children with intellectual disability. This required a personal change where they became more compassionate, confident and enjoyed an increased sense of humour. They had adopted a different perspective of what was important in life, using the values found in their private experience of care, accepted the disability, reframed their beliefs and attitudes and learned to live with uncertainty. Reinders supports the possibility that people have a choice about whether to transcend events. It is not that what we think, feel and perceive that determines what we experience but *how* we experience it. Therefore a sense of coherence between “how we experience what happens in our own lives … and our view of the world at large” is important (p. 187).

### 2.3.2 Summary

The preceding review of literature on interdependence, wellbeing, suffering and personal growth suggests dependence and vulnerability are largely not acknowledged within the Western culture, despite its inevitable presence in each person’s life. MacIntyre’s interdependence framework is of universal relevance for this reason. When threats to personal wellbeing or survival occur, these underlying parts of the human condition are more prominently felt. A conscious choice can be made to acknowledge and accept dependency and vulnerability by anyone at any time but becomes more pressing at such a time of threat. The literature shows that many people with disability appear to adopt at least parts of the interdependence framework and experience wellbeing. The wider relevance of this phenomenon is strengthened by similar evidence in relation to aged people and in dying. Human flourishing is made up of individual and social wellbeing and of an outgrowing of suffering by changing one’s values and perception of reality. Such personal growth occurs in the ongoing process of engaging with the full paradox of life’s dependence and independence. As the literature shows, the interdependence paradigm appears to offer practical approaches to suffering and routes towards individual and social wellbeing. MacIntyre’s framework has many parts in common with other scholar’s views on its cultural and practical dimensions and value and appears confirmed in
some empirical evidence. Interdependence appears as a plausible representation of human nature.

2.4 Distance from death and dying

Most of the *grassroots* informants in my study had little direct experience of the dying of others. They also appeared to be unclear about the nature and practice of possible options at the end of life, such as EPAS or palliative care. They professed a low personal fear of death or dying but thought that such fear was publicly pervasive. There is a vast literature on death and dying. The main purpose of this part of the literature review is to get some insight into whether my informants’ experience and knowledge is isolated or is a more widespread phenomenon. Some detail on availability of palliative care in Australia and the Netherlands is included. The nature and practice of EPAS is of course discussed more extensively elsewhere in this study.

A distance from the experience of dying and death seems to be a modern phenomenon.

As with every other looming terror and looming temptation, we seek ways to deny the power of death and the icy hold with which it grips human thought. Its constant closeness has always inspired traditional methods by which we consciously and unconsciously disguise its reality …. In recent generations, we have added something new. We have created the method of modern dying. Modern dying takes place in the modern hospital, where it can be hidden, cleansed from its organic blight, and finally, packaged for modern burial. We can now deny the power not only of death but of nature itself. We hide our faces from its face…. . (Nuland, 1995, xv)

Indeed by 1987, in Wales and England, less than 32 per cent of people died at home (Seale & Cartwright, 1994, as cited in MacNamara, 2001, p. 73). For America in 1988 this was about 20 per cent (Quint Benoliel & Degner, 1995, as cited in McNamara, 2001, p. 73) and for Western Australia in 1995, 22 per cent (Australian Bureau of Statistics, 1997, as cited in MacNamara, 2001, p. 73). Most deaths occurred in hospital with the remainder in institutions, hospices and deaths elsewhere. Dying has become greatly medicalised and is shaped by the medical profession’s mission for curing disease, set within a highly technological environment (Callahan & Hanson, 1998; Callahan, 1993; Cassell, 1991; Griffiths, et
al., 1998; MacNamara, 2001). This is not surprising in an age where “many have come to look upon the termination of human life as a mechanical failure”, where the expression *pulling the plug* is a phrase that is revealing of this view (Kastenbaum, 2001, pp. 46–47). Fears of a techno-medical approach to dying, which would keep people alive beyond thresholds of futility of treatment and institutionalisation, and involving a loss of personal control, are important factors in the desire for hastened death (Achterhuis, 1995; Griffith, Bood, & Weyers, 1998; Kellehear, 2001; Mitchell, Kerridge & Lovat, 1996, p. 262).

Fear, and consequently, *denial* of death in Western societies is pervasive according to Aries, 1974, 1981; Becker, 1973; Borysenko, 1994; and Gorer, 1955. But unrelated to any belief in their immortality or extinction, many people *say* that they are not afraid of death but are afraid of dying (Loewy & Loewy, 2000). Kellehear (2001) suggests that the Australian culture, like the North American and British cultures, does acknowledge grief and death but not dying, which leads to an “absence of ideas” about end-of-life scenarios.

It is as if Australian culture … readily acknowledge[s] death and grief, but not the process of dying. (…) Is it any wonder that when Australians now face the prospect of dying they are empty of ideas about what is to be done? (p. 508).

Fears of death may not be the same as fears of dying. Kastenbaum (1992, p. 149) refers to literature reviews and cites studies (Kastenbaum & Costa, 1977; Lester, 1967; Schell & Zinger, 1984) which show that death is not feared much at all. However, in Becker’s (1973) analysis the fear of death is ever present as a drive to any organism’s self-preservation. But this fear must be repressed if people are to function. This requires a constant psychological effort that drives the way we live. Many of us attempt hero projects requiring the pursuit of control over life’s processes and which last beyond our selves as a way to meaning and immortality. If successful these projects give us self-esteem.

A low knowledge of end-of-life options has been identified in some studies. Silveira, DiPiero, Gerrity & Feudtner (2000) for instance did find a low level of public knowledge about refusing or withdrawing treatment, euthanasia or physician-assisted suicide and Kennedy (2002) observed a low level of knowledge about EPAS among the Dutch. And palliative care, as another option at the end of life, is not well
understood by the Australian public (Webster & Kristjanson, 2002). In a survey by the Palliative Care Council of South Australia (1998, cited in Webster and Kristjanson, p. 15) half the respondents were not able to describe palliative care. Another survey by Palliative Care Australia (1999, cited in Webster & Kristjanson, p. 15) showed that three in four people did not “understand the meaning of palliative care”. Nor is it well understood by the Dutch public (Enklaar, 1999). Furthermore, diminished distance to death, lack of knowledge of circumstances of dying, and provision of palliative care have been identified as factors in decreasing support for euthanasia and physician-assisted suicide (Braun & Kayashima, 2001; Enklaar, 1999; Ganzini, Nelson, Schmidt, Kraemer, Delorit & Lee, 2000; Portenoy, et al., 1997; Waddell, Clarnette, Smith, Oldham & Kellehear, 1996). Ganzini, et al., for example, found that 46 per cent of Oregonian patients who requested assisted suicide changed their minds when offered palliative care.

Palliative care in the Netherlands has a low public profile. There is evidence of a low awareness of and practice of palliative care in the Netherlands (Zylics, 1998) with only 70 specialist palliative care beds for the whole of the Netherlands in 1998 and little palliative care training for doctors. Dutch palliative care has been described as being in its infancy with palliative care institutions only being developed since the early nineties. The Netherlands had six in-patient hospices and 29 palliative care units by 1999 (Janssens, ten Have & Zylics (1999). Nevertheless, Fraencke & Willems (2000) reported the presence of a “broad spectrum” of palliative care options and some improvements in its availability (p. 21). By contrast, Australian palliative care possesses (Palliative Care Australia, 2002) some 1159 beds and 28, 441 patients receiving assistance through hundreds of dedicated palliative care services.7

7 In absence of national aggregate data, I compiled these figures from the national Directory of palliative care services of Palliative Care Australia. They are not necessarily reflective of the full scope of Australian palliative care services as many services did not list their beds or numbers of patients. However, as a comparison between the Dutch and Australian situations it is perhaps a useful indicator of a significant difference in level of services.
2.5 Dominant social values

The purpose of this section is to give some context to those findings in my study where informants believed that they live in socially declining times while showing some optimism about improving circumstances for people with disabilities. It is not within the province of this thesis to present extensive literature on the subject of social decline and dominant values. However, the presented literature gives a context to my informants’ beliefs of social turbulence and decline, including a dominant Western culture of individualism and losses of community and public trust. This dominant value system is the setting within which attitudes towards EPAS and its policy and practice find their expression. In presenting this context I use individualism as characterised by a culturally dominant over-emphasis on the interests of individual persons with a lesser importance placed on communal interests. Individualism has of course both positive aspects, such as an individual’s responsibility for self-governance, and negative aspects such as an egotistical self-interest.

Kastenbaum (2001, p. 80) asserts a historically “strong connection between ways of life and ways of death in every epoch”. The contemporary Western values of individualism and individual autonomy, together with attendant developments of growing secularism, and emphasis on technological approaches in medical practice, have shaped social attitudes towards death and dying (Callahan & Hanson, 1998; Callahan, 1994; Griffiths, Bood & Weyers, 1998; Mann, 1998; McNamara, 2001; Dworkin, 1995; Dworkin, et al., 1996). The widespread support for legal euthanasia, or the “requested death movement” (McInerney, as cited in McNamara, 2001, p. 4) is a contemporary attitude that is strongly linked to individualist values through its respect for a right to individual, rational choice. Likewise, negative attitudes towards disability were and are also embedded in the dominant values of the time (Cocks, 1998; Wolfensberger, 1998). Contemporary dominant social values of “individualism and choice, materialism, utilitarianism, youth and physical beauty, hedonism and immediacy” (Cocks, 1998, p. 12) have been identified as driving social policies and practices. They pose threats to the lives and wellbeing of people who have disabilities, as these values are reflected in “social dislocation, dysfunctional social institutions, worsening social indicators and weakening of commitments to vulnerable people” (p. 13). Indeed Cocks and Duffy (1993) have
pointed to the presence of these dominant values as in part constituting the need for the strong presence of disability advocacy responses.

Much of modern thought and values are linked to the emergence of the 18th century Enlightenment. Rationality and respect for individual persons in a pursuit of human emancipation were its hallmarks (Harvey, cited in Haralambos, van Krieken, Smith & Holborn, 1996).

The idea was to use the accumulation of knowledge generated by many individuals working freely and creatively for the pursuit of human emancipation and the enrichment of daily life. The scientific domination of nature promised freedom from scarcity, want and the arbitration of natural calamity. The development of rational forms of social organisation and rational modes of thought promised liberation from the irrationalities of myth, religion, superstition, release from the arbitrary use of power as well as from the dark side of our own human natures (p. 721).

Such ideas are still part of the Western worldview. However, there are those who perceive a 20th century post-modernity where modern beliefs that arose from the Enlightenment are no longer necessarily accepted. These include a belief in “the inevitability of progress, the power of science to solve all problems, the perfectibility of humanity or the possibility of running societies in a rational way” (p. 721). In the post-modern era there is a greater pluralism of beliefs and a greater scepticism about the future (Haralambos, et al., 1996). According to Dutch historian van der Horst (2000, pp. 549–560), modernistic progress in the Netherlands appears to have made way for a post-modernist search for meaning in “the most individual expression of [one’s] most individual emotion”.

Hugh Mackay (1993) has identified our time as “The age of anxiety” where stress and insecurity is keenly felt (p. 7.), not only for Australians but for the entire Western world. There are many commentators who complement this picture. Goleman (1996), Saul (1993) and Taylor (1992) for example have also identified a general, overly rational–individualistic emphasis within Western societies. And according to Clor (1996, p. 134), personal autonomy, “a condition of personal independence, freedom of choice, or self-determination” (p. 134), is in our contemporary society much celebrated and glorified. Autonomy involves the individual’s rational agency in order to make her choices. Dominant Western values and Western ways of life are undergoing a very high rate of social change, or
turbulence, and appear to be at a crisis point (Capra, 1982, 1996; Cocks, 1994). According to Capra (1996), this is a crisis of perception where there is a need to recognise the interrelatedness of major social and environmental problems and a failure to perceive the further damage caused by our solutions to those problems within that worldview. Popenoe (1994) perceives a “declining sense of civic obligation and rising social disorder” (p. 7.). Goleman (1996) agrees that we live in a time where “the fabric of society seems to unravel at ever greater speed when selfishness, violence and a meanness of spirit seem to be rotting the goodness of our communal lives” (p. xii).

For social historian Jacques Barzun (2000) contemporary times in Western civilisation are those of decadence and are demotic, a chaotic democracy. It is a world characterised by individualism in a context where one feels hemmed in by both too many rules and too many people: “… the individual came in conflict with his alter ego—his equal in rights—throughout the day” (p. 775). This is of course a metaphor for the tension between individual autonomy and community. Ours is also an age of technocratic managerialism where democracy is more of a façade then reality, being influenced by money, lobbyists and propaganda of every kind. Our dependence on the products of technology has made us more insecure through fears of destruction through nuclear weapons and through a “psychic disarray” arising from manipulation of genes, including cloning. The demotic society places a high emphasis on the physical through sports and image rather than the substance of the person and through its sexualisation of human life. The overriding taste of the “demotic individual” is for the “unconditioned life”, a utopian life where one “acts as if nothing stood in the way of every wish” (Barzun, pp. 780–781).

Dutch historian van der Horst (2000) states that the Dutch are now trying to meet their individual, material desires in a context of a wholesale loss of meaning and idealism at the turn of this century.

… the sort of idealism and meaning for which the Dutch were searching [was] an idealism which was the most individual expression of their most individual emotion. They were desperately looking for a mission. But they could not find it (pp. 549–550).

Increased material welfare has been associated with a growing individualisation in the Netherlands, described as a growing decrease in individual
dependence and increase in choices in life. A result has been that citizens have less acceptance of limitations in health-care and are more used to making demands of services in general such as who delivers a service and its time, place and content (VWS, 2001, p. 13). Charles Taylor (1992) observes that a societal over-emphasis on the individual has seen a decline in a sense of personal inter relatedness and connectedness and a decline in the practice of moral virtues and has eroded a perception of meaning in life. Society has found its highest good in pursuit of material, economic ends. A dominant technological worldview has resulted in creating significant problems for humanity. There are indicators to support these beliefs. The many social problems that have arisen from the dominant Western value framework include rising rates of suicide, depression, substance abuse, stress, anxiety, violence and crime (Goleman, 1994; Norton, 1994; Popenoe, 1994; Seligman, cited in Myers, 1992, p. 145). Presently unipolar major depression is a globally widespread clinical condition, projected to become the leading cause of disease burden by 2020 (World Health Organization, 2003). Seligman (cited in Myers, 1992, p. 145) believes that depression is a “contemporary plague” caused by epidemic hopelessness, which in turn is caused by individualism that prides itself in personal independence. In the Netherlands, Breedveld and van den Broek (2002) underline this situation by reporting a growing incidence of mental illness and anxiety among the Dutch within a demanding and hurried society where myriad choices in many areas are experienced as stressful obligations.

Surveys have reported a public perception of social decline. People believe in the Western central tenet of progress but many of them do not believe life is getting better or believe it is getting worse. Eckersley (1998) reported that Australians, as in surveys in other Western countries, showed a satisfaction with their personal life. However, an Australian survey published in 1997 (CSIRO, 1997, cited in Eckerley, p. 7) showed that 52 per cent of people believed that life was getting worse in their country “taking into account social, economic and environmental conditions and trends” (p. 7). Only 13 per cent thought that it was getting better and 33 per cent thought it was static. Another study (Commission for the Future, 1988, cited in Eckersley, p. 7) found that most Australians thought of life as having become worse in the last 20 years with more believing that this situation would worsen by the turn of the 21st century than those who were optimistic.
The widespread perception that things are getting worse at the social or national level is significant, regardless of whether it is ‘factually’ or ‘objectively’ true. The resulting erosion of faith in our society and its future influences the way we see our roles and responsibilities, and our relationship to social institutions, especially government. It denies us a social ideal to believe in – something to convince us to subordinate our own individual interests to a higher social goal – and a wider framework of meaning (Eckersley, p. 9).

Eckersley believes that such data show such discontent to be based at deep levels, that is, of those values that underlie notions of material growth and progress as the road to better life. Whereas “a sense of meaning and purpose is the single attitude most strongly associated with life satisfaction (Headey & Wearing, cited in Eckersley, p. 9), the “personal, social and spiritual relationships that give our lives a moral texture and a sense of meaning – of self-worth, belonging, identity, purpose and hope” tend to be overlooked in the current dominant social value context. This discontent about life which appears to not be getting any better is demonstrated in national “Genuine Progress Indicators”, which show that despite an ever-rising measure of economic progress (Gross Domestic Product) in Western countries, social wellbeing has actually not improved much with it (Eckersley, 1999; Hamilton & Sadler, 1997; Yencken & Porter, 2001). Currently commonly used indicators of wellbeing such as GDP are inadequate and lack acknowledgement of “the social relationships that link us” (Cox, 1998, p. 158). Indeed a growing gap has been identified in the Netherlands between “dispersed, well-willing and active citizens” and the political sphere’s attempt at judging what are important societal values (SCP, 1999, p. 2). Cox believes that the development of indicators of social, unlike economic causes of wellbeing have been ignored because they are seen as being within the purview of the private sector of daily life. Public policy mainly restricts itself to interventions in exchanges of goods and services. Cox believes that the public/private interest dichotomy is artificial and counter-productive as each sphere inevitably permeates the other.

The dominant individualist paradigm is associated also with a decline in public trust in our institutions, between community members and in our collective endeavours (Cox, 1998; Eckersley, 1998; Goleman, 1996; Misztal, 1996; O’Neill, 2002; Popenoe, 1994). Misztal suggests that replacing lost sources of public goods such as trust: tradition, community and the church with no more than a “vague and
murky concept of …civil society” only returns us to the inevitable paradox between “individualism“ and “collective solidarity”, between “autonomy and community”, within liberal society (pp. 6–7). However, a Dutch trend apparently contradictory to my Dutch informants’ perceptions has also been reported. Measured between 1972 and 1998, trust in one’s fellow citizen rose from 38 per cent to 55 per cent in the Netherlands and participation in voluntary organisations, a public trust indicator was comparatively higher for Europe than America (SCP, 1999). On the other hand Australian public trust in some professions declined “dramatically” between 1976 and 1997 from an average of 31 to 17 per cent, except for physicians, teachers and dentists (Eckersley, 1998, p. 9).

Among a number of possible explanations of the difference between perceptions of personal and general conditions, the “most important” appears to be “the nature of personal happiness and life satisfaction” and its “relative independence to external circumstances and changes in these” (Headey & Wearing, 1992; Myers & Diener, 1996; Hamer, 1996, all cited in Eckersley, 1998). Perhaps this explanation could mean that there is a reservoir of private social values, which are different from those that are associated with negative social indicators and public anxiety about them. Some studies show recent shifts in behaviour, which may support such a notion. Hamilton & Mail (2003) found an Australian trend where 23 per cent of adults between ages 30 to 59 have downshifted over the last ten years. Downshifting means a change involving “pursuing a more balanced and fulfilled life”, which may be “motivated by a desire to live a less materialistic and more sustainable life”. More time spent with family is their most important reason, with a healthier lifestyle, more personal fulfilment, and a more balanced lifestyle also important. Their changed lifestyle may involve voluntarily reducing their income by leaving a career, consuming less and make changes to simplify their lives.

They may make the change following a sudden event such as a severe illness, the death of someone close or a marriage breakdown. More often the decision follows a longer process of questioning. (Hamilton & Mail, p. 8.)

Ray and Anderson (2000) conducted a 12-year survey, focus group and interview-based study among US citizens, finding a personal shift in values which they say is adopted by about 50 million Americans from all walks of life. These cultural
creative reject materialism, and are more interested than others in (re-) building community and environment, and have a greater belief in voluntary simplicity, in helping others, and in relationships. In other words they are less materialistic and less interested in the individual’s good than the common good.

In summary, contemporary Western society places a high value on individual interests. A high valuation of rational–technological pursuits and a notion of largely material progress accompanies this emphasis. Indicators of decline in wellbeing show a dissonance with indicators of material progress. Citizens show dissatisfaction with their public world but not their private world, which could be explained by a relative independence of external factors in private wellbeing. There are some reports of value changes in large sections of the Australian and American population with one associating such personal changes with significant challenges in the lives of these people. Perhaps the currently repressed private sector of relationships represents a wellspring of values that may offer a counterbalance to anomalies of an overly individualistic Western value system.
CHAPTER THREE

CONCEPTUAL FRAMEWORK

In this chapter I will describe the conceptual framework that supports the structure of this study.

3.1 Introduction

The conceptual framework is designed as a theoretical framework to aid exploration of the problem that is under investigation in this study. This problem involves inquiring into the knowledge of a socially devalued group about their experiences and views on euthanasia and physician-assisted suicide.

The conceptual framework of this qualitative study consists of four levels. Firstly, the study’s theoretical approach is that of a phenomenological perspective. Some aspects of grounded theory and heuristics perspectives are associated with this approach. Secondly I have applied MacIntyre’s (1999) concept of interdependence to the design of the study and to interpretation of my findings. In MacIntyre’s concept dependence and vulnerability and independence are important parts of the human condition. MacIntyre shows how a tension between vulnerability and dependence on the one hand and independence on the other can be bridged by acknowledgement of the necessary parts that vulnerability and dependence play in achieving states of independence. The process of such acknowledgement can lead to human flourishing. Thirdly, I have used Habermas’ (1989) theory of critical knowledge to highlight the significance of this study and to interpret my findings. It has been apparent from inception of this study that using MacIntyre’s concept would involve comparison and juxta positioning of Habermas’ empirical analytical knowledge and hermeneutic knowledge. According to Habermas, such synthesis may result in the development of
emancipatory knowledge, which may recognise and dispel false consciousness.

Fourth, I have used Festinger’s (1957) cognitive dissonance theory to try and explain findings which suggested that the informants had not developed such critical knowledge from their applications of two apparently different value systems, one residing in their private lives, the other in the public sphere.

3.2. An integrated phenomenological/ heuristic/ grounded theory perspective

This study’s main approach is a phenomenological perspective. It has also associated aspects of heuristic and grounded theory perspectives. Baum (1995) believes that research in public health issues, and EPAS constitutes such an issue, is most effective when it is “eclectic” in its methodology. This is because such issues result from “complex social, economic, political, biological, … and environmental causes” (p. 459). According to Marshall and Rossman (1995), building flexibility into the research design is crucial. The researcher does this, firstly, by demonstrating how the methodology used fits logically and appropriately with the research question. Secondly this is done with a research plan that reserves the right to adapt the plan during the research process (p. 39). Denzin and Lincoln (2000) agree that the qualitative researcher is a *bricoleur*, a *Jack of all trades*, or a *quilt maker*. The *bricolage* of a “pieced-together set of interpretations that are fitted to the specifics of a complex situation” is a construction that “changes and takes new forms as different tools, methods, and techniques of representation and interpretation are added to the puzzle” (p. 4). Lincoln and Guba (2000) argue that at a philosophical level commensurability between positivist and post-positivist paradigms is not possible but “within [a positivist or post-positivist] paradigm, mixed methodologies (strategies) may make perfectly good sense” (p. 169). Flick (in Denzin and Lincoln, p. 5) holds that qualitative research is essentially multi-methodological in nature, as one of its approaches to triangulation. Patton (1990) agrees that it is possible to combine some theoretical perspectives. What is required is the researcher’s clarity about the orientation he uses and about “the implications of that perspective on study focus, data collection, fieldwork, and analysis” (p. 87). The integrated theoretical framework that is used in this study is *eclectic* in its design, a bricolage, combining elements of a phenomenological perspective with heuristic and grounded theory perspectives.
3.3 A phenomenological perspective

Phenomenology’s disciplinary roots lie in philosophy. It focuses on how people integrate their descriptions of experience and their interpretations in order to “make sense of the world” and “in so doing develop a worldview” (Patton, 1990, p. 69). It assumes that there are mutually understood core meanings in shared experiences. In practice this means that shared themes are looked for in the data and individual voices are not heard (Patton). Consequently, the semi-structured interviews, used in this study, probed for the essential experiences and views of participants and the data analysis sought the themes arising from the data. A phenomenological approach is one where the essence of the informants’ experiences of a certain phenomenon is sought (Colaizzi, 1978; Crotty, 1996; Field & Morse, 1990; Guba & Lincoln, 1985). A phenomenological approach is one without the experiencers’ underlying theories of their causal explanations and is as free as possible from preconceptions or assumptions (Spielberg, 1975). On the part of the researcher personal assumptions and beliefs need to become explicit and set aside as much as possible until such time as all the data are in (Patton). A phenomenological perspective is distinct from a phenomenological approach. It has two possible meanings, which may be used together or separately. Firstly, it can refer to people’s experiences and their interpretation of them (Patton). The second meaning is one where there is a "methodological mandate" (p. 70) for the researcher to experience for him- or herself the phenomenon under investigation (Patton).

A phenomenological perspective was chosen. The study inquired into the essence of informants’ experiences and I was explicit about my own values and background in the design of this study (but not to my informants), aspects reflective of a phenomenological approach. However I did not use the open-ended interview methodology that would normally be used in such a study. Nor did I refrain from developing a conceptual framework for this study. My framework inevitably involved preconceptions and assumptions in doing so. My study involved referring to people’s experiences and views and their interpretations of them as in a phenomenological perspective study. My prior personal insights and understanding about disability within its socio-cultural context, and within its (inter-) personal context of dependency and vulnerability, influenced me to frame the research questions as I have. I found those insights reflected in the literature. In particular, I
found MacIntyre’s (1999) idea of discussion of acknowledged dependency and vulnerability as important parts of human nature, reflected in some of my own experiences with disability.

3.4 The heuristics aspect

Heuristics is a form of phenomenological inquiry where the insights and intense experiences of the researcher and her co-researchers of a shared phenomenon, are examined. It is concerned with meanings, essence, quality and experience rather than measurements, appearance, quantity or behaviour. Whereas phenomenology encourages the researcher’s detachment in analysing experiences, heuristics emphasises connectedness and relationships between researcher and the phenomenon under investigation. Unlike phenomenology it brings out individual voices (Patton, 1990).

This study’s topic, which involves the close examination of the universally confronting human issues of dying, death and disability, has unavoidably invoked my personal feelings and beliefs. This is true the more so because of my shared experience of the specific disability of quadriplegia with my informants. Inevitably a relationship between a researcher and informants who share a prominently present disability of the same diagnostic label will be a different kind of relationship to one where disability is not shared. I have also commenced the study with a conceptual framework, which arose from my personal disability experience of some 25 years. Part of this was gained through contacts with other people who have disabilities and those associated with them. Indeed, “reflexivity” of the qualitative researcher’s historical, geographical and personal “situatedness” and investments in the research has been recognised as an “emerging innovation” in the developing field of qualitative research (Gergen & Gergen, 2000, p. 1027). By acknowledging the heuristic aspect to this phenomenological study I try to show some such reflexivity.

3.5 The grounded theory aspect

Grounded theory consists of “systematic inductive guidelines for collecting and analysing data to build middle-range theoretical frameworks that explain the collected data (Charmaz, 2000). There is a continual analysis of the incoming data throughout the research process. These analyses then serve to “inform and refine”
developing theory (p. 509). In other words, this approach allows the researcher to develop one’s theoretical framework as throughout a flexible research process. Charmaz points to early conceptions of grounded theory as positivist, operating on assumptions of an objective external reality, an unbiased researcher, and verification. But she believes grounded theory “need not be rigid or prescriptive; [focussing] on meaning furthers, rather than limits interpretive understanding” (p. 510); and grounded theory can be employed without positivist assumptions. Grounded theory can be “used with sensitising concepts from other perspectives”. Applicability and usefulness, she says, “are part of the criteria for evaluating grounded theory analyses” (p. 513).

Having commenced with a conceptual framework, I needed flexibility to incorporate any new insights as the findings and their analysis progressed. Festinger’s (1957) cognitive dissonance theory was added to the framework, in order to explain better the emerging, apparently paradoxical, data. I have borrowed this flexibility from the grounded theory approach. I have not used some of grounded theory’s methodological tools to analyse incoming data but my methodology did involve an ongoing data analysis in keeping with a grounded theory approach.

3.6 Summary

The conceptual framework of this qualitative study combines elements of phenomenology, heuristics and grounded theory. The phenomenological perspective is the dominant one in this study, reflected in the study’s search for shared themes of the informants’ essential experience and views. The study aimed for a certain detachment by the researcher, effected through the phenomenological technique of epoche. The phenomenological perspective is reflected in the inquiry into the essential experiences and views of the informants and in the data analysis, seeking the themes arising from the data. The heuristics perspective is reflected in the research questions and my sharing, with my informants, of the intense phenomenon of living with quadriplegia. The grounded theory perspective is reflected in a conceptual framework, which remained open to change.
3.7 MacIntyre’s interdependence

MacIntyre (1999) argues that, despite the prominence given in most philosophical writings to the role of personal autonomy, for human beings to flourish a balance between the virtues of rational independence and acknowledged dependence and vulnerability is necessary. It is commonly unacknowledged that we are all vulnerable, disabled and dependent at some times in our lives, whether in childhood, in old age, infirmity or permanent disability. Not acknowledging these aspects of human nature also means that we are not fully open to our emotional intelligence. A balance, which I have termed interdependence, can be achieved by conceptualising independent reasoning as having been developed from experiences of dependency and which continues to be reliant on others’ contributions to our thinking within unconditional relationships with them. Persons who have acknowledged the human condition as one involving dependence and vulnerability may become independent practical reasoners and experience a human flourishing. Independent practical reasoning, and the human flourishing based on it, involves the development and expression of virtues, such as kindness, courage and persistence and candidness. With such virtues, including self-knowledge, and attendant social skills one would be able to imagine a range of possible and realistic futures for oneself, that is futures that include realities of vulnerability and dependence. Independent practical reasoners can then make judgements based on knowledge of “both the particularities of those parts of the social and natural parts of the world which impinge upon them and of those generalisations which will enable them to judge the probability of different outcomes of this or that kind of action in this or that kind of situation” (p. 94). In other words his concept is in essence one of an ongoing process of human development through application of the practical knowledge of interdependence, or phronesis. He believes that only in the relational context of community, where giving and receiving in social relationships is seen as unconditional, can this balance between rational independence and acknowledged dependence be achieved. In such a community both the individual good and the common good are advanced. MacIntyre argues that disability, characterised by highly present dependence on others and a personal vulnerability, and its support in such a community, is of universal interest:
Our interest in how the needs of the disabled are adequately voiced and met, is not a special interest, the interest of one particular group rather than of others, but rather the interest of the whole political society, an interest that is integral to their conception of their common good. (p. 130)

This theory directly relates to this study’s purpose and those research questions, which inquire into themes of personal autonomy, vulnerability, independence and dependence. MacIntyre’s (1999) theory appears to reach deeply into both the disability experience and our responses to it. It involves an exploration of the human condition that underlies our responses to disability and to other situations of high dependency and vulnerability. It also illuminates the presence of innate resources that enable us to resolve difficult tensions in the human condition. MacIntyre’s theory, together with other literature, provides a starting point to discuss and explain the roles of interdependence and vulnerability in the lives of the informants.

3.8 Habermas’ critical knowledge theory

Habermas (1989) described three kinds of knowledge. Firstly, analytical/empirical knowledge is that derived from positivist science, the still dominant contemporary knowledge base. It involves empirical investigation of natural phenomena under controlled, objective conditions, based on reductionist assumptions, in order to develop a theory of causal relationships. Its modus operandi is that of technical control. Positivist science and its descriptive language make it “obligatory [to filter] out the merely emotive from cognitive contents” (p. 303). Its knowledge is considered value-free or ethically neutral and is committed to a theoretical attitude that frees those who take it from dogmatic association with the natural interests of life and their irritating influence, [with] the cosmological intention of describing the universe theoretically in its lawlike order, just as it is. (p. 303)

Analytical–empirical knowledge thus separates (objective) knowledge from human interests, or in MacIntyre’s terms, from conceptions of the human good. The meaning of such knowledge is its predictive technical employability, “established only by the rules according to which we apply theories to reality” (p. 308). But, so Habermas argues, this objective descriptiveness is an illusion, as the empirical sciences inevitably all have their origin in the life world of human action. Thus
knowledge and human interests are interlocked, but that connection is denied in this kind of knowledge. In this study analytical–empirical knowledge sheds light on aspects of the social (values\(^8\)) environment in which the informants live and on the kind of society in which the Enlightenment project is still dominant, and in which a demand for EPAS has arisen.

The second kind of knowledge Habermas describes is historical–hermeneutical knowledge. It is concerned with the phenomenology of people’s shared experiences, culture and (his)stories, in this case of people with disabilities. It is concerned with the understanding of meaning and its “interpretations make possible the orientation of action within common traditions” because one way in which “the human species secures its existence” … is by “reconsolidating the consciousness of the individual in relation to the norms of the group” (p. 313). Historical–hermeneutical knowledge acknowledges that its knowledge is always mediated through the “interpreter’s pre-understanding” (p. 309).

Habermas identifies phenomenology as the philosophy that is associated with this knowledge. But he also points out that when it asserts that it can separate the generation of subjective data from preconceived ideas about human interests it employs the very positivist, objectivist philosophy that it criticises. It “displaces our connection with tradition into the arbitrary” (Habermas, 1989, p. 316). Thus Habermas’ theory is directly relevant to the choice of a phenomenological perspective associated with heuristics.

The third kind of knowledge is emancipatory, or critical knowledge, being concerned with analyses of any differences between dominant ideologies and how people experience their lives. It is arrived at by reflection on (analytical–empirical) knowledge and (historical–hermeneutical) human interests. Perceiving the difference between knowledge from experience and knowledge of the wider reality may dispel false consciousness about societal realities. Habermas notes that false consciousness has a practical function. It cushions the unease associated with those risks that science cannot solve and which “appear once the connection of knowledge and

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\(^8\) Even though positivist science may consider itself value-free, it is apparent, including in the findings of this study that it is not. It is inevitably associated with values derived from its detached objectivism and material reductionism that lead to theory of causal relationships. Causal relationships are
human interest has been comprehended on the level of self-reflection” (p. 315). Emancipatory knowledge is expressed in daily practice (“of work, language and power”, p. 313), it aids “mankind’s evolution towards autonomy and responsibility”, it … “[unites] knowledge and interest … and it “reconstructs what has been suppressed”(p. 315). Emancipatory knowledge is a logical concept to take into account in this study, as MacIntyre’s discussion of interdependence involves the suppressed knowledge of human vulnerability and dependency in tension with human independence, thus involving concepts of individual autonomy.

This study incorporates the experience and knowledge of people with disabilities (historical–hermeneutical knowledge) and the social setting, their society, in which their views on EPAS arise. Much of their society, Habermas asserts, reflects the dominant analytical–empirical knowledge paradigm. Emancipatory knowledge, synthesised from reflection on any differences between the first two kinds of knowledge, might arise from this study which compares the experience of people with disabilities with their views on EPAS.

### 3.9 Festinger’s cognitive dissonance theory

Upon analysis, the data showed an apparent inconsistency between the informants’ views on similar issues of suffering in their daily lives and suffering underlying requests for EPAS. This could be interpreted as a possible indication of the presence of the false consciousness that Habermas (1989) argues is dispelled by emancipatory knowledge. However these two views, grounded in two distinct kinds of knowledge, as Habermas suggests, had apparently not produced emancipatory knowledge in the informants. Indeed Nagel (in Reinders, 2000, pp. 179–180) suggested that people find it difficult to simultaneously hold an objective and a subjective view of themselves. This is because of the unsettling feeling of seeing one’s life in the objective view as detached and with different meaning than that of the direct experience of living it. Festinger’s approach offers an explanatory tool for dealing with this inconsistency. The usefulness of this framework could not have been foreseen in the original design of this research, only when the data came in. Festinger (1957) holds an inconsistency within a belief system or between belief and

conditional as relationships are within an individualistic paradigm of respect for individual choice. Positivism therefore appears closely related to the values of modernism.
experience creates an internal psychological discomfort. This will motivate the person to want to reduce this discomfort, or dissonance, in order to arrive at a state of consistency and consonance. When dissonance is present, in addition to trying to reduce it, the person will actively try to avoid situations and information that may increase the dissonance. Festinger’s theory includes personal and cultural factors which may cause a reduction in the internal dissonance that people feel. Personal dissonance reducers include changing the view that causes one’s dissonance; adding more cognitions of the type that support the view that would reduce the dissonance; or decreasing the importance of the elements in the views that cause the dissonance. Dissonance reduction by social support, meaning a reassuring support of one’s belief by others, can easily occur. Cultural dissonance reducers may change one’s private view or behaviour in the face of overt dominant beliefs of others. Such a cultural dissonance reducer could be exposure to information, for instance from the media that can be used to reduce dissonance. Another influence towards reduction of dissonance is when many people all carry the same dissonance.

Cognitive dissonance theory may thus help articulate how certain cognitive elements may be involved in development or suppression of emancipatory knowledge in this study.

3.10 Summary

The phenomenological perspective used in this study is in acknowledgement of the nature of this study’s problem, which requires hearing the voices of individual people who have direct experience of disability. It includes aspects of heuristics to reflect the inevitable connection between the informants’ experiences and mine, particularly because we share a type of disability. It also is associated with an aspect of grounded theory in order to reflect the flexibility that was apparently needed in this study’s conceptual framework, once data were received and analysis commenced. MacIntyre’s (1999) interdependence concept informed much of the design, research questions and analysis of this study. His theory illuminates the human condition and responses to it that may not only resolve difficult issues, but may also lead to human flourishing. Habermas’ (1989) three kinds of knowledge are relevant to MacIntyre’s interdependence framework in that the latter’s theory and this study involve analytical–empirical and historical–hermeneutical knowledge and their synthesis into
emancipatory knowledge finds a parallel in MacIntyre’s phronesis. Festinger’s theory of cognitive dissonance is used to try and locate and explain the cognitive elements that may be involved in development or suppression of the informants’ emancipatory knowledge.
CHAPTER FOUR

METHODOLOGY

In this chapter I will describe the methodology that I have used in this study and its relevance to its conceptual framework. I also discuss the study’s ethical considerations and its limits.

4.1 Purpose of the study

The purpose of this study was:

1.) to discover Dutch and Australian disability perspectives towards euthanasia and physician-assisted suicide; and

2.) to find how the life experiences of the informants, within a cross-national context, may illuminate their perspectives.

4.2 A qualitative methodology

The meaning of the word *qualitative* suggests that qualitative methods are indicated where “qualities of entities, … processes and meanings … are not experimentally examined or measured …, in terms of quantity, amount, intensity, or frequency” (Denzin & Lincoln, 2000, p. 8). Unlike quantitative methods, qualitative research can produce rich, detailed data about a population (Patton, 1990, p. 14). There appears to be only one qualitative study that has sought disability views on EPAS directly from people with disabilities. It did so however within a wider sample of non-disabled people (Parsons & Newell, 1996) and did not further specify its methodological paradigm.
This study’s topic, which involves the close examination of the universally confronting human issues of dying, death and disability, has unavoidably involved my personal feelings and beliefs. This is particularly so because of my shared experience of the specific disability of quadriplegia with my informants. Indeed “reflexivity” of the qualitative researcher’s historical, geographical and personal “situatedness” and investments in the research has been recognised as an “emerging innovation” in the developing field of qualitative research (Gergen & Gergen, 2000, p. 1027). While I have throughout the study sought to minimise bias from my personal views such as is required in a phenomenological study by the technique of bracketing, or epoche9(Patton, 1990) I have also commenced the study with a conceptual framework that arose from my personal disability experience of some 25 years. Part of this framework was also gained through contacts with other people who have disabilities. My own prior personal insights and understanding about dependency and vulnerability and about disability, arising in significant part from a socio-cultural context, influenced me to frame the research questions as I have.

4.3 Cross-national research and methodology

This study uses data from two countries: the Netherlands and Australia. The rationale for choosing these two included:

- the countries’ different histories in respect of EPAS, where one allows and the other prohibits it;

- my cultural connection to both countries which offered an opportunity for further informing the study;

- both countries being comparable in their Western liberal welfare state credentials, and;

- samples in two countries provided a means of triangulating the data.

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9 The nature of a phenomenological study is about accepting the experiences of the participants as valid in themselves. The treatment of this topic subject will inevitably invoke personal feelings and beliefs of the researcher. Epoche (Patton, 1990) will be used to minimise the resulting potential for bias. These are phenomenological techniques of making any of the researcher’s beliefs and assumptions explicit. Epoche is an ongoing process within the researcher where the aim is to maintain a fresh and open viewpoint without prejudging or ascribing meaning too soon. Personal assumptions and beliefs need to become explicit and set aside as much as possible until such time as all the data are in (Patton, 1990).
Use of a phenomenological perspective, as in this study, is compatible with cross-national research. Qualitative methods used in cross-national research include life history and reminiscence, biographical-interpretive, ethnographic methods and discourse analysis where biographical-interpretive methods are seen as rooted in phenomenology (Chamberlayne & King, 1996).

As discussed, methodologically this study differs from a purely phenomenological inquiry in that it does not employ open-ended interviews, it uses aspects of a heuristic perspective and grounded theory methodology and there is a preliminary literature review in which to ground the research. Furthermore, the data is discussed in the light of cross-national contexts and of juxtapositions based on some broader national cultural backgrounds and trends, thus not solely relying on the experiences of individuals as data. Having said that, the samples’ primary data are the main source of inquiry and there is no attempt at an exhaustive socio-cultural comparison between the two countries, which is beyond the scope and resources of this study.

Both quantitative and qualitative approaches have been used in cross-national research (Hantrais & Mangen, 1996). Qualitative approaches have been used for instance with frail elderly people in Britain and Germany in the form of “model case studies” (Schunk, 1996, p. 97) and young carers in Britain, France, Sweden and Germany, using semi-structured interview schedules (Becker, 1995). No cross-national studies with a disability focus and/or end-of-life questions were found in the literature.

Cross-national research may aim to gain a greater depth of awareness and understanding of phenomena in different countries or to seek explanations of similarities and dissimilarities and to generalise from these. It may place individual stories and lives in a context of broader social limitations and options (Chamberlaine & King, 1996). Sharpening of analysis of the issue being researched may occur as new perspectives may emerge and the data collected in another country can illuminate the results in one’s own country, putting them in an unexpected light (Hantrais & Mangen, 1996).

It is not necessary for a cross-national study to be fully comparative. Data may simply be placed in juxtaposition whereas in other cross-national studies each country’s wider social context is compared in order to explain data. Exploration of
this context through secondary resources depends on close contact with key informers who are native to the countries under investigation (Hantrais & Mangen, 1996). In this study the cross-national approach is intended to give some suggestions about the respective countries’ dominant values and let the almost uniform cross-national results speak for themselves.

Language skills are important and one must guard against loss of culturally loaded meaning in translation of data (Ungerson, 1990, cited in Hantrais and Becker, 1996). My dual cultural/linguistic background assisted in minimising this potential problem. However I do not assume that my absence from the Netherlands for 24 years has not had any effect on data gathering or their interpretation. On the whole I judge such risks to have been minimal in this study. My fluency in the Dutch language has been largely maintained over that time and I have also maintained an interest in Dutch socio-political affairs.

4.4 Relevance of methodology to conceptual framework.

It is important that the problem under investigation is epistemologically linked with the chosen methodology (Brown, 1999). The conceptual framework’s relevance to methodology is represented diagrammatically in Figure 1., where it shows the connections between the study’s purpose, sample, methodology and conceptual framework. *Phenomenology* in this diagram refers to the study’s phenomenological perspective. The theory derived from a phenomenological perspective with heuristic and grounded theory aspects, from MacIntyre (1999), Habermas (1989), and Festinger (1957), has been described in Chapter Three. The diagram can show only an approximation as to how these aspects predominantly interrelate in this study because they together form a dynamic whole, which is intimately inter-connected at different levels, and at different stages of the research.
Phenomenological perspective,
Heuristic aspects,
Grounded theory aspect,
Cross-national study.

The Problem:
People with disabilities’ perspectives on EPAS are not
heard in the public debate
while the debate is potentially impactful on this group
and disability experience may contribute to the debate.

The sample:
People with quadriplegia and some disability leaders
in Australia and the Netherlands

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<thead>
<tr>
<th>How:</th>
<th>Inquiring about:</th>
<th>Theory</th>
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<tbody>
<tr>
<td>Semi-structured interviews</td>
<td>1. Their views and knowledge on EPAS</td>
<td>Phenomenology</td>
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<tr>
<td></td>
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<td>MacIntyre, Habermas</td>
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<tr>
<td>Semi-structured Interviews</td>
<td>2. Their views and knowledge about vulnerability, dependence, independence, autonomy</td>
<td>Phenomenology</td>
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<td>Analysis of 1. and 2.</td>
<td>3. How daily experiences and knowledge on EPAS may relate</td>
<td>Festinger, Habermas</td>
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<td>MacIntyre, Phenomenology</td>
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<tr>
<td>Cross-national Comparison</td>
<td>4. Possible illumination of findings</td>
<td>Habermas, Festinger</td>
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Figure 1. A diagram showing the relationship of theory to method, in relation to the problem, the sample and the questions under investigation.
4.5 Method of investigation

4.5.1 Sample

The sample was made up of a main grassroots sample consisting of 20 people with quadriplegia through spinal cord injury and a minor leadership sample made up of 8 individuals who occupy leadership positions in the disability movements in Australia and the Netherlands. The leadership sample was interviewed for purpose of any suggestions of a wider context to the grassroots responses and for triangulation purposes.

4.5.2 Grassroots sample

The grassroots sample consisted of people with quadriplegia through spinal cord injury, which had been established for at least five years. This time limit was imposed to reduce any negative effects of recent trauma on reliability of data. Adjustment to spinal cord injury can be a lengthy process of several years (Patterson, Miller-Perrin, McCormick, & Hudson, 1993). Five years has been identified as a period for most people with spinal cord injury to come to terms with the disability to the extent that depression and suicide are not contemplated for most people with spinal injury (Parsons & Newell, 1996).

The onset of their quadriplegia typically happened at a relatively youthful age. For most of the Dutch and Australian samples the acquisition of quadriplegia came in their early twenties with only a few exceptions. Of the Dutch sample, four had had their disability less than ten years, with the others ranging between 12 and 29 years. There were no Australians who had had quadriplegia for less than ten years with many who had quadriplegia in excess of 15 years up to more than 30 years. The average age at interview was 36 for the Dutch and 47 for the Australians. This made the Australian sample as a whole somewhat more experienced in quadriplegia in years and older than the Dutch sample.

Grassroots informants came from a variety of social strata. Four of the Dutch and five of the Australian informants were unemployed. One was studying for a tertiary degree. Of those who were employed their work included conducting their own home-based consultancies, disability support work, low and middle
management, and teaching. Four Dutch informants and two of the Australians had had a tertiary education. Most informants in both countries had been raised with a Christian religion but were not practising it themselves. Three in the entire sample said they were practising their religion.

A criterion for sample selection was that those in the grassroots sample had a traumatic spinal injury. All interviewed informants had spinal cord injuries through accidents, including traffic, diving and sporting accidents. Thus quadriplegia caused by gradual diseases was avoided, as this may involve different variables, such as mental or cognitive effects of a disease, which may make it more difficult to draw reliable conclusions from the data. One potential informant was excluded upon learning of the non-traumatic origin of his quadriplegia.

No lower level of injury than at cervical spinal level was admitted into the sample. The rationale for this was that issues of dependency and vulnerability might be experienced differently by people who were restricted by paralysis of four limbs than for those with a lesser degree of paralysis, such as paraplegia. The higher the spinal-cervical damage to the spinal cord, the greater the part of the body is affected by paralysis. This study included two people with a high C3/4 level, with the rest more or less evenly spread between the various lower levels. One informant had amputations in addition to his quadriplegia.

The Australian grassroots sample was mostly obtained in Perth, Western Australia, with one informant in the Eastern States. The Dutch sample was geographically spread all over the country. In some sense my samples were convenience samples, as I reside in Perth. Given my budgetary and physical mobility restrictions these were necessary constraints on the geographic catchment areas.

The size of this sample was arrived at through my determination that, at some point, no new themes were emerging from interviews. This is termed the point of saturation (Patton, 1990). From that point on I interviewed no other potential informants.

4.5.3 Leaders sample

Four individuals were interviewed in each country who were identified as having leading roles in what is often called the disability movement. This is the
leadership sample. The sample’s size is small and it is difficult to say whether it reached saturation point. The informants in this sample did not need to fit into the specific disability categories chosen for the grassroots sample. However six leaders had a mobility-impairment and used wheelchairs. One had quadriplegia and two also experienced chronic illness. Two interviewees, one in each country, did not have disabilities themselves but had for considerable time worked in advocacy and in other organisations that represented the interests of people with disabilities.

To create this sample, key individuals, known to me in Australia and the Netherlands were asked to participate and nominate others in a snowball sampling approach. For the Dutch sample this process was commenced well before my arrival in the Netherlands.

I have a long-term involvement in the Australian disability area, at local, State and national levels. Although I made contact with various people in the Dutch disability area during the development of this study’s research proposal, my knowledge of the Dutch disability leadership was more limited than in the Australian context. I drew on my knowledge in selecting the initial referring leaders. In order to be able to make any decisions on who could be an informant in this sample I attempted to find and choose two individuals, considered to be leaders in the respective countries’ disability movements, who were asked to refer potential leader-informants to me. In the Netherlands I only received such suggestions from one leader. Despite my earlier decision not to use referring leaders in the sample, I did decide to include that person in my list of to-be-interviewed leaders because of her apparently outstanding credentials. My limited knowledge of the Dutch leadership and time-constraints were other reasons to make this decision. Referring leaders were provided with a clarifying letter (Appendix C). Leader-informants were selected by referral from other leaders based on a known profile and track record of leadership, including occupying positions of moral and/or political power and demonstrated longer-term interest in disability issues. Following receipt of their suggested names, I chose the most commonly occurring ones. Except in one Australian case, I did not have any prior knowledge of their stance on EPAS.

Leaders were found at local and national levels and the geographic sampling area was a national sampling in both countries. Australian leaders resided in three different states and Dutch leaders also resided in various part of their country.
A certain overlap between the two samples occurred in that two leaders had spinal cord injury, one being quadriplegia. In any case it was difficult for all interviewed leaders with disability to separate their private world of living with their disability from the public one of wider issues. Frequently the two perspectives came up. I have taken this as valid and have simply used any of the leader themes to confirm or contrast them with the grassroots data.

4.6 Data collection

4.6.1 Interviews

In-depth, semi-structured interviews were conducted face-to-face wherever possible. Almost all interviews took place at the informants’ place of residence; one was conducted at an informant’s workplace. All but one of the interviews were conducted without the presence of any third parties. In one case, the mother of an informant stayed in the back of the living room during the interview; I did not detect any inhibition by the informant in giving his responses but this possibility remains. Interviews took from one hour to two and a half hours with an average of one and a half hours. Field notes were made not in the presence of the informants but as soon as possible after the interviews. A mixture of face-to-face, phone and e-mail interviews were used. In the grassroots sample most first interviews were conducted face-to-face. One grassroots informant was interviewed via e-mail and telephone, and three by telephone alone. All follow-up Dutch interviews were done by e-mail whereas most Australian second interviews occurred by telephone with some interviewed again face-to-face. A letter of consent for both country’s samples was provided prior to interview (Appendices A, A(NL) and C was signed by all informants.

An interview guide (Appendix E) served to seek the informants’ opinions and experiences on euthanasia and physician-assisted suicide and on their life experiences as people with disabilities. Using the interview guide the informants were prompted for their perspectives on their experiences in their own words where I engaged in active listening to understand and capture those meanings in the informant’s own words. Interviews were commenced with some general questions, inviting the informant to describe how they acquired their disability. Probing was
used to clarify any statements made by the informant or to encourage them to explore a particular theme further. Sometimes this consisted of merely a short summary of what I thought had just been said; other times more specific probing was used.

4.6.2 Procedure

A combination of recruitment techniques was used. Recruitment via major rehabilitation centres and via a Dutch spinal cord self-help group, was combined with snowball sampling. Contact was made with the heads of major rehabilitation centres in both countries. They were asked to send copies of my recruitment letter to some thirty potential informants who met certain criteria. These included a minimum time of five years post original trauma, no diagnosis or feelings of depression and no lower spinal injury than cervical level. Snowball sampling occurred after the first informants were interviewed. These individuals were asked to provide names of potential participants with the desired characteristics. When the same names were being mentioned repeatedly by these key individuals these took on special importance (Patton, 1990) but this occurred only to a limited extent. While in the Netherlands I had to spend some time to recruit more potential informants. My active time in the Netherlands in order to interview people was ten weeks. To overcome the limited time available, I had commenced this process well before arrival.

For the grassroots sample the research method was tested by conducting three pilot interviews. Some pilot interviews were done with two Australians and one Dutch informant, the latter by email. One of these Australian pilot interviews was unusable due to a malfunctioning tape-recorder. This informant did not wish to be interviewed again. The other two interviews were incorporated into the sample and follow-up interviews were done with them. Two changes were made following the pilot interviews. The early methodology used a Q-sort approach where informants selected significant statements, printed on cards, and ranked them in importance. This methodology was found unsuitable as it was physically too difficult to use owing to the impairments that informants had. This methodology also did not lend itself easily to email or telephone interviews. This was an obvious problem that my own experience with quadriplegia should have alerted me to. This may have been a demonstration of how one can sometimes be bedazzled by the technology of a methodology and lose sight of practicality and the human interests of the informants!
Some small addition was made to the interview schedule to include probing on informants’ experiences with dying people.

I did not conduct any pilot interviews with leader-informants. In order to minimise researcher bias, given my knowledge of individuals in the Australian disability movement, the first key individuals whom I approached for names of leaders were excluded from taking part in the study. These individuals were asked to contact the individuals they suggested, asked whether they would be willing to be contacted by me, and informed me of the responses they received. I informed the referring individual at that point that I would then decide whom I would contact. The referring individuals did not know whether I eventually used any of their suggested informants. However they were also asked to keep the referred names confidential. For reasons of transparency and clarity these key people were provided with a letter setting out the nature, purpose and ethical considerations of the proposed research.

This study does not report on individual responses but on shared themes. Even so, in recognition of a small disability field where leaders may be identifiable because of anything reported in the final dissertation, identifying details of such individuals were changed where needed in some quotes. Leaders were asked that where concerned about their possible identification to indicate this to me. Following acceptance by prospective informants I then further discussed the study with them and organised interviews.

Emergent patterns were looked for during the data gathering as well as for any presence of negative cases. The study did identify some negative cases, who stood in contradiction to the dominant themes. Informants were asked for their feedback on my descriptions of their essential experiences.

4.7 Data analysis

A qualitative analysis of the transcriptions was carried out after the manner described by Colaizzi (1978), with some modification from open-ended to semi-structured questioning. This method involved interviewing the selected informants where the following steps were taken:

1.) Review of the literature.
2.) Doing semi-structured interviews, collecting participants’ descriptions of their experiences as people with disability and their views on euthanasia and assisted suicide.

3.) Keeping and reviewing field notes of my experiences, insights and decisions in order to provide a contextual richness of the analysis.

4.) Listening to the tape recordings and reading transcripts of recorded interviews several times to absorb them. Recording of my reflections and emerging code clusters.

5.) Significant statements and terms were then identified and categorised.

6.) These were then clustered into themes with constant referral to the transcripts to verify the themes.

7.) Results from the data analysis were used to write exhaustive descriptions of the experiences and views of the informants.

8.) With these descriptions I then returned to the informants to verify the descriptions of their essential experiences and their views. This was done to clarify the identified themes. Any subsequent data was added to the body of findings.

9.) A research colleague from my university who had extensive, professional and teaching knowledge of qualitative research methodology, reviewed and commented on a random sample of interview transcripts and their emerging themes.

10.) After data analysis further material was added to the literature review, in particular on issues of wellbeing in the face of threats to one’s wellbeing, value change, suffering and growth, and human nature.

4.8 Reliability and validity

Validity is a question of the degree of authenticity, that is the trustworthiness of the findings so that the researcher may act on their implications (Lincoln & Guba, 2000), or it is “the degree to which researchers measure what they claim to measure” (Brown, 1999, p. 159). Reliability is about the consistency of measurement. In other words, would another researcher measuring the same things obtain the same results?
Reliability therefore depends on triangulation in order for potential researcher bias to be minimised. Denzin (1978) identifies the use of different sets of data, different types of analyses, different theoretical perspectives and different researchers to study one phenomenon. Following Denzin this study used the data collected from grassroots and leaders samples in two countries. The combined use of the phenomenological perspective and cross-national juxtaposed data involved different types of analyses. Further, the study uses three different theories in its conceptual framework, namely MacIntyre’s (1999), Habermas’ (1989) and Festinger’s (1957) theories, one a psychological theory and two philosophical frames of reference. Reliability of research rests on the research design and the rigour with which the research is done. To maximise reliability a sample of the interview transcripts and emerging themes were reviewed by an experienced researcher; informants gave their feedback on my descriptions of their essential experiences; and emerging themes were compared with the literature.

4.8.1 Reliability, validity and bias

As discussed, it is important in a study with a phenomenological perspective to minimise the researcher’s bias. This was attempted by setting out my personal beliefs and assumptions on the issue of EPAS in the Research Proposal. However I did not inform my informants of these but asked them whether they had noticed an expression of my own views during our interviews. I consciously tried not to show my own beliefs in interacting with the informants, apparently with some success. One informant thought I supported EPAS, others did not detect my views, as some asked for them. I explained to them that I could not do so until completion of the research. I offered an electronic copy of the completed thesis to all informants.

4.8.2 Reliability, validity and heightened vulnerability of the informants

Demi & Warren (1995) warn that, because of informants’ vulnerability, there may be an adverse effect on the validity of research. This is due to the informants’ perceived power imbalances and cultural differences, and may therefore mean that their responses might not always be entirely truthful. Even though I shared with the informants the status of their disability, power imbalances of some sort no doubt existed in this study. These are embodied in any researcher-informant relationship as
one elicits information from another. This is particularly so in an area of inquiry where many participants may have been subjects of many medical and social research studies in the past. Barnes (1996) cites Hunt (1992), Oliver (1990, 1992), Morris (1992), Abberley (1992) and Rioux and Bach (1994) as “disabled people” who have argued that there is a history of disability research as a tool of oppression and therefore may suffer from research subject fatigue. Barnes therefore finds a wariness of researchers by potential research informants as understandable. A potential validity problem of this kind was probably minimised by several factors:

1.) I have an obvious, significant level of disability, which probably led to some mutual identification of a common condition and experiences with the informants which may lead to increased trust. One informant said that he would not have thought about participating had I not had quadriplegia myself. Frequently informants said that they appreciated the effort involved in undertaking my study with my kind of disability and expressed that their participation was partly to assist. I felt that many informants did talk about daily, private, aspects of their life with disability without reserve, as well as about sensitive matters related to EPAS. Such thoughts may not have been disclosed to non-disabled researchers.

2.) In the case of leaders with other disabilities the common experience was obviously broader but was experienced as close enough to have played a positive role. One Dutch leader who did not have a disability gave, as reason for his participation, that a first-hand disability view is different from anybody else’s and my serious inquiry therefore deserved a serious response from him.

3.) I was born in the Netherlands, am aware of the culture and speak, read and write Dutch. Whereas this is not a disability issue, the obviously shared language and culture did, I feel, help to overcome a certain wariness of “foreigners” visiting to criticise the Dutch on their EPAS policy (Griffith, Bood & Weyers, 1998; Kennedy, 2002, p. 23).

4.) I have tried to be mindful of any ethical aspects to this study. Informants were made aware of any potential ethical issues in relation to their participation before interviewing.
4.8.3 Reliability, validity and fairness

Lincoln and Guba (2000) discuss *validity as authenticity* which incorporates the criterion of fairness. *Fairness* is related to the presence of “all stakeholder views, perspectives, claims, concerns and voices should be apparent in the [research] text” (p. 180). They hold omission of any informant voices to be a form of bias. This research text sought to incorporate any such voices. It is noteworthy in this context that the gender representation in the sample reflects the gender ratio among people with spinal cord injury in general and that both genders therefore appear fairly represented.

4.8.4 Reliability, validity and interviews through telephone and e-mail

It is possible that the quality of data obtained over the telephone is less rich than that obtained through face-to-face interviews as some people may not want to answer sensitive questions over the phone. Some research done in the UK has found this not to be a problem in obtaining such information (Sykes & Collins, 1988; McQueen, 1989). In my telephone interviews, particularly if a first interview had been conducted face-to-face, and a subsequent interview was by telephone, I felt little loss of *richness*. In the first interviews by telephone I did feel some loss in one of these. In some circumstances lack of body language and lack of the person’s observable context probably did affect the richness of the data. Telephone interviews were only conducted when face-to-face options were not possible or too difficult. It was a trade-off that was unavoidable and its incidence was minimised.

E-mail data can suffer from loss of spontaneity. Its use is limited by limited distribution of the technology, due to cost, causing sample bias in terms of gender, income, age and race. On the other hand, distance is overcome easily and a transcript is readily available (Selwyn and Robson, 1997). Markham (1998) noted the greater length of time that electronic interviewing takes, and reported on a reduced richness of data but also observed greater researcher opportunity to ask detailed follow-up questions or do probes.

Bearing in mind the limitations of these media as well as the geographic constraints on this study, telephone and e-mail use also was limited as much as possible. In the only *first* pilot interview with a Dutch informant a loss of flexibility
is acknowledged. This loss of spontaneity was in part due to the informant’s
disability, which saw him able to only type slowly, with a mouth stick. This was to
some extent overcome with the informants’ second interview by telephone. Ideally
this should have been a face-to-face interview but my transport difficulties to the
southernmost area in the Netherlands, where he lived, precluded this. E-mail did
deliver follow-up interviews with most Dutch informants after my return to Australia,
as all but one Dutch grassroots informant used email. In the case of this one
exception there was an exchange by ordinary mail.

Overall I believe that the use of such technologies has been positive as it
allowed informants’ full participation under conditions of geographical remoteness
from the researcher. The benefits have, I believe, outweighed any disadvantages.

4.8.5 Reliability, validity and cross-national research

If, as discussed, all precautions are taken to minimise any adverse effects on
its reliability, cross-national research is likely to strengthen the validity of the
research through triangulation of research methods and through comparison or juxta-
posing of two samples in different locations. Three non-tape recorded general
orientation interviews were conducted in the Netherlands. One was with a
philosopher with interests in the intellectual disability area and its socio-cultural
value dimensions; another was with a palliative care pioneer; the third was with a
head of a major rehabilitation centre for people with spinal cord injury; and a fourth
(by telephone) with the secretary of a Dutch organisation, which promotes assisted
suicide. In Australia an orientation interview was conducted with a palliative care
expert and head of a rehabilitation hospital with expertise in spinal cord injury.

4.9 Ethical considerations

My university, Edith Cowan University, reviewed the study’s ethical
provisions and approved them. I adhered to these provisions. Research did not
commence until its approval was given. In addition, although not required, but in
order to be sensitive to any ethical issues that might have been pertinent to the Dutch
content, Prof. Evert van Leeuwen and Dr. Arko Oderwald, of the Vrije Universiteit,
Faculty of Medicine, Division of Metamedica, Section Philosophy and Medical
Ethics in Amsterdam, also reviewed the study’s research proposal for any specific
ethical aspects that they might detect to be in need of attention. They did not indicate any need to make changes to the study’s ethical provisions.

Given the sensitivity of the research topic of EPAS, it was necessary to have in place qualified counsellors, should any informant become emotionally affected by the research topic. As already reported, people with a recent or current diagnosis of depression or who had feelings of depression were not admitted as informants but the possibility of emotional distress for others who did take part was nevertheless not excluded. In the Netherlands a national telephone-counselling agency agreed to take any calls from any Dutch informant. In Australia counsellors with a major rehabilitation hospital in Perth and with a national organisation that advances the interests of people with quadriplegia, in Sydney, were engaged. I do not know whether any informant undertook any counselling with these sources.

Participation in this research was by informed consent only. All informants signed a letter of consent, which was verbally explained with opportunity to ask questions about it prior to the first interview. All participants were made aware that they could withdraw at any time. The one informant who was unresponsive to my requests to reply to the account of his first interview was again reminded of this but did not take up this option. I had sole access to stored data and ensured the security of tapes and transcripts by keeping them in a locked filing cabinet.

Confidentiality of data seen by transcribers, during data analysis, was safeguarded with signed confidentiality assurances from these persons. A research colleague in my university reviewed a random sample of themes arising from transcripts and assured her confidentiality. In order to protect the confidentiality of the data a code number was assigned to each participant, thus maximising anonymity. Tapes will be destroyed immediately upon completion of the study and transcripts will be kept for a period of five years in a locked filing cabinet in keeping with NHMRC requirements. They will subsequently be destroyed. No data deemed harmful to any participants will be published.

4.10 Limitations

This is a qualitative study involving a total of 28 informants in a subject area where no previous, similar research has been undertaken. Qualitative research is
valid despite using relatively small numbers of informants. Its richness and rigour in the methodology it uses are key contributors to its validity. Nevertheless caution should be applied in assuming the study’s generalisability. This study appears to be unique in illuminating EPAS issues in the way that it does. It is important to recognise that this study and its conclusions presently stands alone and cannot be contrasted with any from comparable studies. In the interest of greater validity follow-up studies of this kind ought to be conducted to confirm or challenge this study’s conclusions.

The main sample consists of people with quadriplegia. Although the literature suggests not, it may nevertheless be that different results would be obtained with other diagnostic disability categories of physical disability. Although, again, the literature suggests not, it may be that different results would be obtained with a non-disabled sample of people who faced a severe threat to their being.

Whereas the greater part of this study used face-to-face interviews, some loss of richness may have occurred through the use of telephone and e-mail, limited as the use of these was.

One Dutch grassroots informant died from his long-standing health problems soon after the first interview. Therefore, with regard to his interview there was no possibility to verify the interview’s data and of course a follow-up interview could not be conducted. Another did not respond to my requests for his comment on the written summary of the first interview. His reason for his non-response was that he had not yet had the time to respond to it and would, but he never did. He had been made aware on several occasions that he could withdraw from the study at any time but he did not do so. After analysing all the data I decided to use these incomplete interviews as their themes were common to those found for the entire sample.

The cross-national nature of the study posed limitations of time and financial cost. Only a limited time could be afforded in the Netherlands for these reasons. An added dimension were my disability-related costs, including need for a personal assistant in travel and during the stay in the Netherlands. A private driver with car was engaged to visit the Dutch informants as use of public transport would have been too cumbersome and time-consuming. My disability made it too time-consuming to transcribe the interviews from their tapes myself. Dutch and Australian transcribers were paid to do this. My university made some extra funds available. Non-solicited
gifts were received from a home-nursing agency and some friends in Queensland, active in disability advocacy, after these parties heard about my research. I perceived no conflict of interest in accepting these gifts as none came subject to conditions.
CHAPTER FIVE

FINDINGS

5.1 Introduction

This chapter presents the study’s findings based on interviews with 28 informants. The interview data from the grassroots sample of 20 informants, that is informants with quadriplegia, are treated as the primary data. The data from the leader sample, totalling eight informants is mainly used to illuminate the data from the main sample. Such illumination could arise from confirming or not confirming grassroots themes or by raising additional issues. Where they were present and pertinent, leader themes are presented immediately below the relevant grassroots theme. Leader responses did not greatly differ in substance from grassroots responses although in several themes they show more nuance and are more moderate. Where I found important differences in responses between national samples I have indicated these. On the whole the national samples did show a great similarity with few differences.

The chapter is written in two parts, each reflective of data relevant to the first two research questions. Five major themes and their sub-themes are presented in the first half of this chapter, which addresses the first research question. Three major themes and their sub-themes are presented in the second half, which addresses the second research question. The last two research questions are answered from an analysis of the data in response to the first two questions and will be discussed in the next chapter. Each theme will commence with a brief overview before setting out specific examples.
There is a small number of informants within the grassroots sample who spoke of their life as unenjoyable and unfulfilling for reason of their disability. For them this was sufficient reason to claim that they would want EPAS for themselves. This small group included one Dutch and two Australian informants. Their contributions often contrasted with that of the majority of the sample and are presented throughout this chapter.

**Table 1. Themes, sub-themes and sub-subthemes**

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<tr>
<td>A.a Advance directives</td>
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<td><strong>B. The primacy of rules as safeguards</strong></td>
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<tr>
<td>B.a Legality as safeguard</td>
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5.2 Conceptualising euthanasia and physician-assisted suicide

This section describes the nature and degree of knowledge and the beliefs that informants had of euthanasia and physician-assisted suicide (EPAS) and the closely associated issue of advance directives or living wills. Conceptual understanding of EPAS was often incomplete and the informants’ descriptions of it were mostly not based on first-hand experience. Informants in both countries, but mostly the Dutch, raised advance directives as being an integral part of EPAS and its procedure. Only one informant possessed an advance directive.

Throughout these themes, where euthanasia and physician-assisted suicide is used as a collective term for both life-ending procedures, I have abbreviated it as EPAS. Physician-assisted suicide is at times abbreviated as PAS.

An overview of this theme is that informants used broad descriptions of euthanasia and PAS. They confused the two terms and used them interchangeably or associated them with suicide. Withdrawal and withholding of treatment was seen as the same as euthanasia and PAS because the outcome, death, is the same. Informants appeared to often jump to expressing their views on euthanasia and PAS before answering a question on what they thought the terms meant. There appeared to be a widespread assumption that everyone knew what euthanasia meant. Informants from the leaders’ sample reflected these grassroots views.
In both countries most informants were unclear when describing euthanasia and physician-assisted suicide (PAS) or, in Dutch: “hulp bij zelfdoding”. It is not a topic that many participants had considered deeply: “I hadn’t given a great deal of thought to the topic until you mentioned you were coming over”. Most appeared not well-informed. Dutch informants were more likely than the Australians to say that they do not know much about EPAS – because they were not interested in the topic.

You hear things on TV but it does not really interest you. You don’t remember. (…) It doesn’t happen that often, does it? It is not [like] every day three people receiving euthanasia. I cannot believe that. In the Netherlands perhaps 100 per year?

The terms euthanasia and physician-assisted suicide were often used broadly and interchangeably. Informants often did not draw a distinction between the two terms “because the end product is the same” or otherwise explained the terms in unorthodox ways. Informants spoke of euthanasia as a cover-all term for various life-ending scenarios, mostly, but not necessarily, with the involvement of a doctor. Withdrawal or withholding of treatment, or increasing pain-relieving medication, was often seen as no different from euthanasia.

I remember seeing a TV program once, I can’t remember what it was and they said something about that and they said they just upped the morphine or something and if you upped the morphine it makes them die. So to me whether the person is there an hour before they presumably die but they give them morphine, it’s still the same as euthanasia.

To me, in some ways, pulling the plug is very similar. I mean, OK, … you might be brain dead but you are still stopping your heart from beating by pulling that plug out.

I don’t know. I thought they were the same. I mean euthanasia I guess can be performed by anyone. That’s possibly the only difference that I can think of off-hand. The fact that euthanasia can be carried out by anyone, whereas doctor-assisted suicide can obviously only be carried out by a doctor.

A few informants only, on the other hand, did make a point of emphasising that there is a distinction between EPAS and withholding or withdrawing treatment.
I don’t see it as euthanasia. If actually they are withholding a drug, … an artificial means to keep someone alive, then that really is the opposite to euthanasia… because one is allowing an natural process to take place and euthanasia, as I think of it …, is that euthanasia is providing someone with a black box that will inject a lethal substance into their vein…

When Australians claimed to know that EPAS did go on despite its illegality in their country, they often included withdrawal of treatment, which is legal medical practice.

Well, of course, it happens all the time. I mean doctors are doing it all the time. I mean, my wife’s ex partner, I mean they did it fairly much with him, when they said – because he was on a ventilator at that time – they switched the ventilator off him.

In defining euthanasia and physician-assisted suicide some informants associated suicide with medical life-ending procedures.

Euthanasia is technically someone helping you to die. I think it's (for) someone who has lost the ability to commit suicide.

Euthanasia or self-killing I literally see as help with self-killing.

Some Dutch informants distinguished passive and active terms. Most saw both as euthanasia.

… I have always understood that there were only two kinds of euthanasia. They call it passive and active forms of euthanasia. And passive is, say that you stop a treatment, or stop giving food or fluids. And that a person then dies. While active, then you give something that causes someone to die…. Help in suicide by a doctor then you could perhaps think of something like asking your doctor: which pills are best for me to take so that I die? … That you ask a doctor to guide you and that you are more actively involved in the process.

(Leaders)

Australian leaders reflected the grassroots’ broad interpretation in defining euthanasia and PAS.

Euthanasia … is that people, either the individual or the individual person and/or their immediate associates have or want an option at times to be able to take their life or end their life prematurely by some form of intervention whether it be drug induced or whether it be
withdrawal of medication or withdrawal of some forms of support that would be maintaining them or keeping them alive. To end their life, or patient directed, or individual assisted suicide enables someone [via] a mechanical device or some sort of method to actually facilitate that process to happen.

Dutch leaders were more specific but included *advance directives* in their definitions. They were more able to distinguish between euthanasia and physician-assisted suicide although some could not.

In physician-assisted suicide the doctor is providing you with a substance. And you act and kill yourself. With euthanasia the doctor does it.

Some Dutch leaders distinguished between euthanasia and physician-assisted suicide in the sense that in the first a doctor was there to “travel the last bit together” and in PAS “you act yourself and that can be very lonely”. Some included withholding and withdrawing treatment in their definitions, some did not.

### 5.2.1 Advance directives

In overview, the theme of advance directives shows the centrality of relations with others in whether or how one’s future wishes about interventions at the end of one’s life is honoured. The Dutch informants raised advance directives in the course of describing what euthanasia and PAS means to them. However, few have made advance directives to cover end-of-life scenarios for themselves. Reasons for not doing so included an awareness of a possibility that life might still be worthwhile at any point and a mistrust of doctors’ use of the advance directives. The nature of the advance directives made out by the one informant turned out to cover withholding or withdrawing treatment, not euthanasia. Coercion of people who have signed an advance directive to have euthanasia but are hesitant when the time comes appeared as an issue in one case.

Dutch informants raised advance directives as part of their description of euthanasia and PAS but Australians did not.

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10 In the Netherlands advance directives have been used for some time to direct under what circumstances one would want euthanasia. Their legality is enshrined in the Dutch euthanasia law of 2002.
I think that is how I see euthanasia or *self-doding*\(^\text{11}\) as having a grip on things when you have reached your limit, that you then want to make use of it … a kind of decision-making authority that you can use very consciously.

However, almost all Dutch informants said that they had not made advance directives. Reasons for not doing so partly revolved around relationship issues, unpredictability of future ill-health scenarios and not knowing what thresholds one might be able to cross in the future, not trusting doctors to act on advance directives or the uncertainties about who would be carrying out the directives.

No, … because I love life … I would in very many situations, of which maybe you now imagine that you wouldn't want to carry on, … at that moment you might choose to carry on after all.

Some people have arranged that with their doctor and then the doctor changes his mind. … Better if he said ‘no’ straight away.

An informant further added to the uncertainties about making decisions in advance about conditions that one knows little about, suggesting that others may act from a different perception of what is life worth living than the focal person feels it:

[Before her accident] I saw someone in a wheelchair from time to time. Well, no, I would not accept that then [as something she would ever want to live with]. And people around you [me] say that now too of course: well, I don’t know how I would handle that. No, you don’t know. You absolutely don’t know. So I don’t know either how I would deal with it if I had cancer tomorrow. I have no idea.

For the one Dutch informant who did make advance directives, and who had multiple health complications, it emerged that the directives were related to refusal and withholding of treatment, not euthanasia or PAS. It involved refusing antibiotics, and refusing hospital treatment or referral to a nursing home in favour of going home to die. The only Australian who was in the process of drawing up a ‘living will’ stipulated withholding of treatment should any serious “long-term illness or cancer” afflict her. And another Australian who talked about advance directives echoed some

\(^{11}\) *self-deathing or self-killing*, an otherwise untranslatable Dutch term in favour of suicide. The word *self-deathing* has replaced the commonly used *zelfmoord* or *self-murde*, for *suicide*.\(^8\)
of the Dutch concerns about them noted the importance of knowing who would carry out the directives.

I’ve always seen doctors as key people in the community because that’s the way we were brought up. (…) But if you had someone who was a real prick and didn’t want to listen to your wishes, you’d be in bloody trouble and if you couldn’t change that doctor to another one, like if you were in an institution, like if you were intellectually disabled and you just didn’t have the communication skills, you didn’t know the system, that would be quite bloody confronting.

A Dutch informant related a story in which he was directly involved, which appears to confirm some of the informants concerns about who is involved in end-of-life decision-making. Coercion and a breech of one of the Dutch EPAS criteria – the presence of a durable request – appeared to play a role. The story is about the informant’s relative, who “was also a supporter of euthanasia”. They often talked about it. Now that the relative had cancer we said:

gee, it is time you obtain the documents [advance directive format for euthanasia], because you are already going down hill. So, in the evening we talked with him. Filled in all the papers [advance directives]. … In spite of that he had not mailed them. Everything went so fast.

The relative did then receive euthanasia in hospital when he went to see a doctor for a check-up:

Then they kept him in hospital straight away. But he had a good doctor straight away. (…). The lungs began to seize up. So they helped him. But imagine that the doctor had said: No, I won’t do it. [As] he had not completed those forms. (…) Then he would have hung. (…) Because if you get a religious one [doctor], you can wait a long time. (…) … he was sure about it but always procrastinating. Oh, that will come tomorrow. It will not come around that quickly. But it came quicker than he thought.

(Leaders)

Only Dutch leaders mentioned advance directives as part of an EPAS definition that for them also involved withdrawal of treatment.
Euthanasia is an advance directive that you make ... where you put down, if such and such happens to me then I don’t want to go on. You may cease treatment.

They also expressed ambivalence about advance directives. One who had a “euthanasia declaration” said that she had now come to think about it differently and wondered whether she “can do this to other people”, who would have to assist in killing her. Another says that end of life decisions are made in a context where others, including family also have an input and are thus not always honoured. A third had not signed a euthanasia declaration for reason of having experienced a near-euthanasia with a family member as a disturbing process.

I felt: can you really do this. We did respect that choice but the idea of it. She was just at home and everyone would come to say goodbye. And then an injection ... and with the thought of that I got nightmares. And when she died naturally and perhaps then also because she knew that the euthanasia [act] was close – that she did find peace, that she no longer has to have that pain. I am confused about that myself. I have not signed a euthanasia declaration for instance because I really don’t know.

5.3 The primacy of rules as safeguards

Primacy of rules as safeguards covers the informants’ faith in the desirability and efficacy of law and rules as the primary safeguards to rely on against abuse of EPAS. Informants mostly supported the practice of EPAS if legalised as a safeguard. This belief stood, in the face of their awareness that not all abuse could be stopped and safeguards ultimately depend on the people involved in the EPAS process. Dutch participants hardly mentioned any discomfort with any perceived efficacy of their country’s rules when they related any breaches of them from their experience, such as doctors not reporting EPAS. They also did not know much about the nature of the rules in place in the Netherlands. The medical profession was seen as playing an important role in the carrying out of the rules.

5.3.1 Legality as safeguard

Informants mostly supported EPAS if safeguarded from abuse.
I think it should be legal. Yes. I think a person should have that right to say yes but it would have to be screened.

Society must remove euthanasia as an unlawful act.

It is good that the opportunity is there. I am not negative about it. I am indeed a positive supporter.

One informant only, an Australian opposed the practice of EPAS outright.

Well, I don’t agree with giving people something, with or without disability, the right for euthanasia. That’s the right that I don’t believe should be given because it would be too hard to police and it will end up being abused.

Reasons for making EPAS legal revolved around illegal practice of EPAS, an associated need to protect doctors and so that not just anybody can have EPAS for any reason. All Australian informants assumed that EPAS was being practised in Australia despite its illegality. Two Australian quotes first, then two Dutch quotes.

It’s no use sticking our heads in … the bucket (sic) saying it doesn’t exist, because it definitely does. Doctors are, as I said, doing it all the time.

Q: Do you have ideas about legalising or not legalising? A: You are better off doing that because otherwise you keep having disputes. [Rather] then every doctor who does it is a murderer. Because you do kill someone.

… I think they would still have to screen. I mean they cannot go and say to people: do you want to die? (…) The person would go to the committee or whoever … and just say, you know, I would like the opportunity to die with dignity. What do I have to do?

The law has to take voluntary euthanasia out of the criminal sphere, after very thorough discussion with doctors, family and others, and should not have repercussions for people that assist with it.

Overall Dutch and Australian informants had faith in the efficacy of legal rules as safeguards but there was some understanding that avoiding all instances of abuse of EPAS was not possible but that having legal rules offered good protection.
Yes it should be legal. There is no doubt about that. If euthanasia was legalised I am sure they would still make it so difficult for, like a family member to say, oh yes, this person wants to have euthanasia. I’m sure there would be such involvement and checking and interrogation that people would not be easily bumped off. There are so many ways in which it can be written up legally.

To really have one hundred per cent secure rules that prevent abuse is not possible. People who have wrong interests and want to do wrong will probably always find a way to abuse something – [you can] make it difficult by having simple law that cannot be used for different interpretations. But for the normal and official world where people are humane towards one another, and have solidarity with the weaker ones, a law like that and rules should prevent abuse.

A more uncommon view was that the best possible application of EPAS ultimately depended on people’s relations with each other:

In the final analysis your family has to make a definite decision. Well just let them decide then. Hopefully they know what you would or would not have wanted.

Most Australian informants correctly indicated that euthanasia and physician-assisted suicide were not legal in their country, though some did not know. A dominant theme across both countries’ samples was that euthanasia should be legalised, but must be safeguarded from abuse. There was a strong theme of reliance on, and faith in, having “strict” and “secure” rules and guidelines in place to protect people from abuse of EPAS. This was the primary safeguard against abuse of EPAS that informants offered.

Q: Do you think that if it was legal that we can make it so that it’s safe and it can’t be abused? A: Of course we can, anything can.

Even I suppose if euthanasia was legalised I am sure … the government would make it so difficult for say a family member to say: oh yes this person wants to have euthanasia. I am sure there would be such involvement and checking and interrogation that people would not, as we’re being told now, people would not be easily bumped off because they’ve got a fortune in the bank that the rest of the family wants or because they’re a nuisance and encroaching on the lives of the people that are caring for them. … [T]here are so many ways that it can be written up legally to keep the legal eagle people happy.
No-one should be afraid of having things done that they do not want. This should be safeguarded in law.

There have to be good rules, about who can do it, how they do it. To really make it safe for someone … there have to be good agreements.

It seems that the Dutch trust the rules that are in place despite not knowing much about them.

And the rules are well kept? Yes, from what I hear and see in the Netherlands. By chance I just read an article about it in the newspaper the day before yesterday …about euthanasia.

Most Dutch knew that EPAS is allowed in the Netherlands, if certain guidelines are followed, and is otherwise an offence. But most were unsure about how this is organised or knew the precise content of the guidelines.

I don’t know how euthanasia is organised. I just know there are four conditions and that it is still an offence.

There is a duty to report I think, for the doctors. But for the rest I know little about it. You hear things on TV, but because it does not really interest you, you don’t remember. It is not legal I think, and that duty to report. Those are the only things that I know about it.

At best, some Dutch informants could refer to some incomplete knowledge of the existence of guidelines that doctors have to follow.

I don’t know the rules very well. It’s something like this: if someone is in a terminal phase and after repeated requests to his doctor, the doctor asks another doctor. I don’t know how or when. This will be reported to the Attorney-general who checks the procedure. I don’t think there’s anything yet for non-terminal people.

I think that in the Netherlands, only with severe suffering, and there are some terms for that, by which the doctors are formally allowed or not allowed. But it is allowed as far as I know. They have to report it. But I think that in those cases where you have to actively administer something, that that is still an offence in the Netherlands.

The one Dutch informant who cited the most guidelines, though not correctly, had consulted a doctor associated with the Dutch euthanasia society [Nederlandse
Vereniging Voor Euthanasie], who had informed him of the guidelines. This was to pre-arrange his euthanasia at a time when he had enough of living with quadriplegia.

Unbearable suffering, and I think quadriplegia is that; consent of family, and they do not agree; not being clinically depressed and I had that assessed and I am not. There is another one that I cannot remember.

Two of the three informants who would rather be dead than live with disability expressed that they saw no need for complex guidelines, while all other participants preferred strict guidelines. They required little more than just “a couple of checks” and acceptance that some people would rather be dead.

I think that it is very much a personal matter. I mean, whether you have a physical disability or a mental one. Or that you say: I have not succeeded in life and I cannot make anything of it and I don’t see a point. Then I think people should be able to make such choices. I don’t think we should be attached to too many rules. Because they do it anyway. If they want it, they’ll do it.

That’s the whole point, euthanasia should be about the person, it shouldn’t be whatever…. Now what I care about and what the person next door is to do is irrelevant. It’s what I want to do with my life – it should boil down to the individual. (…). Q: Do you think it would be a safe thing to do? A: Well I think so. As long as there’s a couple of checks – like I say as long as it’s not down to one person. (…). [E]ven if you’re perfectly healthy. If you decide to make that decision why shouldn’t you be allowed to go down to the doctor … and if they’re perfectly coherent and understand what’s going on but they’re just not particularly happy with life and don’t really see the sense in going on, why should they have to. I don’t understand that.

5.3.2 Doctors and professionals as safeguards

An important safeguard, seen as part of EPAS rules, was an assessment by doctors or other “professionals”, as implementors of the strict rules, of the person requesting EPAS with regard to their competency to make such decisions.

You’d have to be of sound mind to be allowed to have euthanasia. … a process that you have to go through where there are professional people involved. (…) if there is rigid and strict guidelines to follow I think it would be safe and I don’t think people would be able to fall through the cracks….
The doctor knows when the time has come, that it can really be done and is possible. I think so.

I think there has [sic] to be safeguards. That’s probably why the medical profession has to be involved. I think here in Australia they involve psychiatrists and people like that. They could view the person’s mental state and make sure they’re not being impulsive.

People have to be very carefully checked psychologically. There has to be a deep reason for it I think. You cannot just say: I don’t like my life, everything is bad, my wife is gone, I lost my job.

Doctors were seen as needed in an EPAS individual assessment process but there was also some caution about their roles. Several informants suggested that the doctor who engaged in euthanasia should be trained in assessment and communication or be a euthanasia specialist.

So, therefore I would say, any doctor, because he is a doctor, doesn’t mean he’s qualified to decide whether that’s something that’s an option for that person.

I certainly think that the people, the doctors especially, need to be well trained as far as how to deal with people and how to deal with the sensitive issue of it, how to put enough of the criteria together to decide whether that person qualifies or not. Certainly a minimum of two.

5.3.3 Others as safeguards

Both Dutch and Australians often referred to the need to involve family and the need to take time in an assessment of the capacity of someone who requests EPAS as well as assessment of the motivations of the request.

I think that a psychological assessment is good, a medical examination and in the end the person’s own choice. And also family members ask: how is the person, … and why is he in this state. A bit of investigation is necessary I think.
5.3.4 Open discussion or bespreekbaarheid as safeguard

Dutch informants in particular regularly mentioned that open discussion and level-headedness (being *nuchter*), together with strict rules, about EPAS is a good thing in the Netherlands and this was implied to be an added safeguard to its practice.

I am a supporter of talking about it openly but keep to strict rules. I think so because those strict rules must be there otherwise it gets out of hand.

It should not be so that if I think one day: gee, I don’t feel good guys, I should end it all today. Of course it has to be very well considered. And discussed with a lot of people. That you know for sure what people want.

For one Dutch informant this discussion could normalise EPAS and lead to a situation where EPAS could become more easily available.

I can imagine that euthanasia will be more easily available. Because there has been a lot of discussion about it and situations develop where it will become more normal, or easier. In the Netherlands there is of course a lot of discussion about it.

5.3.5 Safeguard breaches and caution

Some Dutch examples of informant’s knowledge about possible cases of EPAS involving people with disabilities were given, where doctors did not seem to have reported these. Such informants did not draw any conclusions from these instances in terms of their support for EPAS or of the efficacy of safeguards.

But I have experienced from close by, a woman who lived where I did. Also a high level quadriplegia, and who really has not been able to deal with it from the beginning. She had studied psychology. She gave a very big party. And after that she went on holidays with some girl friends, and suddenly she was dead. That was very strange. Well, she has had help with that for sure. Well, then think, that is really fantastic that that has been possible. If she [had] wanted that for 20 years. And from the start she had not wanted to live with quadriplegia. Well, then it is good, isn’t it, that there are girlfriends who want to do this? … Liver failure was [put] on the doctor’s death certificate.

Another Dutch informant, who had herself been suicidal during rehabilitation, related a story of an apparent act of euthanasia on a woman who was still going
through her rehabilitation in the first year of her injury. She was upset about this and thought it problematic:

And one time she went home in the evening, all packed up. So, I said: hey, how nice, are you going home, all cosy and blah, blah, blah. I never noticed anything. And then it appeared that the general practitioner [huisarts] …, and she received an injection. The next day we heard that she was dead. Yes, then you do project it on yourself. A similar situation to mine. I was quite upset. Also that she did not have the courage anymore to go on. She was still in rehabilitation. I found that very problematic.

It was not clear whether the rehabilitation hospital staff had been aware of the intended euthanasia before the event. However both these informants did affirm the importance of strict safeguards as minimising abuse of it. Despite such knowledge of apparent breaches of these safeguards informants thought that the option for euthanasia should be available.

The option should be there. I’ve always felt that because … I have spinal cord injury. I’m not sick and I’m not at this stage ready to stop what I’m doing in my world. But even before the accident, it’s just an option that should be allowed to be there. Particularly when it’s a person that can make an informed choice.

At most there was some Dutch caution towards the use of rules, held only by a few. Australians all relied on law and rules as the main safeguards. There was only one articulate Dutch voice of doubt about safeguards in the Netherlands. The efficacy of safeguards depends on the intentions of the rule makers. This man, who “hesitate[d] to reject euthanasia in all cases”, expressed a declining faith in his country’s rules as he knew of a low reporting rate by doctors of instances of EPAS, as legally required. But he still had some faith in the intentions of the regulators themselves: “I have faith in the intentions of most policy makers but some rules do not appear to be functioning so that my trust has diminished”.

Two Australians only were doubtful about the efficacy of guidelines. They thought that EPAS would be too difficult to “police” and “will end up being abused”.

It’s really a thing that they should put up really tough guidelines for. (…) again, it’s difficult as well. I mean anything can be abused a la our tax system. There’s clear guidelines out for that. I think, yes it can, it can be possibly abused and that’s why it’s very difficult to make up my mind about the whole issue.
Most Australian leaders confirmed the grassroots theme that it is difficult to safeguard EPAS from all abuse. These leaders believed legalising it would make it unsafe for vulnerable people with disabilities. An Australian leader with disability who has had life-threatening health conditions himself said:

I’ve got support for the concept of euthanasia. I mean I would like to be able to say that if I’m in this type of situation I would like to be able to have assistance to commit suicide if my quality of life was ratshit. However I don’t see how you could give an adequate definition at all that could be followed that would protect everybody else.

By contrast, another also saw potential abuse of rules with regard to people with disability but believed safeguards could be developed to protect them:

[Let’s not stop everybody from using a euthanasia Bill because someone may misuse it. Let’s make sure that the safeguards are strong enough to withstand that.

Some Dutch leaders acknowledged that not all abuse can be prevented, because of the social context in which it occurs.

Of course it will always remain a process between people. And whatever wonderful legislation you make people often do not keep to it.

Of course you have strange things happening anywhere in the world. (…) and you cannot do anything against that. Everywhere you have mad people walking around. So these two things are totally independent of each other. And I think that euthanasia practice is reasonably careful.

However, all Dutch leaders expressed faith in their country’s rules. They approved of the Dutch system of monitoring committees and the (then) pending law to allow EPAS. They believed that EPAS is done in accordance with “very strict guidelines” and that “great care” is taken by doctors.

Because a number of matters are now settled in law and you can test them. That means everyone will have to remain alert.
Safeguards include: That there are all sorts of bureaucracy around it [EPAS], before one decides yes or no, [in] ending life and who does it. That there will be an assessing committee that supports the doctor and says it is accountable and I say it is accountable and I think it’s all fine. It has to be done carefully. (...) And I know that that happens with great care.

One leader stated that she thought that the euthanasia debate in the Netherlands is more about the technical issues than the substantial ones, which she sees as existential questions.

When we talk about euthanasia here it is always about protocol. Euthanasia guidelines and what we think is better or worse about that. Or the regional committees … of a lawyer and an ethicist and a doctor who have to judge the doctor [who has reported euthanasia]. For me they are political topics. But not the existential subjects that it turns around.

Reflecting grassroots informants’ apparent contradictions, one leader said that: “within Dutch society I am in no aspect of it afraid of euthanasia practice”. But he also related how after his mother’s death the doctor gave a death certificate stating that she died of natural causes while this leader suggested that her life was ended by a doctor in an act of EPAS. This seemed to have come about as a result of an agreement between the doctor and the family.

My own mother formally has in her death certificate [death] by natural causes, but it was not. We had a good agreement. Everyone happy. I say it a little hard and unfriendly but there it was prevented what happened with my grandmother [dementia]. And that is good but the problem is you can argue about the question of incompetence [to make one’s own decision] but in principle it means that with incompetence options of euthanasia and [help with] suicide are not present.

It seems that this example confirms the grassroots’ theme of wanting strict guidelines but not when they stand in the way of anyone’s choice.

5.4 Death and dying as a distant experience

An over view of the theme of “Death and dying as a distant experience” is that most informants had a limited experience of death and dying in their immediate environment. Death is for most at a distance and meaningless. Leaders had more
first-hand experience. There was no expressed personal fear of death while dying was hoped for as short. There was some reference to a fear of death in others. Some meaning could sometimes be derived from others’ deaths experienced in one’s own life. Most informants had no wish to have EPAS for themselves.

Most informants had parents, other family, friends and acquaintances who had died but had had little involvement with the dying person at the time and had not been present at their dying.

No, I haven’t had any major experiences. No, I haven’t seen anybody [die]. Well, the closest I’ve seen is a chap with emphysema but again, I didn’t live with him.

I was around when my grandfather died but not so consciously. I deliberately took less notice because you don’t want to see someone go backwards like that. Just keep the picture of the person you know and not the picture of someone at the end.

Death was seen as relatively meaningless and as the end to life.

Not living any more, just gone. Nothing. Death is nothing.

There is always the question in the background whether there is anything after life, whether there is some higher power. Well, I am not convinced of that.

5.4.1 Private and public fear of death

Informants expressed that they had no personal fear of death but they thought that most people did have such fears. Dying was something that informants hoped was short. It was not something informants had clear ideas about.

[You] go to sleep and you don’t wake up so therefore you just don’t know anything about it. People are shit scared of death, most of them. I don’t think I am but then again I haven’t got to that point yet. But death is unknown because people don’t know what happens after that but death is like a – to be honest for a lot of people it’s an easy option, an easy way out. Living can be harder for people than dying.

Yes, in any case I don’t want a long dying process. Two, three or four weeks in bed and waiting for what’s coming.
A few who had engaged in some spiritual practice and were most doubtful about EPAS made an association between a societal sense of meaninglessness and a public fear of death.

[H]umans are not on earth for nothing, a coincidence, or a collection of genes and molecules. Look, there walks a person and he walks here, he originates because his parents have slept with each other, and he happens to die. That would make my life terribly meaningless. You live then, but for what? And I get the impression when I look around me, and especially when I read the newspaper, that the realisation that life was given and that it is not up to me to end it [is getting less]. Because that comes from a realisation that I have, that life is a gift. That is connected. And when I look at society I think that realisation is getting less. Death is sometimes drowned out. Then you get billboards like: ‘Is there coffee after death?’ And then I think, why do you yell so much at death? Are you perhaps scared of it? Would that be it? Do you want to make life normal in this way?

A lot of people believe that you’ve got one life, you live it the best you can, you make as much money and have as much fun and then ‘beep’, you die. Now I think society reflects that that is the majority attitude.

Most informants did not say why they were not fearful of death but two did. One of the few informants who had experienced frequent patient deaths close up in a hospital said that his disability has removed his fear of death. And another had been “acclimatised” to his own future death by seeing other family members die.

It was a big ward. There were twelve people in that ward, a lot of older people. But they had a kind of trolley to collect dead bodies with. And that went like: jolly, jolly, jolly [sound of the castor wheels]. (…). You heard it quite often. Then it was collecting another one. … the funny thing is because you experienced it so often, that people are dying, and I also had experience with walking people who died. In the first instance there’s a kind of a fear of death, but that fear has been overcome.

I know that it’s inevitable that I’ve got to die sooner or later, hopefully not too soon. But, yeah, I don’t really find it confronting. I don’t really find that an issue. … Seeing aunties die and uncles die and Mum pass away and Dad go, I suppose we’re all getting trained up as we get older.
The same informant, who had the above experience of frequent death in hospital and was strongly in favour of EPAS, described the peace people experience close to a natural death as opposed to the fear he thinks most people have for it.

I think, very many people fear death. Because the strange thing is, I have experienced it with a few people, then they took the decision [to let go], then they are no longer afraid. They can do it laughing. Very strange. They get a peaceful feeling [in the last few hours], have you ever experienced that? (...) They laugh, enjoy it. You can say goodbye, thanks for the good friendship, thanks for what we meant to each other. I think it is wonderful.

Deaths of those who are close can also influence one’s view of life. An informant whose father had died was prompted by this to live more for the moment:

Yes, I am totally a supporter of ‘carpe diem’ [seize the day]. You think that that tomorrow [death] will never come but at a certain moment it is there of course.

(Leaders)

Leaders, at a personal level, described a somewhat greater degree of direct experience with death than the grassroots sample. Particularly some of those who have disabilities themselves, had been with many family members and friends when they died, including in a nursing home: “I have had a lot to do with death because I lived in an institution where they fell in droves”.

Some have derived meaning in their own lives from the deaths of others that they were close to.

I am not a supporter of dying. [But] it taught me this. I keep on where the others stopped. And that I took over from them. Because every now and then there were very special people there, people of whom I thought they could have gone far, if their bodies had kept up.

Her grandmother’s undignified dying in a nursing home prompted a non-disabled leader, to look after her mother at home when she died. She concluded that this period with her mother “ended up being one of the best times both of us had ever had and neither of us had expected that”.
5.4.2 No personal death wish

Some informants have had suicidal thoughts themselves but these were temporary and were overcome. They were glad not to have acted on them at the time while they were well aware that their disability was no barrier to committing suicide. Informants knew of suicide of other people with disabilities. Some Dutch informants saw this as a brave act whereas some others saw it as a selfish act. Dutch leaders suggested the existence of their society’s view of deliberate life-ending as courageous. Australians did not ascribe such moral values to suicide. Suicide was seen as having a negative emotional impact on others and this provided a reason for preferring EPAS over suicide as it is seen as less emotionally burdensome on others. Most did not see EPAS as applicable to themselves and certainly not for reason of their disability.

Some informants had thought about their life with a disability when in hospital and rehabilitation, post-accident, or at later times, as to whether they would like to continue. They were, in the main, now glad that they never acted on their feelings then as they now enjoyed the life they had. An informant who had a bad time in the acute stage and another who has some bad days speak next.

I probably would not have accepted it (euthanasia) but it certainly was touch and go…. There is a period of anger and anguish and a real down feeling and God this is the worst thing that’s ever happened to me and maybe death would be better. … Then I look at my life now and I think wow, what a path that I’ve come and it’s just so different. Life’s just so wonderful now and there’s no … knowing I was the same person back then.

Have you ever thought about that yourself [suicide]? Finishing myself off, no. [I] have thought when there are some physical problems, and you clash a bit more in everyday life than normal, than differently: when I go to sleep – I don’t necessarily have to wake up. These thoughts never last long.

Where most did not, a few did consider euthanasia or suicide at those times. One informant tried to stop eating or drinking but the hospital said that they would feed him by tube if he did. Another discharged herself from the rehabilitation hospital to kill herself at home. A friend caught on to what she intended and stayed with her until she was no longer suicidal.
There was a realisation that one could commit suicide if one really wanted. Examples were given of the possibility to cease eating or of others who had drowned themselves by driving their wheelchairs into the water.

But I think that if a person really wants to these days, they can do it at the drop of a hat anyhow.

One guy, it was rather bizarre, he was in an electric wheelchair and he just got his taxi driver to drop him off at the wharf and he just rode off the end of the wharf, straight into the drink.

Most informants, in both countries, were in favour of allowing euthanasia or PAS for persons who wanted this, but not necessarily for themselves, and not for reason of having quadriplegia. For themselves some held the door open in case of a future situation that might require EPAS but most tied this to extreme circumstances only.

I would not easily agree to euthanasia for myself. Then it would have to be very bad. If I would really see that there is no road of return, and I am totally finished. Then I think that I would say: you know what, just end it all. Because I am only going to suffer more and more now. While in the end I will die anyway. So just finish it then.

Personally in my case, I can’t speak for anybody else, I would continue until such time as if mentally it had become an anguish or a problem.

(Leaders)

One Dutch leader was unusual within this sample because of her experience with EPAS. She had been present during the dying of many friends. She would not want EPAS for herself because of the bureaucracy of the process.

… what disturbed me the most is the procedure you have to go through. It is good that there is a procedure, but you have to keep making it clear to various people that for you it is unbearable suffering and why. I thought [if it] does it have to be like this in the last phase, just leave it. (…) It [EPAS] is an attempt to guarantee a careful approach with respect to our fellow human beings. But at the
same time it has been so bureaucratised that when you open up a question like that – such a request – that then you are taking a taken up into a new system. That new system then determines the quality of your daily … and last day of your life. Personally I have difficulty with that. Don’t ask me how to do it differently but my experience is that road is not the easiest one.

5.4.3 Dutch courage

Dutch informants at times referred to acts of suicide as courageous where Australians did not. A Dutchman provided some clarification of his apparently contradictory stance of suicide as brave while he also saw it as egotistical. It was brave because he would not dare suicide himself and he had seen the emotional impact of suicide on others.

I know some that have done it. They hanged themselves or ate too many pills. That is a real shock. They are all young people. I knew them very well. That guy just did not see any purpose anymore and he did it. Quite brave. Right after [rehabilitation]. And a friend of mine did it.

Q: So you think of him as brave?

How they did that. I would not be brave enough myself. They would have been quite depressed, I understand that. But then, to just do it. I think Goddammit, they did do it. In itself I think it is very egotistical. Look at all the grief you give your family and all those people that love you. If you think of that then you won’t do it. When you see how much sadness those people had then. … I think it so egotistical like, then I’ll just pull the plug. You should not do that.

5.4.4 Impacts on others

Suicide by oneself was seen as too upsetting for others that are inevitably involved and this was offered as providing a justification for a formalised availability of euthanasia and PAS, which was seen as less upsetting.

… a lot of it is not very pleasant. … Gassing, or you know cutting your wrists or whatever they tend to do. It’s not nice for people to find them like that so if they were able to just have the needle…
These people commit suicide in the most terrible way. A train driver gets a trauma from that. Better to give the euthanasia syringe. It is neater, you lie more comfortably in your coffin and nobody else suffers from it.

Not committing suicide for the sake of others could create a feeling of being “obliged to live” for those few informants who were gravely dissatisfied with their lives with disability.

I’ve discussed it with people in the family, not saying I was going to do it or anything like that but just sounding out how they would react to it. … it probably won’t be in their [parents] time. I don’t know. It depends on how long they live obviously.

The few informants who said that they were interested in EPAS for themselves, for reason of their unsatisfactory life with disability, also all decided against suicide because of an impact on others. A Dutch informant who had pre-arranged EPAS for himself for when he has “had enough”, went through a struggle some years ago about whether to kill himself.

I thought about throwing myself off a bridge or rolling in front of a truck but I could not physically manage that in the first years. I could not even get a pill out of a box. I also thought that I would burden others if I threw myself in front of a train, a bus or truck.

And an Australian said:

But I realised and I thought a lot about it that you can’t do it without it affecting somebody, and that’s the only reason that perhaps I haven’t got rid of myself. (…) I can’t make somebody else responsible.

(Leaders)

Dutch leaders but not Australians, referred to the courage of suicide or of having EPAS, some in a positive sense, some not. This confirmed that attributing courage to the ending of one’s life was a distinctively Dutch feeling. There was some reference to this being a wider Dutch social phenomenon, related to unrealistic media stereotypes of disability and death.

And I think [that with a positive disability image campaign] those images will change. Look at an American program for instance. (…)
then you do see someone in a wheelchair pass by every now and then. Perhaps they don’t have much of a part but is someone who works there. Get it? You don’t see such images in the Netherlands. Yes, you do in a soapy for instance … that you see someone walk again who has just suffered a spinal injury. That sort of nonsense. Or indeed people who are heroes because they have a disability and straight away ask for euthanasia.

5.4.5 A low awareness of palliative care

The theme of “A low awareness of palliative care” showed that in both countries there was a low level of awareness about the nature of palliative care and its availability. This was most noticeable in the Dutch sample. Of those who had heard of palliative care many had difficulty describing what it was. Of those who did know what palliative care was some believed EPAS was, or should be, part of palliative care, thus offering choice. Others saw EPAS and palliative care are separate approaches to issues in dying. Dutch informants believed palliative care practice in their country was not good compared to practice elsewhere but was now improving. Australian leaders believed that palliative care in their country was good and improving. Leaders in both countries had a better overall knowledge of palliative care than that of grassroots informants. Dutch leaders echoed the grassroots’ theme of EPAS as an integral part of palliative care whereas the Australians did not.

Half the Dutch sample had not heard of palliative care (palliatieve zorg) and did not know what it was.

I would not know what that means. What is it?

Australians, apart from one informant, had heard of palliative care but many could not correctly describe what it was.

I don’t know a lot about it. I believe it’s when someone becomes so sort of out of it, they really cannot feed themselves. They get fed with tubes or fluid … and they are kept alive that way until their last days. I don’t know whether that’s right or not.

Those in Australia and in the Netherlands who did say that they knew about palliative care gave a fair description of it. They described it in general terms as reducing the pain and suffering at the end of life, that is at a stage of terminal illness.
It’s mainly used in terminally ill patients and they sustain you and they care for you. And they take care of your physical needs, whatever you need. They just make you as comfortable as possible until your death.

I think that’s basically providing a pain-free quality environment in the last days, weeks of somebody’s life.

These informants saw palliative care practice as a mix of medical and counselling support or as one offering comprehensive support to the patient.

Making life as comfortable as possible for the people that are probably going to die. So all you’re doing is trying to improve the quality of life for that person.

For me palliative care is better pain control, those kinds of things. Pain control, and for me that’s not only pills or painkillers, but also in other areas, to be with somebody, those kinds of things. I think that that would help well too. That does not mean that you solve everything though. That goes too far.

The Dutch often associated palliative care with voluntary workers, home help or community nursing.

Yes, there are volunteers, called ‘mantelzorg’ [informal care by family or friends] or something like that. That’s a volunteer group. They are in the neighbourhood quickly, home help or the doctor. (…) Somebody will come and visit and talk with you. Until you are dead they come. (…) The palliative care is more, people with a listening ear, you can say. (…). People in a terminal phase want to talk. And not be alone. You have someone to hold your hand. And pain control, that is the medical side.

Some saw EPAS as actually (in the Netherlands) or potentially (in Australia) being an integral part of palliative care. This way palliative care and euthanasia were seen as options that one could choose.

It is part of it [EPAS]. Also, somebody who has euthanasia done can do this with support. Look, somebody with a terminal illness then has somebody with them who can talk things through.

Well, that’s one choice someone’s got but like I said, it’s a choice. I think euthanasia should be another choice. Everybody’s situation is different … . Two people might have the same diagnosis but like for
example my pain tolerance is a lot higher than other people’s, so I can handle a fair amount of pain but I know there are other people that just can’t handle that sort of pain, they’re just – they’re made that way so that their pain tolerance is low, so they’re different. I might opt for just palliative care, heaps of drugs and whatever pain, the rest of the pain I can tolerate and when it naturally goes, it goes. Whereas someone else might be screaming in agony to the point where they need to be padded or tied down or whatever because they just can’t handle the same sort of pain.

Some others saw ‘euthanasia’ and palliative care as separate practices.

So it is more help in the terminal phase, like I understand it. Where everything is being done to lighten suffering and take it away or whatever. But not to take steps towards euthanasia. (…) People who really are in pain, who just get morphine till they drop. People don’t have to suffer pain in such circumstances. Then I think that’s what you should always do. Always try to minimise suffering. If not necessary it should not be done [euthanasia].

Some of those few Dutch informants who knew something about palliative care did not think that the standard of palliative care was as good as it could be in their country.

I think it is not being done well, that it is being done badly. And we are soon exhausted in our options, because act as if we have so many painkillers – people do not have to suffer. Well, I see with my bladder and the pain I have from that, that there is no painkiller for that. Well or you are completely drugged and then you no longer live. That is no choice. Then I think, it is not like that. Because how many people do suffer pain. Yes, we do act as if we don’t have to suffer but in practice that is just not true. And … one cannot fix all that. Can that situation be improved? I certainly think so.

But perhaps more is possible in palliative care. And accompanying people towards lightening of pain and the creation of options so that people can, for example, die at home. That you don’t arrive at euthanasia that quickly…

(Leaders)

Dutch leaders were aware of palliative care, as treatment for pain and suffering at the end of life, which they described as being delivered in hospices or at home by volunteers. They mostly saw euthanasia as part of a continuum at the end of
a process where all palliative care options were exhausted. The state of palliative care in the Netherlands was seen as inadequate but also as now improving.

The euthanasia possibilities and the resultant discussion have had a very positive effect on thinking about palliative care. That has really been a stimulus. And there’s a lot to be still be achieved. But that has really been opened up through the euthanasia discussion. I think that the medical profession was a bit slack on this point. It [palliative care] was behind whichever way you look at it. And now I think that gap is fast being covered.

Australian leaders described palliative care as care for terminally ill people and the relief of their pain and suffering, including grief counselling. Most thought that there was a good availability of palliative care in Australia and that it was improving. Some did not know.

The palliative care technology and supports … is [sic] improving all the time and I think, from my experience, where that can be delivered in an environment that the person wants it to be delivered in, in their own home or wherever they have that comfort.

5.5 Suffering and EPAS

The theme “Suffering and EPAS”, and its sub-themes present the various kinds of suffering that informants thought of as playing a role in requests for EPAS. These motivations were mainly concerned with how they thought about EPAS for others. Most informants, as presented, did not wish EPAS for themselves and most particularly not for reason of their disability. For some others, unbearable suffering arising from their disability experience could be acceptable as a valid reason to have EPAS themselves. Unbearable suffering of various kinds, particularly pain and loss of dignity, were strong sub-themes. By contrast, depression was generally not considered a valid reason to have EPAS as it was thought treatable. Suffering was seen as a subjective individual experience. Whereas everything possible should be done to address such suffering it was, in the final analysis seen as the decision of suffering person whether they had had enough and request EPAS. The suffering of those close to the primary suffering person was seen by some as legitimate suffering to be weighed in making EPAS decisions for that primary person. Some leaders added that a person’s suffering is better understood and ameliorated by people that
know each other well. For them, suffering was seen as part of the human condition yet as something to be minimised or avoided, if necessary by EPAS. Leaders also added to grassroots informants’ themes of suffering by emphasising fears of death, dying, disability, illness and of suffering itself which they saw as features of life that needed to be accepted as part of the nature of the world.

### 5.5.1 Unbearable suffering

Unbearable suffering of various kinds were important factors in the informants’ support for EPAS, whether for themselves or for others.

If suffering is so unbearable, inhuman, then everyone should have the right [to have EPAS].

To physically suffer pain, really suffer pain, then certainly these days that can be suppressed in very many ways. But if at a certain moment a situation is hopeless, for yourself, that it is really a declining situation, then I think it [EPAS] is a consideration.

Terminal illness was considered as a legitimate reason in itself to allow EPAS but was not necessarily the only reason. Informants often wanted to include an individual’s unbearable suffering of various kinds as sufficient reasons to have EPAS.

I think probably dying, you know, like terminal illness or whatever, is probably high on the agenda. If you don’t have a terminal illness then you may not be considered but I think there are certain circumstances where you don’t want to be around.

Q:. To get this clear – are you saying that euthanasia is more appropriate at the end of life? A: Oh no, If you have something that cannot be cured. [Or] something that you cannot live with. Q: So that could involve people that you might know, people with quadriplegia who do not want to live … Should euthanasia be possible for someone like that? A: if they wanted that, yes. If they don’t allow it they will jump in front of the train. They will just roll their wheelchair in front of the train.
5.5.2 Subjective experience of suffering

Most informants held that, in the final analysis, the individual’s subjective experience of their suffering, from physical or psychological pain, or other conditions considered to be unbearable, should determine whether anyone chose to end their lives through EPAS.

There’s all different types of pain, not just physical pain, psychologically you know, coping with things and … it’s just you know any amount of reason … to have it [EPAS], so people have got the choice.

Everyone determines for themselves what is unbearable suffering. Someone will likely find something not reason enough [for EPAS], like disability, incontinence, dependency, sex and dignity of life, to desire this. But someone else does not see why he should not be allowed to turn off the light [for such reasons].

Mostly informants advocated that while everything possible should be done to alleviate suffering, at some point it was the individual’s legitimate call should they still want EPAS.

But if, at a certain moment, a situation is hopeless, for yourself, that it is really a deteriorating situation, then I think it is a consideration.

I think everything else has to be dealt with first and then euthanasia. it should not be a first step. (…) if at a certain moment a situation is hopeless for yourself, which is really a declining situation, then I think it is a consideration [EPAS].

What constituted unbearable suffering was held to be subjective and it could be reason enough for EPAS when a person has “had enough”. They held to this legitimacy of subjectivity of suffering while knowing that, unlike themselves, others often saw life with quadriplegia as unbearable, perhaps even as worse than some other conditions.

Who am I to determine what suffering people should be able to take? What they do or don't want.

I know a guy who lived to 29. He died of cancer, really terrible. A terrible disease, really. And who did say to me: it seems more difficult to me to have quadriplegia, while I just see it the other way around.
That shows you of course, when you are in a certain situation, it is
difficult to estimate how another person experiences it.

And for some the subjective experience of suffering could lead to EPAS for
reason of any suffering arising from life with a disability as well.

For some people their daily experiences of disability can be suffering.
For that woman who was never able to come to terms with her spinal
injury from day one [and who received EPAS], that was really
psychological suffering. If it is no longer worthwhile for yourself,
that’s suffering, yes.

Some made distinctions about what would be legitimate suffering in order to
constitute a reason to receive EPAS, such as in extreme circumstances only. There
was a hesitancy to let any subjectively unbearable, individual reason, including
quadriplegia, be enough to approve a euthanasia request. This hesitancy was related
to their own disability experience of having overcome effects of disability on many
occasions.

I have thought about it in a perhaps more concrete fashion (than
others) because it is of course a situation of which another person
would say: for me this is too much. Or you would have said this about
yourself sometimes.

Those few informants whose experience of life with quadriplegia had led
them to desire EPAS for themselves were among those who were most absolute
about “a right” to define for themselves what constituted unbearable suffering for
them in order to undergo EPAS.

I think that people have the right to decide for themselves when they
think, whatever anybody else may think about that, that life is no
longer meaningful for them, to make an end to their life. Someone
who is healthy or disabled.

I just don’t see the point in enduring it all, for me. I only speak for me
obviously. That’s the whole point. Euthanasia should be about the
person…. Now what I care about and what the person next door is to
do is irrelevant. It’s what I want to do with my life. It should boil
down to the individual.
5.5.3 Whose suffering?

The relativity of subjective suffering from pain was also illustrated by near-death and altered-consciousness experiences related by a small number of informants and one leader. While from an observer’s point of view they were in a state of acute suffering, they experienced it differently. They related their readiness and desire to leave their bodies or told of observing their choking, gasping body in an unconcerned disembodied state. The example below concerns the experience of an informant who was severely burned and had an arm and fingers from the other hand amputated after his accident that led to spinal cord injury. The regular cleaning and bandageing of burns in intensive care was extremely painful and distressing to him. He asked to be left alone for four hours during which an experience happened which transformed the way he was dealing with his pain.

I mean I’ve never been in lots of pain apart from my accident … and a month later or two months later when I made a decision to say well I really want to get on with my life. I mean there was – I call it the spirit you know it was in the background – it said how’s it going John. I said I’m pretty pissed off actually, I’m in a lot of pain, I can’t walk, my arm’s burnt, my hand’s burnt, I’m bloody paralysed – what’s the point of life you know. And the spirit sort of said do you want to keep going or do you want to stop, and I said well I’ve really got a lot of things I want to do – I still want to get married, I still want to have some kids, I still want to get my business up and running, … there’s still lots of things I would like to do even though I’m paralysed. And then the next day I woke up and I just changed my train of thought. (…) but that time when I made that decision after seeing the spirit or whoever or whatever, from the following day or day morning when I woke up I said, OK I know it’s going to be a hard battle and a hard ride but I want to give it a go you know.

Suffering, relevant to end of life decisions, did not need to be that of the primary person only. Suffering of those involved with that person was also seen as relevant and important in making EPAS decisions.

I would not like to see my mother suffer for five or six years from cancer. If she says beforehand, no, I’d rather have euthanasia because I cannot manage this, then I say, OK, you can go it’s your choice. Of course I would be very sorry about her death. But I think I would rather have that. I think that if I had to experience those painful six years, that I would hate that much more. You would suffer from that yourself.
A Dutch informant described in a hypothetical example how observing and feeling another’s pain can contribute to an EPAS decision for that person.

It is exactly the same if it happened in your family and you see your father sitting on the couch, suffering great pain. And then something breaks inside yourself. Then you think next time it could be your father-in-law. Then I think, well, I saw it in my father, let’s spare him the suffering.

An Australian (who was not satisfied with his life) thought that it hurt his mother more now to see him suffering from his quadriplegia than if he had been able to have EPAS when he had his accident. Another described the pain of watching children with cerebral palsy on television

It really hurts me sometimes when they show on the TV some of those children. There’s 20-year-olds in 12-year-old’s bodies. [EPAS could be a legitimate response] for the person who is suffering and the relatives, wives, children, whatever are suffering because they're seeing the person they love suffer as well. So it's a relief for both of them.

Several more informants also believed that, for reason of a burden of care on the parents of people with intellectual disability, the parents could decide for their child to have EPAS.

5.5.4 Physical and mental suffering

Physical or mental suffering was a major theme as a reason for people requesting EPAS. It was seen as important to see to the relief of pain and its causes before EPAS was considered. If that were not possible, then EPAS was seen as preferable to possibly having a person commit suicide.

You have to solve the problem first of course. It’s just the same as if you, with your spinal injury, said: I want to be dead, but in one way or another can be cured with an operation.

You should always try to minimise people’s suffering from pain. If it is not necessary [EPAS] it should not happen.
Pain and cancer were often mentioned in this context, grouped together with various other conditions. These were seen as constituting legitimate reasons to request and receive EPAS.

I think probably severe pain would be the biggest factor. I cannot think of any other. Why should one have to suffer to the bitter end if one doesn’t want to?

… if you’ve got a medical condition and the pain associated with the condition, as well as maybe being permanently in bed, having to be bathed in bed, not getting out of bed so you’ve got no quality of life at all. You might still have a little bit of brain functioning and I then think, yeah, ask, do you want to carry on?

Some informants related their experiences of seeing others with cancer and the pain associated with that, but mostly had not had a very close involvement in dying. Generally their beliefs about pain were not explicitly generated from their own experience.

Well, I have had family members die of cancer, an aunty, … she died of bowel cancer. A very nasty death. She should have been given the option of euthanasia if she wanted it. I know she refused painkillers and all that sort of thing… it’s just from what I heard being said by my parents and that I know she died a very painful and a long death.

Mental suffering was often described as depression. The dominant sub-theme about depression was that it was seen as a treatable condition, which could not justify EPAS.

Depression is also an illness of course. And some people cannot live with that. I know somebody who is very depressed but who has not yet let it be done [EPAS]. And she wants to die very much. … . And when you see her she always says: I want to die, I want to die. But she does not do it. She is old and does not want to be [old]. You can of course treat depression. … you always have to solve the problem first.

That’s where a qualified doctor needs to decide that person is just going through a bad case of depression and I don’t think that’s reason for euthanasia …because depression can be treated with drugs admittedly.

Several informants expressed that to know that one could have EPAS if pain and suffering becomes unbearable was a relief from suffering in itself.
That the moment that the person knows that it is possible, there is a feeling of relief. But if you know three months ahead, well, if I then really cannot go on I will get a pill. (…) Because it is a burden that people carry, that fear. Look, everyone fears dying but the fear of dying in that terrible pain, that makes it for many: I don’t want to know. I do not want to have that, period.

5.5.5 Terminal illness and loss of meaning

Suffering during a terminal illness was mostly considered futile and little meaning was ascribed to this time. Such life was considered better to be cut short with EPAS: “whether it’s two hours before they die, what’s the difference?” Such meaningless was also perceived in conditions which involved a loss of cognition and which then becomes a reason to have EPAS.

But if I would at some stage just lie there and not hear or see anything, then I think why? But then I think that people at that moment – look as long as I know that when things are like that, that I can call on my doctor.

A Dutch informant told of the meaninglessness of his father’s suffering when close to death. A Catholic doctor ignored his father’s covert (his father also being a Catholic) pleas for EPAS where this informant believed that EPAS would have been preferable.

When he could no longer get up from his bed there was no meaning left in his life, and for no-one else either. He was just waiting engulfed by pain, waiting for death for a long time. How good it would have been if, when the pain took the meaning from his life, if the doctor had given him something to allow us … to say goodbye in a calm way, after which he could just have gone to sleep.

On the other hand a few others wanted to leave the door open to include the possibility that life was still worth living while terminally ill:

That could be a big factor too, terminal illness. But again, it has to be weighed up. Can medical advances improve it and miracles happen every day. I mean, is it totally terminal and what is the person’s quality of life?

Those few informants who had expressed an interest in EPAS for themselves referred to the presence of meaninglessness in their own lives with disability, which
they thought should entitle them to EPAS. One such an informant related explicitly to his loneliness and the way others treated him as constituting his motivations to want EPAS for himself.

One day the moment will be there that after a certain number of years in a wheelchair, maybe twenty-five years, that I will be so tired and can no longer deal with the sorrow and adverse events or insults from people. (…). Death is final rest. No more pain and going to another world where there is no more guilt. Without being lonely, without being unhappy.

5.5.6 Medical treatment, care, relations and dignity

A sense of loss of dignity was woven throughout descriptions of the impacts of pain, medical treatment, including over-treatment and some approaches to care. A loss of personal dignity could arise directly from conditions one suffers from and could be reason enough to have EPAS.

When life is no longer experienced as a dignified existence... That is different for anyone but you can call that a common denominator to be so psychologically ill that life is only a black hole. Then that can be enough I think.

The treatment of severe pain itself was sometimes seen as undignified. Some informants thought that such treatment necessarily involved the administration of high doses of drugs which could cause an undignified state of mental incapability or unconsciousness. Such unconsciousness could be a result of treatment or the person’s condition. EPAS was then seen as an answer to such indignities. About the euthanasia practice in the Netherlands it was said that: “if the person wants to go they go in a dignified manner and painless”.

I think it’s more to do when the quality of life slips below the point that you don’t want to be here, but you don’t even have the ability to commit suicide if you want to. Your choice is taken away because … when medical expertise cannot do anything more for you. Well, they can relieve the pain but you are so far out of it that you don’t know what day it is or … you are just in a non-compos mess. To relieve that pain you have to be drugged to the eyeballs that you might as well not be here anymore.
EPAS was seen as an option in the face of the indignity of medical approaches that keep people alive when they were not able to live a quality life, they might be unconscious, or “a cabbage”, or “vegetable”, incontinent, a burden to others and not receive the necessary care. Some saw a bad quality of care for many of those who are close to death.

[The carers in hospital only] pump more painkillers into them, [and don’t] clean them up after they shit themselves. Don’t worry about dignity and all those sorts of things that we treasure.

So what if they don’t want to be here, so what if they shit themselves. They haven’t got a clue half the time. Our job is to keep them alive. … the relatives are worn out, stretched to the limit. Had enough kind of thing and so has the person. They’ve got nothing to live for other than pain and no dignity and what have you.

Fear of future conditions of severe pain or prospects of entering a nursing home could also be reason enough to assure people that they could have EPAS should the situation become unbearable. Such assurance could make suffering more bearable. A few informants would consider EPAS for themselves if they would ever have to enter a nursing home.

[T]hat the moment that the person knows that it is possible, there is a feeling of relief. But if you know three months ahead, well, if I then really cannot go on I will get a pill. (…). Because it is a burden that people carry, that fear. Look, everyone fears dying but the fear of dying in that terrible pain, that makes it for many: I don’t want to know. I do not want to have that, period.

If something would happen to my wife and I would enter a nursing home, then I would observe it for a while and if I did not like it I would consider it [euthanasia].

An Australian informant, who did spend some time in an institution and would consider death if a return to it were necessary, described her fears as a lack of genuine interaction with others and boredom in such a setting. She had a very high level of quadriplegia, being able to move her head only, and had been subject to significant health problems. She found her will to live in the enjoyment of her family relations and with others.
Q: And if you were by yourself and not have your family and friends around, are you saying that you would then think differently about euthanasia?

A: Yes, yes. Particularly after my experiences in X [the institution]. You need to be able to bounce off people Erik, everybody does. You need to feel some worth, everybody does. And its only the people around you that bounce off that feedback to you, that assist you, but not in a condescending fashion, but are just as normal with you as they can be. In a hospital and in an institution no-one is normal with you like that. (…). Anybody that’s not fast and furious and cut-throat, there’s no time for them. And the people that drop into that category are the elderly, they are people alone, including people with disabilities, depending on their disability, and obviously people who are terminally ill. They have the right [to EPAS].

Where disability experience had influenced informants it was to support euthanasia because they saw that there were sometimes conditions that constituted a level of suffering with which one might not want to live. Experience of disability seemed to have been a minimal influence in how informants thought about EPAS, with many saying that their disability experience had not changed their views.

The [disability] experience is a separate issue to [my views on EPAS]. To start off with I was bothered by it [disability] and that’s just how it is. During the day I just had no time to think about it. Look, you just keep on living and breathing and we’ll see what happens.

I think I was always for it [EPAS]. It’s [life with disability] probably given me a different look at it … . I’ve got to experience what we always feared.

Some others said that they could understand better why someone might want EPAS because of their own experiences with suffering and hardship.

Before my accident I thought: I can do what I want, my own choices in life…. Now I know how life can take a funny turn over which you have no control. I never knew that. I thought, nothing will ever happen to me. … then you’ll look at it differently. You understand others’ suffering better.

One thought that his disability experience had given him insights that had helped him form his opinions on EPAS, which included a greater caution in supporting it.
Leaders confirmed the grassroots theme of suffering as being unavoidable. They expressed the need for disability and suffering to be seen as part of the human condition, and as something to be lived with. They thought that in their societies there were many efforts to avoid this human condition, including through technical/medical approaches, genetics and professional specialisation. The common belief was that much suffering could be solved or avoided.

What I was going to say about suffering I suppose is that we’re so used to popping pills for a headache … if you’ve got some problem you go and get antibiotics to solve the problem. We no longer think it’s acceptable to suffer, so we think that there should be an easy solution to remove that suffering.

Health care in Holland has gone very far, and you see now, with them being busy with the revealing of DNA, the gene technology, that people get an increased notion of ‘Ah’ they have found a solution for something else, so we can prevent it. Or we no longer have to get it [a health condition or disability], or whatever. So you get a picture of some things can be avoided, and you have to always prevent them (from happening), because there is really a very large group of people who thinks that being disabled also always means suffering, and is to the detriment of a quality of life. (...) If you cannot give a place to disability, illness and suffering anymore in your community and put it away, sometimes literally, … in what you have got these days, houses where you can die [hospice] … then I think what have we done, that we need special houses to die, we cannot do that within the family anymore, at home, but we have to go to a special house.

They thought that fears of dying, disability and illness affected how most people think about suffering.

I think it plays a role, that unconsciously the average person thinks of disability and illness as something terrible. [The fear of] dying first that is also something you’d rather not talk about and after that comes [the fear of] disability and illness. And we keep those from the door as long as possible.

Personally I think that the entire euthanasia debate is fear of illness and disability, just with broad sections of the population, fear of suffering. And they think that euthanasia is the best solution. It has also replaced what churches had to say in the old days. Then suffering was part of life. It was a process towards death. Nowadays we no longer have time for that or something. (…) … [B]ut people have
been dying miserable, bloody horrible deaths since Adam and Eve, there’s nothing unusual about that. What is unusual now is a change in our social values where there’s a significant number of people say, well we should terminate life when it gets past a certain point.

Like the grassroots sample they thought of the experience of suffering as subjective but also as complex. Knowing the suffering person increased one’s knowledge of the kind of suffering that that person experienced.

It is of course a terribly difficult dilemma: when is somebody really incurable, or in the terminal stage. And when does somebody have a mood change or a depressive episode or has very great physical suffering in which it is really not possible to fix it medically? There are all sorts of grades in that. Pain barriers are lower with one than with the other. And for myself I always have pain in my body but at a certain moment you move your boundaries again. But you can't determine for someone else what their pain barriers are. And not only physical pain but also existential pain. At best you can, because you had a very long-term relationship with someone and have been walking with him, see how much somebody is suffering.

A leader who had tried to commit suicide described his dual experience of simultaneously feeling in the choking body that he observed from the ceiling in his disembodied, unconcerned state, confirming the subjectivity of suffering at a metaphysical level.

I had surgery in 1985 and nearly died – I had an out of body death experience (…) But I know very clearly regardless of what scientists may be able to explain away in terms of lack of oxygen to my brain and a range of other things, that I was going somewhere that I really wanted to go (…). And I had a very, I guess, typical out of body experience in actually having two separate parts of the one but being able to experience someone who was suffocating and on a bed and someone who was up near the ceiling and who wasn’t suffocating and you actually knew what it was like to be pain free. And I hadn’t experienced that for as long as I could remember so I actually felt myself going somewhere else ….

5.6 Rights, choice and compassion

There was a strong theme of the belief that people have a right to choose and determine for themselves to have EPAS. This belief was more often expressed as a right for others rather than for oneself and could be triggered by various kinds of
suffering, including loss of meaning in one’s life, incurable conditions, prolonged unwanted medical treatment, cancer or pain. The emphasis was on the person’s choice of exercising one’s right to self-determination as a means towards ending one’s suffering. The kind of suffering to be addressed was of lesser importance.

If that’s their choice, … it should be made available to them. It’s their choice. Rights and choice are the euthanasia problem in a nutshell.

… [P]eople with cancer, things like that, naturally any terminal disease. If they’re of sound mind the person should be given the right to decide whether they want to end their life or have it dragged out by a hospital.

It was often not considered necessary or appropriate for another person to make a judgement about what kind and degree of suffering warranted EPAS, if the suffering person determined that it was too much for them.

All types of pain. Coping with things, and you know, other people, it’s just you know any amount of reason to have it so people have got the choice.

It is each person's choice. You never know what people live through. I had pain in my abdomen for six months once. Then also thought: well I can't keep this up anymore. I didn't want to be dead, but I thought: I can't live this way. If I can't find a solution, if this has to be part of my spinal injury, chronic pain, then I can't live. I had spastic intestines, that can be very painful. So well, then I can't laugh everyday anymore, and I don't like that at all. Other people have other things. Maybe their face is disfigured. Some people don't want to go on then. Well just let them I think.

Quite often informants insisted that everything possible should be offered and done to alleviate suffering. But, in the end it was for most seen as a choice to accept suffering and its treatment or choose to get away from it by using EPAS. A Dutch informant had described what she thought was EPAS on a woman with quadriplegia who was still in rehabilitation. She felt uncomfortable about this but insisted on a right to choose.

You can talk with these people. You can do therapy. You can show them how others try to make something of their lives. If for you it’s no longer worthwhile then that is suffering. So it becomes a choice.
At one end of the spectrum of responses were those of the small number of informants who would rather be dead than live with their disability. At the other end were those who enjoyed a very good, or even better life, than before the onset of quadriplegia. Both sub-groups thought that everything should be done first to alleviate suffering and both deferred to an individual’s right to choice in alleviating suffering. For the first group the emphasis was on the exercise of a right to choose EPAS with the least importance attached to the kind of suffering being experienced. In this group an informant described how an elderly relative had been in a nursing home for some years as “a vegetable”. He did not visit because this was “too much” for him to bear to see. Even though she was not in a position to choose, he believed that it would be “compassionate” to “put her down”.

Even if you are perfectly healthy, if you decide, … why shouldn’t you. They understand what’s going on but they’re just not particularly happy with life and don’t really see the sense in going on. (…) I get people riled up [in expressing his death wish] because they say I am OK but they don’t have to live it. I don’t judge others. My choice alone. The wheelchair is irrelevant. (…). Once you’re of consenting age and if you don’t want to be around then (fades). Unless there’s a reason that they can come up with then I can’t see the problem. And that’s really simplifying it and people would really laugh at you and I know that would never happen. But certainly when it gets to the stage of anything being wrong, a person should have the right but they haven’t.

For the second group the emphasis was on EPAS for reason of “extreme suffering” that could not be otherwise alleviated. In the first group this was least important.

Compassion is to care and allowing EPAS in extreme circumstances only.

Always ease the suffering. Ease what’s causing it. Keep occupied. (…) I cannot say that people should have EPAS when they want it but it would not be for me to judge that kind of thing.

Despite many informants’ insistence that “everything be done first” to alleviate the suffering and “people should not be killed too quickly”, there seemed to be little faith in the possibility of actually achieving this through care.
We should talk with them and treat them. But after all is said and done and someone decides that they’ve had enough that should be possible.

It’s individual choice to fight till the very end but there are others who’d like that choice [to have EPAS].

In both countries a number of informants drew on knowledge gained from the media, especially television. On several occasions informants mentioned a television program that had recently been aired in giving examples of suffering that might be enough to warrant EPAS. In the Netherlands it was a program that had just shown a case of a woman who wanted to die for reason of her severe facial disfigurement. In Australia it was a program showing children with cerebral palsy who were thought to have a “bad quality of life”.

There are things that are worse for some people: a woman whose face was very disfigured [was shown on television]. You never know what people experience. Some then just don’t want to go on. Who am I to determine what people should suffer? If they don’t want it?

It really hurts me sometimes when they show on the TV some of those children. They’re 20 years old in a 12-year old’s body. (…). … a person like that, someone else, either their parent or someone thinks that the quality of life that they have – and even they cannot handle it either, seeing their child like that, say, well look this isn’t fair. … at least let him die with a bit of dignity. (…) [Euthanasia could be a legitimate request] for the person who is suffering and the relatives, wives, children, whatever are suffering because they’re seeing the person they love, suffering as well. So, it’s a relief [EPAS] for both of them.

A certain personal distance between the suffering person and others who might be involved in end-of-life decision-making, such as EPAS, was often implied. There was not much talk of supporting the person in their suffering beyond ‘doing everything possible’ in a medical sense. Informants did not want to interfere in another’s end of life decision. For instance, not long after the injury that caused his quadriplegia a Dutch informant became suicidal and had received help from his friends for which he was grateful. But he still believed that personal autonomy is the overriding factor in end-of-life decision-making. He could “walk a little way alongside” the suffering person but was otherwise “a blank slate”. He was the only grassroots informant who mentioned the word autonomy in the interviews. He was
Dutch and was employed in a counselling position with a residential facility for younger people with intellectual disability. He told of bad quality of care and services for people with disabilities. He thought that an EPAS request for such reasons should be taken seriously in order to respect the person’s autonomy, although he would have difficulty accepting the reasons for it.

I should not say that euthanasia is not allowed for non-terminally-ill, badly cared-for people because I think that it is important that people keep their autonomy. That we should not assume that I can decide about you, how you should live, or what you can, or cannot deal with in life. That is not up to me. It is for me to walk alongside you for a little way. (...) I would have trouble with that but I would understand it. I just think the reason is impossible. Politically that is not on, … in this way we really don’t meet their needs. Q: Euthanasia is not allowable under such circumstances you mean? A: No, I say, on the one hand you look at who says this, who wants euthanasia because they cannot go on any more. I say you have to take them seriously, and you have to seriously address the question. So I don’t say that’s not allowed because I cannot say that. Because you want that. How can I say then, you’re not allowed? But at the same time I cannot accept the situation that has led to it ….

Few informants said much about any role for compassion in relation to EPAS even when prompted on this aspect. An Australian informant who reported a very good experience of life did “not see how compassion comes into it” and another, also with a high fulfilment in his life said that: “compassion is to care” while allowing EPAS in extreme circumstances only. Compassion was linked directly with individual rights to choice.

The compassion is really about having the compassion for that person to have that right to go in dignity, to go peacefully.

Compassion and suffering are very important. If people choose for the normal way of waiting for death and are ready to take the suffering with it, then this must be seen as a good choice for them and they should be supported in that.

In both countries informants implied a kind of interpersonal distance in decision-making about EPAS. For most informants EPAS was not something they had considered for themselves or would.

I would never give anyone an injection myself.
[EPAS] is not for me. What others want to do is their business. … they die because [their] life is over and they only have pain and sadness.

Some felt empathy for another’s request to die if one was constantly experiencing health problems associated with quadriplegia such as bladder infections, headaches and pressure sores. However, most informants did not think about EPAS for themselves even though these health problems were part of their own experience.

I live and I have quadriplegia. It is not the case that I have quadriplegia and I try to live. That is the difference. From my situation, quadriplegia is no reason to want to be dead.

Never thought like, let it all be finished, but I did of course think about it. Like, would that be better than to have to live like this? For me that has never been an option.

A Dutchman with 20 big hospital operations behind him underscored the dual approach towards a right of others to have EPAS and their own choice in this matter. He says about euthanasia: “I would never do that [EPAS], without doubt. It is something in which I have changed since my disability”. But he also believed that, regarding EPAS, “others can do as they please”. A few others wanted to leave the option to EPAS left open for themselves.

The option should be there. I’ve always felt that because … I have spinal cord injury. I’m not sick and I’m not at this stage ready to stop what I’m doing in my world. But even before the accident, it’s just an option that should be allowed to be there. Particularly when it’s a person that can make an informed choice.

5.6.1 Impacts on others

“Impacts on others” is a theme that describes the informants’ acknowledgement that choices involving EPAS are not, and would not, be made in isolation from others involved in that process, chiefly family and doctors. Those who would rather have EPAS than continue to live with their disability shared this perception. To enter into any deliberate act of ending one’s life seemed to require a distancing in relationship with those who would be directly involved in this act. It
was suggested that such distancing would minimise any emotional impact of the act of EPAS on such parties, especially in the case of Dutch doctors. Nevertheless doctors were seen as the natural professional to carry out EPAS because of their powers of assessment and diagnosis and their medical/technical ability to kill safely. Thus the professionalism that informants often referred to may imply that a certain legitimacy is lent to the killing process by the medical imprimatur. Notwithstanding this, doctors were not necessarily accepted as the natural assessor and executioner of the EPAS procedure. Some Australians thought that family members should be able to decide on and act in EPAS. Doctors should have a choice whether to engage in EPAS or not. They were thought to have inner wrangles in carrying out EPAS within its context of complex ethical decision-making. Possible legal consequences in either country were thought to be of influence on doctors’ consent to participate in EPAS, despite the legal toleration of EPAS in the Netherlands. Some Dutch informants thought that complex documentation was required of doctors who reported EPAS. They saw this as another consideration for doctors not to participate in EPAS. There were suggestions that some doctors may incorrectly report EPAS as a natural death as a result of family’s wishes for the death to be reported like this. Some concern was expressed about compromising the doctor’s role of healer. There was also a contrary theme where some participants said that EPAS is part of a doctor’s natural role. However others suggested that a specialist EPAS doctor who had less emotional involvement with the person having their lives terminated is preferable. This presumably made it easier for the doctor to carry out the killing procedure as well as for the recipient to receive it.

Despite the strong theme of rights to individual choice with regard to EPAS generally there was a strong sense that choices are not made in isolation and that others are involved and feel the impact of an end of life decision. Involved parties included family, friends and doctors.

I mean obviously, you take that individual choice. The choice is made up of different reasons affected by, you know, your partner or your family or friends but that’s all taken into consideration.

You must of course make clear arrangements with your loved ones and those who stay behind so that their conscience is at peace and can digest it psychologically.
There are very few things in life that are a matter of individual choice – there’s always someone out there who would … . You’ve got to think of the rules of society, the regulations of society and the needs of other people and that as well. So in this case you’re talking about the family and how this is going to affect the family and how it’s going to affect the doctor, the sort of effect is on them.

Those few who did say that they would want euthanasia at a future time for reason of their disability or at some possible time in future, due to unforeseen deterioration, also said that one’s decision to have EPAS involved others. They underscored this by saying that it was not dying that concerned them, it was the impacts on those left behind. Those who would rather be dead than live with their disability also felt this.

The only thing that ever worries me a little bit is the effect it would have on people you leave behind. And you know, I don’t know whether it’s selfish sometimes, because I’ve seen how they act, you know after a serious accident, and how it affects them, and you wish it hadn’t sometimes. It does affect their life, of course it does…. Now I’m not saying she [mother] would have forgotten [him by now if he had died in the accident] but I still think it would hurt less than what it does now, having to come up once a week and see you go through it, because she knows what I. [fade out]. I can’t hide it from her. And your sisters know as well, they know what you …[fade out].

I don’t worry about that [death]. But the worst thing about dying I think is the sorrow that others have from it. Because there are people, I am sure of that, who will miss me. And you leave an empty spot behind. And I won’t notice that then but they will. That I think is the worst aspect of dying.

The responses from the small sub-set who said that they would rather be dead than continue to live with quadriplegia, revealed a sense of impact on others of their possible EPAS. For that reason it seemed that they were distanced from such others. The one Dutchman who had pre-arranged his euthanasia at a future time of his choosing, had pre-arranged his future EPAS with a doctor he had met once only and did not know well. He “want[ed] to keep it that way” and had thus distanced himself from an emotional content in this doctor-patient relationship.

I do not know this doctor well. It is a superficial contact that I want to keep that way. But he understands me and I find that important.
The impact on others of any future decision by him to die was experienced as so strong that he complained that he felt under an “obligation to live” as a result: “Over the years you are obliged to live. This is how I’ve always felt”.

Two Australian informants, who would like euthanasia if available, argued that if family understood a person’s wishes to die they would agree to EPAS and find that an easier course than to watch their persistent suffering.

Well, obviously the person with the illness would be the one [to feel the impact of any EPAS decision]. I mean, they’re the one suffering so I don’t think it is really anybody else’s concern. But OK, it probably would impact [on others]. There’d be sorrow as there would be at any type of death but I think that if people understood that that is what the person wanted that it would be easier for them rather than to watch them over a period of … years or months, of a nasty illness.

I don’t think they’d [family] be concerned. I think everyone knows me well enough to know that they’d be helping me. … [I]f it was legal I don’t know in the end whether they’d be able to go through with it or not, that’s their choice. But if I wanted to they certainly wouldn’t hold me back.

There was some recognition that EPAS was an emotionally difficult thing for families and could involve conflict between those who agree with medical killing and those who do not:

… [T]here will perhaps be members of family who say we do not want that. Others will say they can do that … and they wife says no and the husband says yes.

5.6.2 Involvement of doctors in EPAS

Doctors were seen as necessarily involved because they were needed for their medical knowledge in an act of EPAS. Their ‘professionalism’ was often referred to as if to add legitimacy to the EPAS process.

I think it is probably a desirable thing to involve the medical profession. … I think that they can probably make it easier for people. Well, it makes it easier in that they can use drugs that make it a bit less traumatic I guess. … yeah, I think they know what they’re doing.
Some Australian informants thought that the family should be able to decide on EPAS. The decision should not necessarily lie with a doctor, who needed to be “detached”. Some also thought family members themselves should be able to perform EPAS.

It should be a doctor obviously … you should have to go through a very rigid screening process with health professionals. I mean, OK, it doesn’t have to be a doctor that actually is with the person, it can be a family member but it needs to be a doctor … or a family member can … give somebody medication that’s going to kill them.

There was also some doubt about the doctor’s role in EPAS. They had the needed expertise to kill but the decision should not be all theirs, nor should they necessarily be the only ones to assess capacity to make a decision for EPAS.

Well, I guess you would assume [it would need to be a doctor] since they spend their lives keeping people alive, they should know the best way to let someone go…. I just figure that they are the ones that would know how to do it. For no other reason. … I don’t believe that their opinions necessarily should be – you know other than whether you are capable of – even then it’s a pretty touchy one, whether you are capable of making a decision. I mean who decides whether you’re you know sane or insane if you like.

Of course a doctor should take part in it. If they’re actually involved they’re the ones that are going to be carrying out the euthanasia. So they are professional but certainly their professionalism is not – I mean it shouldn’t only be their decision. … I think it shouldn’t obviously be only a doctor. (…). Who’s the experts in these sorts of situations, that’s a difficult thing. I mean even people that judge quality of life – how could you – I mean a doctor is not necessarily an expert on quality of life.

Doctors were seen as needed for their professional skill in the assessment process and conducting of EPAS but there was also some caution about their expertise in this role. Several informants suggested that the doctor that engaged in euthanasia should be trained in assessment and communication.

I certainly think that… the doctors especially need to be well trained as far as how to deal with people and how to deal with the sensitive issue of it. (…). So, therefore I would say, any doctor, because he is a doctor, doesn’t mean he’s qualified to decide whether that’s something that’s an option for that person.
Both in the Netherlands and in Australia a theme of doctors who would specialise in EPAS and who were detached from the healing part of the medical profession emerged. This was prompted by a desire to keep the healing and killing roles separate and, again, to keep the emotional impact on others at arms length.

I think we should have different doctors for that who will move throughout the country. They are people who do it from a sense of professionalism. (…) If it would be my ‘huisarts’ [general practitioner] and my mother would commit euthanasia then I think it absurd to have that same doctor attend to me who killed my mother with an injection. I just think, let it please be done by people who have no other role to play. In a kind of anonymity.

I think it should be somebody separate from the medical profession. So it’s done with dignity and peaceful you know. (…) I think you should have it separate … I don’t know what you’d call them. Dr. Death is not a very good one but something along those lines… (…) I don’t think that doctors – there would be certain doctors I think where they would see the pain and the anguish more than anybody…. 

On the other hand there were also many informants who saw no problem in having doctors perform EPAS as part of the doctor’s natural role. Overall, the doctor was very much perceived as in a purely instrumental role in performing EPAS and doing assessments for eligibility for EPAS. There was no mention of the doctor in any supportive caring role towards the person who requested EPAS. The first quote is by a Dutch informant who said that she did not have good relationships with the three consecutive ‘huisartsen’ (g.p. ’s) whom she has had and who did not know her well. Contradicting the main theme of detachment, she assumed that engaging a physician for EPAS purposes would lead to a closer doctor–patient relationship. The second quote was by an Australian who had a long-standing relationship with his local doctor.

Q: Does the role of doctor change then or does it [EPAS] belong with medical practice? A: No, I think it is part of medical practice. Because he is the one that can bring it about. Yes, I think so. I do think you get a different relationship with your doctor, if you talk about that [EPAS] and actually do it, that you get a very different relationship. Q: And how would that relationship change do you think? A: It would be much more intimate. Something that is so close to you. But yes, I do think it’s a task for doctors.
So is it a part of normal medical practice would you say? Well, it isn’t now [in Australia] but it should be. A medical person brings people into the world. They treat them for whatever their problems are. They deal with them throughout their lives. … [A]nd then the person at the end of their time, whether it’s through old age or whatever, if they decide, then why should the medical person not have that ability to deal with it.

There was acknowledgment that some doctors might not wish to perform EPAS because of their own moral objections or, in Australia, because of its illegality. Consistent with the informants’ dominant pro-choice stance towards EPAS in the sample, the doctors were thought to need a right to choose whether to engage in EPAS or not. Australian informants saw legalisation of EPAS as for the benefit of doctors, offering them legal protection. Some also thought that such legalisation would offer doctors some protection against their possible emotional distress from acting in EPAS as he would be acting legally on someone’s choice. In the Netherlands, where EPAS has been tolerated for a long time, more emphasis was given to recognition of the doctor’s inner dilemmas. The dilemmas were said to occur as end of life decisions often have to be made in “grey areas” and within a field of tension between a healing and a killing role.

Yeah the doctor’s got to have a choice …. I mean the doctor has got to have the right to turn around and say, well, no. I’m against it, no. (…) I mean, obviously he’s got to believe in euthanasia or physician-assisted suicide otherwise he’s going to have, well, it’s a moral question for the doctor really. … [I]f they participate directly and it’s still illegal, well, there’s legal ramifications and this has happened in America with Jack Kevorkian. … [I]f they just give somebody the means to do it … the mental ramifications might not be there because it’s not up to the doctor. He’s not actually committing an act himself. He’s just – it’s like putting a … gun in front of someone and it’s their choice whether they want to pull the trigger.

He has taken an oath to save life so he harms that in principle. I think that can be rather difficult for him. I would say you can have EPAS if it really is that bad but I think that often it’s a grey area. Of which they [doctors] think, well maybe we’re in too much of a hurry. Maybe there is yet another option. Because it’s not always crystal clear. I think it will then be difficult. Even if you have requested it beforehand, in specific circumstances, than the situation is still not clear … (…) So he will have a difficult time when he is in a grey area like that.
Highlighting informants’ regard for the impact of EPAS on others, one Dutch woman thought that she would not ever have EPAS because of the impact on the performing doctor. She saw suicide as preferable.

Even for a doctor it is very difficult. I don’t know whether I can do this to the doctor. So in that sense I would rather make an end to it myself if I had the courage.

(Leaders)

As in the grassroots sample, leaders saw choice and self-determination as important concepts with regard to EPAS. In contrast to the grassroots Australian sample, some Australian leaders were more reluctant to support EPAS on the basis of self-determination than Dutch leaders were or rejected EPAS as a public policy: “I am not clear myself on the use of euthanasia or physician-assisted suicide where there is a high level of suffering and pain”. They worried about an adverse impact upon people with disabilities.

You’re arguing for rights and you’re arguing for people’s self-determination in many ways as an advocate. But when it comes to the ultimate self-determination, I just have real concerns about those things that may happen, and decisions being made prematurely because legislation or policy enables it to happen.

Another Australian leader did support EPAS on the basis of an entitlement to choose this for oneself.

I can understand that when your life’s not easy and you make the decision – and I believe people should be able to make that decision

Most Dutch leaders supported EPAS as public policy on the basis of self-determination, although one stated he had a different personal opinion on this than he had as ‘leader’.

Euthanasia is acceptable, as long as it is the free choice of the individual.

Leaders mostly agreed that EPAS decisions involved others and had an impact on the family and doctors and that this makes EPAS complex. A few of them thought it better if EPAS were considered in terms of an inter-relational process.
I really think euthanasia is context bound. You cannot arrange that separate from people, circumstances or situation. (…) I think the emphasis is too much on the legalistic and medical aspects. It would be better [discussed] at a social level, on living together. [In] a social or an existential dimension. (…) With self determination I do not go so far as to say it has to be to the cost of others’ lives. It has to be balanced by connectedness, with lives of others, that is where the boundary lies.

Some Dutch leaders who personally knew some doctors as friends confirmed that there were impacts on doctors by participating in EPAS. Like the grassroots sample, leaders thought doctors needed to have the choice whether or not they engage in it.

I have friends who are doctors and they are totally destroyed. Even though they agree with that. Even though they do it. Emotionally they go to pieces. And then I think your own rights and choices and freedom have limits. And that limit lies with others. (…) I think he needs the freedom to say no because he does so much with those people. For days or weeks he’ll be thinking about that. It stays with them.

Interestingly, the only non-disabled Dutch leader said that he saw no change in a doctor’s role if they practiced EPAS. He also thought that the impact on others of EPAS decisions is of secondary importance only. The decision by the primary, suffering person is paramount: “They may think that is terrible but that is just a pity. That is then their own problem”.

Australian leaders believed that in their country EPAS was widely practised illegally. An Australian leader who was most in support of EPAS suggested, along with other leaders, that legislation would protect doctors.

I know a number of doctors who assist people to die and recently when I was working with [an AIDS organisation] they came out and said, I’ve done this and I will continue to do this …so I think there’s a double standard in relation to that…(…) I think some doctors [in Australia] would not want to, and don’t, practice euthanasia or doctor-assisted suicide and I don’t think anyone should be forced to do that.. (…) I don’t think that we, as a society should get to a point where it’s taken for granted that that’s what doctors will do but I think it should be open to them to practice that openly without being penalised in a number of ways.
In both countries leaders, like the grassroots sample, raised concerns about the dual healing and killing roles of doctors who are involved in EPAS, involving their ability to assess life ending and the focus of their training towards cure.

I really have concerns about someone from a medical background administering and involved [sic] in someone’s life. …[T]here’s no indication to me that doctors are the best qualified individuals to be able to make those decisions and take and whether they have a good value base and have a good understanding of individuals wanting to struggle to stay alive etc. I really struggle with that question.

Every doctor’s dream is of course to keep everybody as healthy and vital as possible. All of rehabilitation is aimed at that. Only when it is certain that you cannot walk anymore, then they will think about what you will still be able to do. But then their real work is really finished. Yes, then they have not achieved anything – really it’s a kind of failing. So if they would look at death in the same way then you come to some interesting conclusions.

Some leaders confirmed the grassroots theme that the involvement of the medical profession in killing people gave it an air of professional legitimacy.

[I]f you start to get other people [doctors] involved in it that legitimises it more.

Only doctors can determine whether there is unbearable suffering, according to the law-makers and politicians in the Netherlands. You might think nurses that cared for you for years would also know. But the judgement is always a medical judgement. And that judgement is given exclusively to the professionals.

Like in the grassroots sample, some leaders also expressed support for specialist EPAS practitioners to remove some of the discomfort about the dual role.

I think there’s a lot to be said for having a specialist in EPAS. I’d feel uncomfortable going to my regular doctor if I’d known that he had taken steps to end my mother’s life. And I think it would be hard to see them in the same light.

Dutch leaders, some of whom had doctor friends and colleagues, confirmed that they believed doctors still did not report all EPAS cases in the Netherlands due to a large amount of paperwork involved in processing EPAS reports. One Dutch
leader reported an instance in his own family where family and doctor tacitly agreed to have the death by euthanasia reported as a natural death as preferred by the family.

5.6.3 Non-autonomy: complexity and confusion

In an overview, the theme “Non-autonomy: complexity and confusion” explores the complexity and some confusion involved in considering medical killing in relation to people who have a diminished capacity to make autonomous decisions. Such people include those with intellectual disability, people with mental illness and also others such as permanently unconscious people and children. This theme adds depth to the earlier presented theme where informants held with some certainty to the moral correctness of individual rights to choose EPAS under circumstances of individually determined unbearable suffering. When it came to people with diminished capacity to make their own decisions, such as people with intellectual disability, some informants supported a right to decide on EPAS for themselves. When pressed to answer how they saw this for people who were not able to make such decisions, parents and doctors together were proposed to make such decisions for them, as a private affair. Grassroots informants often described people with intellectual disability as “children” and some informants compared EPAS decisions for such “children” with the right to choose abortion. No reservations about doctors’ roles were expressed in this context whereas they were for people with capacity to make decisions about EPAS. However, some more general concerns in comparison with killing of people with intellectual disability in Nazi Germany were also expressed. Leaders did express concerns about doctor involvement in EPAS for people who lack capacity to make their own decisions for reason of power differences between doctor and patient. Grassroots and leaders expressed confusion about this “grey area” of EPAS and diminished capacity.

When it came to people with diminished capacity to make decisions about themselves, such as in intellectual disability or mental illness, the right to EPAS was experienced as increasingly problematic. Yet the data also revealed a theme where informants thought that sometimes such people had the capacity to decide this for themselves or it was a matter of justice to allow them a right to choose.
I think everyone has that right. You cannot estimate how they experience things but if they [people with intellectual disability] ask for it then there will be a reason for it.

Very difficult, very difficult. This is where the abuse could come in. I’m aware of that. (…) But then it’s the same as people saying that two people with intellectual disability shouldn’t get married and if they do they should get sterilised and shouldn’t be allowed to reproduce. It’s supposed to be a free world out there …

Questions of choice and self-determination to decide EPAS for people with diminished capacity were a source of confusion for many informants. They were often glad that they were not in a position to have to make such decisions.

[I]t remains a very difficult question. I’m glad when I am not involved in it.

With people with psychiatric disability I think that is really difficult because you do not know when you give people a good treatment … whether the situation might not change in such a way that in the final analysis people do want to carry on again. (…) [For] people who have been in the psychiatric treadmill for many years, you can be sympathetic to their request. But who decides?

Yes well, that’s the hard one isn’t it because they really don’t – mmmmm.

Where informants thought that people with such diminished capacity may not be able to make end-of-life decisions, there was a strong theme that EPAS for people with intellectual disabilities was a matter for their parents to decide. This could be done in concert with doctors, with a suggestion that it be an act done in privacy. Parents, or sometimes a doctor, could best assess how genuine the wishes to die of someone with intellectual disability were. Many times informants, in describing the ability of people with intellectual disability to have EPAS, referred to children, not adults.

I think if the parents or the family who have been in charge of that child for all their lives regarding their welfare and that they should have the choice at the end but to coincide with the medical practitioner or whoever. To be a thing between them both.
I think if it’s their wish and I am sure these people have very good doctors … I am sure that between a doctor and themselves and a local area co-ordinator or someone … would keep an eye on them. I think if that’s their wish, that’s their wish.

In line with seeing *people* with intellectual disability as children, a few informants drew comparisons with abortion in arguing for a right of parents to decide on their children’s EPAS.

It’s the parents’ prerogative just like in abortion.

I would almost say that if a parent made the choice to let such a child come into the world then we say, OK, the child was born. We have to respect that. Then I think it is up to the parents to decide what happens.

Doctor involvement in EPAS for people with diminished capacity then drew none of those reservations, such as some lack of trust in doctors’ decision-making or their expertise, which informants had expressed in relation to competent people who wished to die by medical killing. But some informants obviously did feel some unease in proposing EPAS could be used with people with intellectual disability. They raised the Nazi extermination of people with disabilities in this context and a few informants did object to any EPAS for people with intellectual disability.

But of course people with severe, particularly intellectual disability, young people, it would be very difficult and that’s when it could also be construed that we’re going back to the Hitler regime whereby we kill all the Jews and kill all the people with intellectual disabilities and kill everybody that’s not an upstanding citizen of the world. It would be a very difficult one to address. There would have to be a lot of thought in that because obviously the parent or the partner of that person, it would have to be their decision, not the individual person’s, and that would be a difficult one.

[Y]ou certainly cannot do it for people with ID or mental illness, there’s no way you can do it for them … . If they’re given access to services and a good life, they can have as good as or better than anyone else’s can. (…). If it goes in the wrong direction it can have the effect of – I mean say it goes to the other, to extremes, that people with disabilities or mental illness or psychiatric disabilities and intellectual disabilities and other categories for people to consider severe disabilities. If they’re euthanased, I mean what a huge impact
that would have on society. It’s like very much this whole debate about gene technology.

(Leaders)

Leaders agreed that EPAS for people with diminished capacity was problematic. At the time of the interviews in the Netherlands some of the leaders’ responses were influenced by a prominent public discussion about the value (of life) of people with intellectual disabilities. This occurred as a result of comments made by a Dutch philosopher in the mainstream media. A prominent Dutch leader in the disability movement publicly lodged a legal action against this philosopher and his organisation publicly condemned the comments. There was also a public debate about EPAS for people with psychiatric illness. It is of note that no grassroots informant mentioned these public discussions.

The big discussion is now about euthanasia with those who are mentally incapable, what do you do with them? People who are in a coma, people who do not have the capacity to decide, or new-born babies for instance. We are not done with that in Holland – that is a very complex discussion.

Self-determination is problematic for people with intellectual disability. It is an extra difficult process. It is made even more difficult because of a mental dependency rather than just a physical dependency [on others]. (…) [For people with intellectual disability] autonomy is sooner a theory than practice.

[W]e do of course have experience with neighbouring countries, how quickly something can be blurred. ‘Child euthanasia’ for instance, that’s how it was called in Nazi Germany. That was also intended to address suffering and so on.

In addition unequal power relationships between doctors and people with intellectual disabilities were raised by leaders in both countries as an obstacle to good EPAS decisions for people with intellectual disability. One Australian leader raised the concept of choice itself as problematic in end of life scenarios, for individuals and in its impact on the nature of our society. Other Australian leaders reflected these concerns and pointed to the inherent difficulties people have with dealing with death and disability.
And I think when you start to give choice, it makes it even that much harder because if you don't have the choice then it's not so much of an issue, when you do have the choice then you start to question well what do you make that choice on. (…) Most people do not ever consider euthanasia, but when the choice is there and condoned by society, then that says it is OK not only to think about it, but also society values you if you do it. Systemically driven choice in this instance is more about control – to get rid of people who are seen as a burden, a threat or an economic drain to the society. In this way it can undermine the total good of society and the notions of what a civil society should be.

Yeah, it’s a grey area and it’s a struggle that I’m sure a lot of people have … [in] arguing for rights and you’re arguing for people’s self determination in many ways as an advocate but when it comes to the ultimate self determination, I just have real concerns about those things that may happen and decisions being made prematurely because legislation or policy enables it to happen.

This is a terribly difficult thing to discuss … because it raises so many emotions … people’s inability to cope with some of those things and also the whole issue of: there but for the grace of God go I. And it’s how do people deal with the difficulties of things like death and dying and disability, because I think the issue of disability is also one of those issues that people have great difficulty in coming to terms with.

Some leaders also expressed personal confusion about the question of EPAS for people with diminished capacity. An Australian describes her support for “the woman’s right to have an abortion” on the basis of disability of the unborn baby, and for EPAS if it is the person’s choice. She also states concerns about the lack of available support to people who have disabilities and about cloning:

… because it buys into what I think is at the bottom of the psyche of a lot of us which is about our human fragility and how precious that is. And often the difficulties people face changes self-image etcetera after a traumatic accident. So, … there’s a lot of things happening and I think being part of a minority group who [sic] is marginalised and oppressed and at a systemic level sometimes that’s not obvious. But I actually don’t think I’ve got consistent things about many things. (…) I mean I hold life as very valuable at the same time as well as being pro-abortion. So that’s why I say I’m confused.

Another Australian leader reflected on the dangers of implementing EPAS based on a very complex subject matter:
Look I think it’s a very complex debate and discussion and I think to say yes to it at a policy level I think is really quite dangerous. I think it’s really dangerous because I think everyone’s level of acceptance about what extent and when is it OK is very blurred, about when is it OK to happen.

5.7 Summary

Most informants had a low conceptual awareness of *euthanasia* and *physician-assisted suicide* with withdrawal and withholding of treatment often included as part of EPAS. The Dutch also included *advance directives* to have EPAS in their definitional approaches of these terms. Yet no informants had made such an advance directive for themselves. Most had little experience of people dying and knew little about palliative care. Leaders showed a somewhat greater awareness of palliative care and had somewhat more experience with dying, compared to the grassroots. Most informants supported EPAS as an individual choice, though did mostly not see EPAS as applicable to themselves, least for reason of their disability. Australian leaders were less supportive of EPAS on the basis of individual choice than their Dutch counterparts were. Support for EPAS was associated with a need for *strict safeguards*, mostly in the form of legal rules. Doctors were also part of such safeguards but also needed to be safeguarded against. Everything possible should be done to reduce one’s suffering. However, they also thought that legitimate motivations for having EPAS included an impact on others of committing suicide in lieu of legal EPAS; or any other individually defined suffering, apart from depression. Sometimes the suffering of others than the person wishing an assisted death could also be included in weighing up a decision to have EPAS. There was acknowledgement of an emotional impact on doctors who performed EPAS and there were divided understanding about whether EPAS was a natural part of a doctor’s medical role. However, on the whole doctors were seen in a naturally instrumental role in EPAS where a certain professional detachment was important to minimise emotional impacts of EPAS on the various involved parties. Many informants were confused about EPAS under conditions of a person’s incapacity to make their own decisions. Those who thought that incapable people could also have EPAS for reason of their suffering did not raise the same concerns to participating physicians in EPAS in such cases as they had raised for others.
Research question 2.: What are the life experiences and views of Dutch and Australian people with quadriplegia, and leaders in Dutch and Australian disability movements, with regard to issues of vulnerability, autonomy, dependency, independence and interdependence?

5.8 Vulnerability: physical, psychological, and social factors – threats to wellbeing.

The major theme “Vulnerability: physical, psychological, and social factors – threats to wellbeing” presents the dominant, perceived threats to informants’ physical, psychological and social wellbeing. These threats came from the informants’ own health problems, associated with quadriplegia; from ways in which the type and quality of care affected them; from public attitudes towards them as people with disabilities; as well as from declining social trends. In the face of such vulnerability, informants felt a sense of invulnerability while they also knew themselves to be vulnerable to the above factors.

5.8.1 Vulnerability and physical health

Daily discomfort, due to their disability, was part of the lives of informants. Severe health conditions were, or had been, experienced by most informants from time to time. Most informants did not rate these conditions as a problem but clearly they had significant impacts on their physical integrity with significant consequences such as long-term hospitalisation. Indeed, as mentioned earlier, a Dutch informant, aged 34, died from his multiple health problems during the course of this research. For the few informants who experienced their lives as unsatisfactory and who would rather not be alive, their health conditions were deeply felt. Those few informants who experienced no health problems at all counted themselves lucky.

Health issues were an important feature of life with disability for most informants, who experienced significant health problems. They experienced periods of wellness and periods of sometimes-serious illness, arising from their disability but most did not indicate that these were distressing them.

Their health conditions included skin breakdown resulting in pressure sores (decubitus) and persistent underlying fistulas; urinary tract infections; kidney problems; blood poisoning; pneumonia; broken limbs; blood clots; and multi-
resistant bacterial infections. Some of these conditions at times caused lengthy hospitalisations, from three months to one year. One informant had had twenty hip operations to remove excess bone growth, following pressure sore problems, and needed more. He experienced constant pain from this hip condition but said that he overcame this by “keeping busy”. About this health problem he said: “Yes I have experienced a lot. Things have not been boring”. He looked forward to meeting new people on his next admission.

Problems were often recurrent. They were minimised with great personal vigilance over skin care and other matters. When something went wrong, problems could easily escalate. An example was a man who had previously spent 12 months in hospital for treatment of pressure sores, and who lived by himself.

I had a period of time in bed here. Then I had to go into hospital and have a skin flap done. But then that healed and I came home Christmas this year and I stayed in bed over Christmas just to soothe things over and then I started getting up two hours, four hours and so on. But my cushion had a ridge going along it and it went right across the middle of the flap and so we got another pressure sore. But they treated it here, I didn’t have to go into hospital so I spent from end February, beginning of March, in bed.

A few informants only, those who would rather have EPAS than live with their disability, told of the presence of constant pain, tiredness, the discomfort of “constantly holding yourself up”, and of strong abdominal spasm in their daily lives. However, in contrast with many other informants, they experienced no severe health problems.

I’ve got no feeling from there down and yet my stomach’s always killing me, so I’m not sure if it’s bladder, bowel, it’s just always sore. So yeah, and shoulders and [fades]. Not having the balance is really difficult. Even though you’ve got no feeling it’s – I don’t know, it’s hard for people to understand I suppose that you’re uncomfortable without actually feeling pain in all parts of your body. But then the bit you can feel – my neck’s always sore, I’ve always got a headache and (fades). Just trying to hold yourself up, it’s not comfortable. So yeah, I don’t have any days when I’m comfortable. There’s not a day that goes without that, so again that’s one of the reasons that I would have euthanasia.
The few informants who had no health problems to speak of counted themselves fortunate as they were aware indeed of the health risks associated with quadriplegia: “I do not have any health problems and I am fortunate in that”.

5.8.2 Vulnerability arising from treatment and care

Long stays in hospital could result in iatrogenic conditions, some severe. I found contrasting themes of, on the one hand, enjoying stays in hospital during initial acute care and in rehabilitation centres, and bad experiences in these settings on the other. Those who did not ‘progress’ well in rehabilitation felt abandoned and felt that their emotional problems were ignored. Negative attitudes from some staff and professionals devalued and disempowered some informants.

Entering hospital for any conditions could bring its own risks of iatrogenic complications. Frequent hospitalisation for long periods was a common experience. Several informants related such experiences as development of pressure sores in hospital (which required long stays in bed). Another acquired unnecessary deformation of his hip after non-diagnosis of multiple fractures at the time of accident. Yet another had been operated on without anaesthetic under a false assumption that the patient had no sensation in his buttocks. Another informant spent considerable extra time in hospital being treated with highly potent intravenously delivered antibiotics, which carries further risks to health. He did not realise this until later when he discovered by chance that he had been treated for a highly multi-resistant pathogenic bacterial infection and its associated risks.

I accidentally read in Times Magazine that the bacterium was in the top five of most resistant bugs. … I had a lot of poison in my body [to fight the infection]. If you read the side effects – you could go deaf.

There are contrasting themes of having been well treated during acute care in hospitals and in rehabilitation on a physical level while not having one’s emotional needs met. Rehabilitation typically took between eight months and two years and was described as a hard but rewarding time for most informants. The Dutch sample in particular showed a theme of finding times in hospital and rehabilitation as very good: “[my] time in intensive care was one of the best times in my life”. Staff were “very empathetic and friendly”. And rehabilitation could be fun:
I had a lot of fun there, yes. That is strange isn’t it. … we do have a reunion from time to time and we still all come to the conclusion – what fun we had. And certainly with the staff, I can tell you that.

However, negative staff attitudes had also been experienced, described by an informant as “flippant” and “derogatory” towards him and other patients.

You’ve got a definite power structure there where the patients are very much at the bottom of the ladder. … that’s a very bad way to start off. … at the time you are going through a huge amount of trauma and shock and thinking this is the worst thing that ever happened to me and then you have staff that are saying virtually the same thing, that … you are no longer a powerful person, … or that you are somehow lower than me …

When people were struggling to cope or their own high level of injury incapacitated them to a relatively greater degree compared to others going through rehabilitation, they felt ignored and abandoned.

… then you saw that in the rehabilitation centre I could not progress further [and] I had the feeling they dumped me. … Like I say, you sit in a wheelchair and no shred of aftercare.

In hindsight I think they should have supported me better. And I think that [is] because of my own behaviour, that I think quickly, that I can nut things out, and I give that impression. But that was not the case at all.

For some the actions of (rehabilitation) hospital staff and professionals confirmed their loss of control over life by virtue of their physical disability. One female informant found out later that the hospital social worker had advised her husband to abandon her.

[T]he marriage would not survive and he wouldn’t survive and his best bet was to put me in the X [nursing home] and go home and carry on with his life with the two little children.

(Leaders)

Leaders in both countries told of rehabilitation periods getting shorter due to changes in health care policy and contended that personal issues were often inadequately addressed. They confirmed the neglect of personal issues within these institutional settings.
You have to go home within the shortest possible period of time. In one sense that is positive of course. But you see that issues such as sexuality and relationships are totally forgotten.

5.8.3 Public attitudes

Informants experienced good as well as bad attitudes from doctors and talked about their experiences of mostly negative public attitudes.

They noticed different attitudes being displayed towards them since they acquired a disability. Some experienced a detached attitude from doctors, lacking attention to the emotional side of their nature and a lack of “follow-up”.

I try very hard not to go to the doctor at X [a rehabilitation centre] because I do feel as the years have gone on that once they ... see you’re stable, and organised and on your bike, there’s this air of nonchalance. If you go there ... there’s this off-handish ‘take a pill, you’ll be fine or its just in your imagination’. ... they do not pass all the information on to your own general doctor outside. ... so I give up because all my own doctor can do is listen to what I have to tell him…. In that area I am disappointed.

An informant who experienced his life as unsatisfactory life reported that his rehabilitation doctor, whom he saw for yearly check-ups, did not listen to his problems. He felt that he was not being treated as a human being but as a number: “every now and then you think that they think, there’s number such and such”. Doctors could be ignorant of the needs of someone with quadriplegia.

My regular doctor knows nothing about spinal injury. If you don’t make very clear to him what you feel and why, and how that’s related to your spinal injury, then he does not know what’s wrong with you.

Doctors were not always seen as good communicators, which was experienced as frustrating.

Quite often you don’t get the chance to ask the questions that you want… you have to more or less just about grab him by the scruff of the neck and hold him in place to ask him anything.

By contrast, some others experienced good attitudes and friendships from doctors. Some Dutch informants in particular saw their rehabilitation doctor in a positive light.
I know him personally rather well, and his wife too. Very nice guy. I have been sailing with him once.

There were certain public attitudes that annoyed many informants, particularly those where they were avoided, stared at as an oddity, as “you are not like us” or seen as mentally deficient. Public assumptions that any companion of theirs was a carer were experienced as patronising. Often the informants would take action themselves when such situations occurred.

… I know what it’s like to be stared at because someone’s blowing my nose or whatever. I know what it’s like when people look the other way quick in case you go up to them and dribble … and they don’t want to be caught standing next to you.

… I attended the reception of a wedding and that the waiter came past and asked my sister who sat next to me. And he asked her ‘did I want coffee?’. My sister said ‘ask him!’. They are things that hurt. Then you think, have I really become such an alien appearance?

5.8.4 Bureaucracy

Informants experienced some obstacles to the flexible care arrangements, accessible housing and aids and appliances that they needed to function well in their daily lives. Dutch leaders in particular described bureaucratic rules as standing in the way of flexible care. Long waiting lists for access to personal care funds existed. More money was now being applied to reduce waiting lists but this did not address the problem of a dearth of people willing to work in care roles. People with disabilities were, in both countries, still seen as ‘care objects’ and there was some way to go yet towards their inclusion in community.

In order to reduce their vulnerability and maximise their wellbeing it is very important that dependent people with disabilities have reliable and flexible support.

In both countries most participants received funds to employ their own carers on personal care budgets, where they need them. They most often employed a number of carers for different tasks and times. Most were directly involved in recruiting and managing these employees. Others used community care organisations and one, in the Netherlands, used “FOKUS”, a service model that provides a package of a home in the community with attached personal care. Many and varied tasks were
carried out by such personal assistants for those with the greatest dependence on others.

[They] Dress me, take me to appointments … basically anything that I need doing. Showering me, bowel treatment, sometimes cooking, driving me.

On the whole most were very satisfied with these arrangements where they had them.

I am very grateful for the arrangement… But I do feel if it was all gone, I wouldn’t be very happy and I know if I had to stay in X [an institution] or somewhere like that, I think I would just give up.

It’s a bit more of a personal approach. I think that works really well and it has worked really well and there’s no reason why it won’t keep working well.

This satisfaction showed for instance in the long tenure of many assistants who had employed by Australian informants under this scheme. The same carers had been employed for periods of five to eight years and one for eleven years. The same could not be demonstrated for Dutch informants, as the personal care budget had been a part of Australian policy for several decades, much longer than the only recently introduced Dutch policy, which at the time of the interviews in 2000 had been in place for some two years. Australians showed this long-term stability in retaining their carers. On the whole most informants were satisfied with their particular personal care arrangements, with individual care budgets giving them the greatest flexibility as compared to assistance from service organisations.

Some informants were not satisfied with their organised care and support. Their complaints mostly related to arrangements where care came from an agency, without a say in carer selection and less influence on times when carers come in. Some such agencies for example did not allow their personnel to accompany clients on holidays as assistants and would not always be allowed to attend to home help tasks other than personal care.

A few Australians had received personal accident compensation payments, enabling them to purchase their care directly. This worked well for one but not for another. The latter, with a high level of quadriplegia, felt trapped in a complicated
life, dominated by organising his many assistants at set times and managing a high
carer turn-over on his highly taxed funds which did not allow him the 24-hour care
he felt he needed. He also found it difficult to find carers and “understood” that few
people were willing to care for people like him. He was constantly engaged in
finding carers to fill vacated timeslots because of a carer’s absence for any reason or
finding new employees for those who left.

With carers and organising things, I find it a very complicated life
whereas before my most difficult decision was what sort of day it was.
I’ve got someone that comes in between one and two for an hour… I
can only afford these part-timers. … they’re hard to find. …I also
understand that there are going to be very few people out there that
want to look after you. Unless you’ve got loads of money and can pay
people it’s more difficult.

Dutch informants experienced frustration due to bureaucratic approaches
from those authorities involved in modifying access to their homes, and in processing
applications for accessible cars, aids and equipment. The transfer from rehabilitation
to an accessible home or being on a waiting list for a personal budget could take up
to two years.

But there’s a lot of procedure to go through. Because you need a long
breath to get it all done. But once you know the routes to take … You
say, I want a bed, or I want a hoist or a wheelchair. Or I want to adapt
my home. And that they then take care of that. No, they’re all
different doors to knock on.

(Leaders)

Dutch leaders confirmed the impacts of bureaucracy on people’s lives. They
spoke of government-provided permanent loan cars with tabs kept on the number of
kilometres driven, a bureaucratic organisation of personal care budgets and
accessible transport schemes, and multiple service points for different needs.
Australian leaders did not raise bureaucracy as a pervasive obstacle.

Dutch leaders welcomed the move towards individual care budgets, or
“Persoons Gebonden Budgets” (PGB’s). However, they pointed to obstacles to this
concept working well such as excessive bureaucratic rules about what paid carers
could or could not do and a declining availability of people wanting to work as
carers. At the same time *mantelzorgers*, that is family and friends, were increasingly less willing to take on long-term care roles.

… home care, that is tied to all sorts of rules so your canary is not allowed to be fed by them and the cat cannot be let out. With a PGB (individual assistance budget) you can determine that and I think that is important.

You can buy your own support. But it does have to exist [to be bought]. And when giving that profession a bad image is undermining care then perhaps young people do no longer wish to work in health care.

Dutch and Australian government policy towards people with disabilities was “care-focussed”, turning people into “care-objects: “at a policy level care is still very central. That is of course connected to the fact that the Netherlands knows very big service organisations”. Dutch Government is cutting back on social benefits and this is having an impact on people with disabilities.

A few years ago you could still get help like cooking, taking the dog for a walk, looking after children during illness. That is now all past. You have to arrange all that yourself now as a citizen and pay for it if you do need it.

Waiting lists for home help sometimes last more than one year while waiting lists for an operation or treatment in hospitals are extremely long.

People with disabilities are still mainly seen as ‘care objects’. Most people think that someone with a disability receives a social benefit. I think that marks our position.

They also saw an image of people with disabilities as being framed within in a “welfare context” and government programs being designed within a welfare model.

The general community, whoever that is, often puts people with disabilities in a welfare model. I think they’ve [government programs] been designed to keep people with disabilities in a welfare model.
5.8.5 Vulnerability within a context of social decline

Informants held apparently contrasting views of social developments. On the one hand they held a negative view of current society and a view of its further decline. They described society as one where people were increasingly estranged from each other and were increasingly individualistic and materialistic. On the other hand they also saw an upward trend in their societies’ support towards people with disabilities. This was thought to be so, even as, in the Netherlands, informants reported a lack of acceptance of people with disabilities in their neighbourhoods. Some Dutch leaders also perceived a reduced tolerance of parents choosing to have child with a disability, because of the financial cost to society. Euthanasia was thought to be more easily available in the future in a context of a greater public tolerance of the idea of EPAS, a declining health care sector, changing values, greater profit motives; greater costs of care; and population pressures. They did not think that their projected direction of society would change. Informants did not connect the wider societal issues with the desirability or otherwise of EPAS. Leaders echoed these themes but were more cautious about the effects of EPAS on people (with disabilities) within the negative society that they described.

5.8.5.1 Decline in trust

In both countries’ samples, there is a negative view of current society and a view of its further decline. Dutch informants in particular remember times where people were closer than they are now, particularly where they used to live in the country and now live in a city.

Everyone just walked into each other’s homes. With us at home too. The door was always open. Here I don’t know some of my neighbours. And I have already lived here for five years.

Current society was experienced as one in which relationships between people were more distant.

In this street I do not have a closeness with anyone. I know who lives here, but that's where it stops. If I really had a need, I could ask the neighbours. But like it used to be in streets with neighbourly contact, I think that is a lot less these days.
I see it in my work. We think it is very bad to have so many people in an institution. They should all go and live in smaller accommodation. It sounds very wonderful of course, but then you get six people with intellectual disability living in one house who are allowed to care for themselves and can decide all sorts of things. But they will land in a neighbourhood that does not accept them because the neighbours do not come and visit. Myself – I don't know who lives here either. It just doesn't work and is getting worse. People are getting lonelier. At least you will if you're not able to make or maintain contacts with people yourself.

Relationships between people are less close because life is faster, thereby excluding people with disabilities; because life is increasingly violent and people are ‘harder’ and more individualistic and materialistic.

It’s very busy, people don’t have much time to relate to anybody. I have lived what I consider two lives. One in the busy world and one in the not busy world and people don’t have time for people. Returning to the disability side of it, a lot of people still don’t have time for a lot of people who are disabled in any shape or form, not necessarily spinal cord.

European society, and I think in America and in most big cities in the world, is rock-hard. Sometimes it gets so busy. The hospital, it’s just like conveyor belt work, you know how it goes.

Violence was seen as on a rise, in their own countries and globally.

Well, when you look at recent times, it seems as if people are getting angrier with each other. I think it will swing the other way again one day. (…) If it keeps going this way, it will get worse … (…) Well, I think that everyone will shield themselves from one another, that you will no longer know your neighbour.

5.8.5.2 Increasing self-centredness

There was a view that people were increasingly becoming self-centred and were more interested in their own wellbeing than of those immediately around them.

People are becoming more assertive and demand more. I think that if you look ten years ahead people’s autonomy will go further. (…). I think society will become more and more individualistic. I don’t have a very optimistic picture of that. I think people are hardening. It is more about each for themselves and in the end I think it will get worse.
I think the world is going to become very cynical and develop a very hard shell to protect themselves or people, you know except for their close family, and eventually we’re going to basically be living in a situation where – basically it’s going to be every man for himself.

Life in the future was also seen as one which is less compassionate and where life is valued less.

You do hear that often, people don’t care about each other. (…). In the future I think human life will be worth less.

I don’t see society as getting more compassionate. I think with growing urbanisation you’re getting more problems. People probably get less caring in many ways because they don’t have other people around them so [fades].

5.8.5.3 Decline and technology

Genetic screening and a social pressure to abort babies with certain disabilities is a concern, mostly expressed by Dutch informants. These were seen as potential risks to the social status of people with disabilities.

Gene technology is removing birth defects and that before they come about, whereas in the other one you’re talking about removing quite often with euthanasia and removing people with disabilities, easing their suffering by putting them to sleep or whatever. The other one is getting rid of people with disabilities in the womb. And so I think you could be, in both cases, you could be setting up very extreme sort of scenarios where you [fades]. I mean I don’t know what you call it, getting rid of suffering, but certainly getting rid of in many ways diversity too in society.

I get the feeling that sometimes, in our current society, in its rules and so forth, now you are still allowed to have a disability but when my wife is pregnant, I have the feeling it’s going towards this, then she has to take a test. Amniocentesis or a lumbar puncture. Spina bifida, … you can let it be born but the costs are for you. That’s the scenario I see in front of me. And everyone says now, no, that’s not true, that’s not right. But I think you can see it shift like, we first make it very compassionate, about suffering unbearably.
5.8.5.4 Worsening negative trends

Not only did informants see the current world in a generally negative light but they saw it as getting worse in the future.

Unfortunately I think it is going to get worse before it gets better. Just looking at the youth of today and the attitudes, the violence level towards other people and themselves. They don’t seem to have the same respect for other people or themselves really. They don’t see a future.

People will not have time anymore to think about quality of life. It is all about busy, busy, busy, busy. I think that people will think little about life. I think that will get worse.

Informants did not see that the societal trends that they described would change for the better. An Australian summed up the feelings about a negative state of society by referring this situation to how she used to be before her accident as “arrogant, selfish, bombastic, what’s in it for me”. She had earlier described her personal transformation to a kinder, more patient person:

Q: How do you see society as developing? A: Developing? Well, the society is a mirror of what I used to be, and you don’t develop when you are like that. Q: So, you’re saying we cannot change the way society is? A: No, unfortunately. It’s not possible. It’s like everything else. I suppose you’d call it evolution. We are evolving into these kinds of people because of the surroundings that we create for us to live in. I feel that there are other things that we can look at and deal with. But I feel that also comes with maturity. As people mature they go through a few of life’s beatings and life’s joys they can start to see things differently. But I think as a younger person and as a young parent you’re just too busy wrapped up and locked into what society expects us to do …

5.8.5.5 Improving conditions for people with disabilities

Informants saw improving scenarios for the societal support of people with disabilities, despite the other negative trends, but when prompted to qualify the improvements they were expressed in terms of improved physical access only. This apparent contradiction occurred within individual informants, rather than represent contrasting themes from different informants.
I think that people with quadriplegia … will be quite well accepted. … It is now a standard that everything that’s built is made to be accessible. Look at big shopping centres. We can get in, fantastic. Almost everywhere you have disabled parking spots. We can park for free everywhere. Those sorts of things. But that is only in the last ten years or so.

I think you can wait 100 years but they will never accept disability completely. But I do think it will get better. Better access and that sort of thing.

Informants appeared to apply some wishful thinking to their improved social acceptance in the simultaneous knowledge of declining social trends. Below is an example of the two views within individual informants. This informant for example simultaneously projected a future where people interact less and one where people with disability are included in society:

There’s not a lot of interaction with your immediate neighbours although I always say hi if I see them, always wave … I think in ten or 20 years time if it keeps on going I don’t think people will know who their next door neighbour is, because there seems to be less and less interaction.

And:

I think the interaction will be so much better. I think being accepted into the community is happening more and more and more no, becoming more the norm and I think it will be the norm in ten years time. And because kids are going to school with people with disabilities, all sorts of disabilities, I think that’s a great move to have that interaction and then the kids don’t see it as us and them.

5.8.5.6 Tolerance and use of EPAS

EPAS was thought to become more easily available in the future. This projected trend was often described in association with increased ‘tolerance’ to other issues, such as drugs and abortion, including euthanasia. The first quote is from an Australian who saw society becoming less compassionate, the second from a Dutchman who sees life getting faster and more reliant on technology in fixing problems.
I think in the long run it [euthanasia] probably will be legalised but it’s like the women’s struggle over abortion. (…) But I think generally as people get more educated that they become more supportive. They’ll be more tolerant. I think if it was legalised it’s probably because people have become more tolerant as has happened in Holland.

I think that it will just get easier because people are getting more easy going. Q: How do you mean? A: [They] tolerate more. So, for instance drug taking, who moans about it? Your neighbour could have a cannabis garden … Who cares? … So humanity is getting more easy going. And I think in that sense too [EPAS].

5.8.5.7 Declining social trends in relation to EPAS

Only some informants thought that pressures in health care and issues of profits, as well as overpopulation were factors leading to EPAS becoming more easily available.

Perhaps they can reduce the waiting lists in nursing homes, when they ‘shoot up’ a few more. I don’t approve of it but that’s what’s coming.

I feel that euthanasia could become part of an industry, a profit-making industry that’s lost the plot in regard to health care.

Money is very important in this [Dutch] society. Hospitals are just like a business, so it will be easier [obtaining EPAS], I’m convinced. (…) they will sooner look at cost-benefit than look at who it is. Who is the person, is there still a possibility – how they look at the life of a person.

But most informants did not draw any conclusions from their prediction of a generally more available EPAS in the future and their negative view of current and future society. They drew on, or referred to, the use of strict guidelines to minimise abuse in EPAS and the Dutch also a safeguard of ongoing public debate. EPAS was seen as peripheral to the broader social trends and there was a disbelief in any eventual misuse of any legal EPAS.

I think it’s not a mainstream issue. Really, it’s impacting on very few people. Very few people, I think, actually choose it.
I don’t think they’re connected … I mean economic rationalism is very much the global picture, whereas euthanasia’s a small part.

The possibility of a slippery slope exists. I am not afraid of that as long as people can reasonably discuss things. As well, the practice of euthanasia and its rules have to be well tied down and has to be transparent so it’s not possible to cheat. There have to be good rules to legally assess euthanasia afterwards. (…). [In] a society where the value of people is determined by wealth and health, there would be no place for ‘damaged people’ – people with disabilities and older people – in short people that cost extra money, … the solidarity between people would disappear. It would really be each for himself. I don’t believe that that will ever be possible. It would mean the end of the human race.

(Leaders)

Leaders in both countries shared this negative view of their societies. They described loss of values and increases in individualism and materialism and a growing importance of financial costs of suffering, affecting people with disabilities also.

Modern values highlight the cult of the individual with Nike’s “Just do it” epitomising the way society is heading, placing less value on sharing, co-operating and doing things together.

For the last 50 years or so Australia has become a country that places an increasing value on individual rights and I’m a bit cautious about supporting individual rights above social rights.

People are getting older. That means that that period where you no longer undertake work is longer. Then you are a liability. You see now too that there are a number of people who have the feeling of, towards their children too, that they are a burden for them. So the chance that those boundaries will shift is relatively great.

Developments in genetic screening, resulting in abortion and the quest to clone people worried leaders also.

I am afraid that now with the gene research they can predict quality of people, that it would become difficult to lead a good life with serious disabilities in the community. Because they are getting fixed on perfect bodies, functioning according to a norm and produce according to their norms. Not my norms. I think it will all become
more difficult because you have to justify yourself [with a disability] more.

The belief in improving circumstances for people with disabilities was not as great as in the grassroots sample. Yet some leaders also had a sense of an improving climate for people with disabilities, expressed in better access to opportunities for personal choice and economic status.

And I think that society will be a great deal more accessible, through which people will be able to meet each other more readily, that you don’t have the apartheid that there is now. That you have a society that everyone can use where people can make decisions about having their own aids and equipment, that one looks more to the needs of the person rather than the profit. And I hope that in 15 years time people with a disability will have an economic standing that they do not have now. Now they are not really players.

Other leaders were more cautious about the future for people with disabilities and referred to developments in genetics, governments cutting back on benefits and making tighter rules about these.

I think through we’re going through a high reactionary era. I think if I wasn’t an optimist I’d probably be a bit concerned – on one hand we clone sheep and think that that’s OK and say that it’s got nothing to do with human beings, you can relax about that – when clearly those issues do have a human impact. We’re living in an era where we’ve got governments who are wanting to put more and more systems into place, for what they call public accountability, where it feels a bit more to me like they’re wanting everybody to toe the line and they think that line is just one line. (...) I think we’ve got a long way to go in the valuing of difference because we’re setting up systems which assume we’re all the same and we’re going to react to situations all the same.

I think part of the acceptance of disability in Western society … is … that we have the wealth to accommodate people who are not productive. But if we go back to that situation where it’s expedient to get rid of people who acquired some disability then I think we run the real risk of society reverting to having that negative stereotype … for all disabilities.

Like the grassroots sample, most leaders agreed that EPAS will eventually become more freely available.
I do not think it will get easier [to obtain EPAS]. I do think that people will want to have it sooner. Because the boundaries of what people find acceptable are shifting. Where people are 50 years old, they’re written off now.

I’ve got no doubt that it will continue. Whether it’ll get up, I guess I take some solace from the length of time Parliaments in Australia have tried to legislate to legalise prostitution.

Like the grassroots sample, most leaders did not make a direct connection between the nature of the declining society that they described and the desirability of legal euthanasia. However they expressed some caution about EPAS within our turbulent society.

The Netherlands has been the first with euthanasia now for quite some time. I do not hope that human norms and values will go backwards even faster. I do think that something like this [EPAS] has to be done very carefully. People have the right to live. People also have the right to die in a humane and dignified way.

I’m not a right to lifer. I believe strongly in a woman’s right to abortion and at the same time I believe that all this stuff around cloning really worries me because it buys into what I think is at the bottom of the psyche of a lot of us which is about our human fragility and about how precious that is, and often the difficulties people face changes self image etcetera after a traumatic accident. So, I think there’s a lot of things happening and I think being part of a minority group that is marginalised and oppressed and at a systemic level, sometimes that’s not obvious. But I actually don’t think that I’ve got consistent views about many things.

Only some Australian leaders made a direct negative connection between the state of society and impacts on people with disability from legal EPAS:

Down the track euthanasia might not be so much an issue of individual rights as a social necessity. It’s the most effective way for society to manage the numbers of people with disability and the numbers of frail aged. Q: So is that the way you see society going? A: No, I don’t but I guess it’s a grim possibility that it may be. How is society going to cope with those changes [growing numbers of people with disabilities and aged people]?

Once you allow the individual to make that decision [EPAS] then it has systemic ramifications. (…). It’s often by devolving those societal
things to the level of the individual that we can create in fact systemic
tings that undermine the total good of society.

Leaders found it difficult to say whether a change from the current negative
society that they described is possible:

In the last four decades we’ve had really major swings in the sorts of
ings that people have believed were important. I think at the
moment we’re moving towards talking about community membership
but when I say ‘we’, I mean, as a society we are not good at doing that
stuff.

I think we’ve got a long way to go in the valuing of difference
because we’re setting up systems which assume we’re all the same …
People say if people need assistance then they can have it – but you
know it’s just another system set up to separate people.

5.8.5.8 The disability movement and EPAS.

In both countries disability movements were hardly at all involved in the
public debate about EPAS. Leaders believed it to be an important issue to be aware
of and gave a number of reasons why the disability movement has not been involved.
This theme arose exclusively from within the leaders sample. Grassroots informants
did not discuss the profile of the disability movement in EPAS issues and were not
asked about it. This theme is included for its direct relevance to the significance of
this study, that is, in part, a lack of a disability voice as participant in the wider EPAS
debate and reasons for this.

Leaders in both countries saw little involvement by the disability movement
in the EPAS debate, as is also the case for other bioethical issues.

You saw this with the debate on genetics, that everyone was talking
about it. Ethicists, medical people, politicians but not people with a
disability. That is rather strange. Then you are never on top of events.
And you see that with the euthanasia debate as well.

Well, I’m disillusioned that the sector hasn’t taken it up as an issue.
Last year I called a couple of meetings … I circulated to all the local
disability groups … I invited about 30 people … and the first one had
two people turn up so we called it again and the second one had five
people turn up but four of these people were from the same agency.
Because of potential negative impacts of the EPAS debate and practice on people with disabilities, leaders thought that the disability movement ought to keep an eye on the issue. It is also thought important to contribute disability perspectives to the issue of EPAS.

I think it’s really important that we maintain our involvement in the debate and the discussion. I just think there are dangers there for people with disabilities with this policy and we have to be very mindful that decisions and policies are not going to be legislated that will mean that people will have their lives ended prematurely because of a value base of the time or of some of the decision makers of that time.

We are forced to think about it. Others can put the problem away as being not close to them etcetera and then you do look at these things in a different way.

In both countries three reasons for non-involvement by disability movements were expressed. Firstly, diverse views within the membership of disability groups made it difficult to speak with one voice. Secondly, EPAS was not seen as a practical disability issue or a priority and as not easy to discuss as an existential issue. Thirdly, there was a fear of provoking a debate around questioning the existence of people with disability.

Our membership is very diverse. There are many and different Christian ways of thinking or from humanitarianism … there are people who are very much for euthanasia but also people who are very much against it. (…) It is difficult to represent one voice in this debate, informed as it is by individual experiences and beliefs.

I think it’s a bit like the other things I was talking about – the issues of unemployment [are] what are concerning people. Housing, all those very basic to people’s survival issues are dealt with. Not the other issues that I would see as equally important which is about the relationships, which is about choice and people’s right to make those sorts of decisions for themselves.

You know, people sort of think, well you know we’re more concerned about life rather than death. (…). Families won’t touch this sort of stuff with a hundred foot pole. That’s been my experience because of the difficulties particularly around some of the genetic stuff.
I don’t think this is a topic, how shall I say this, which they can talk about as practically as the struggle for the personal budget. Like vulnerability. I don’t know whether you have ever had a discussion about it, vulnerability and dependency. But with us [in the Netherlands] it is purely in political terms rather than in existential terms. Not about what that means for somebody because before you know it you’re a wimp.

5.8.5 Felt vulnerability

“Felt vulnerability” is a theme that describes the personal experience of vulnerability. Informants felt invulnerable at the same time as recognising that their disability, health issues in particular, made them more vulnerable. Feelings of vulnerability arose from dependence on equipment and on others for essential care and assistance with many aspects of daily life. These feelings were diminished with availability of good and reliable assistance. A feeling of vulnerability was further reduced by focussing on living in the moment rather than on the vulnerability.

Feelings of invulnerability and resilience arose from a feeling of having overcome major challenges in their life with disability. They also appear connected with an innate sense of invulnerability of a part of themselves that is beyond their intellectual reasoning. Leaders echoed the issue of good care and assistance and added other factors which could contribute to vulnerability such as limited access to transport and buildings and being financially less well off. In their view, negative images of people with disabilities, arising from materialistic dominant values in society, further added to vulnerability of people with disabilities.

There was a constant awareness of depending on a number of arrangements with others to be able to function in daily life, including for toiletting, dressing and undressing, and preparing and assisting with food and drink. This caused a feeling of vulnerability. For example, an informant who lived alone, and who needed assistance at home and at work, confirmed this feeling.

I think you are very vulnerable. Because if all the equipment and help around you falls apart – and of course it doesn’t all collapse at the same time. But you do realise. If all that were not there.

Another with complex care arrangements and multiple carers felt vulnerable in case a carer was suddenly unavailable.
If they trip over and break their leg, God forbid, you’re stuck, so you’ve got to have at least three for every area of your caring – and it’s not easy to find people.

A feeling of vulnerability was for some also present in relation to potential embarrassment in managing continence from day to day. This could result in a frequent checking that continence aids and appliances were working well. For instance, an informant with an implanted electronic bladder stimulator, giving her increased bladder control, had purchased a spare control device in case she lost the original. Where there was good and reliable care with regard to basic needs such as toileting, dependence on others to ensure against such embarrassment involved a lesser degree of a felt vulnerability.

I still get embarrassed if I wet myself or if I mess myself but touch wood, I haven’t done that for years, because the carers do their job properly and unless the equipment fails that’s the only time I get wet or as I say I haven’t messed myself well since I left X [institution] anyway.

In contrast to a felt vulnerability there was also an expressed feeling of invulnerability.

Well, I don’t feel it like that [vulnerability] but it is a fact.

That wheelchair of mine. I sit in it but really it does not exist. Your intellect knows you are handicapped but in a way I am not.

This feeling of invulnerability was related to a sense of triumph of having survived and having lived through the initial spinal cord injury and the treatment phases and having been able to live successfully with the experience of a significant level of disability: “I feel more invulnerable I think, because you have survived this thing”.

I think that on the one hand it makes you more invulnerable. If something happens to you, you can put that in a certain context. But I can imagine that if you break your arm, that that can be a nuisance for someone. While if I broke mine, well that would also be a nuisance but I would think, so what? So on the one hand it makes you more resilient.
Leaders confirmed the inevitable over-presence of vulnerability. They spoke of people with disabilities being vulnerable because of a number of factors, beyond those that the grassroots sample recognises as contributing to their vulnerability. These were a lack of good care and assistance, transport, limited physical accessibility and financially being less well off.

I think that no matter who you are, that if you end up in a situation where you're devalued, that society isn't good at dealing with that and unless you have people constantly needling the consciousness of society then things don't change. But my sense is it'll never get perfect. You know we've been better than in certain times in history, perhaps accepting people of different races or people of different sexual persuasions or people of with different disabilities. But I think there will always be a need for vigilance around people who are not seen to be as valued as other people in a particular society.

People with disabilities are also second rate citizens. They get excluded from many things. I cannot spontaneously say, shall we go to Amsterdam? Cannot be done because giving the train 24 hours notice is impractical. Money for a taxi is unaffordable. You don’t have equal opportunities in education and in work.

Dutch leaders in particular perceived a negative public image of people with disabilities as dependent people. People with intellectual disability in particular are being excluded and teased in their neighbourhoods as “one doesn’t know how to deal with them”.

People with disabilities are often teased in society. I live in a neighbourhood where there is a lot of integration now from big institutions for people with intellectual disability, for people with visual disabilities. And when I see how in that neighbourhood people are being teased, that is really terrible.

5.9 A good, difficult life: responses to threats to wellbeing

The theme “good, difficult life: responses to threats to wellbeing” presents the responses of informants to the threats to their wellbeing. These threats are represented within the above major theme on vulnerability. This section describes the informants’ experience of life with disability which, in the main, was experienced as good while also as a difficult life. It presents ways in which informants dealt with
these. Their responses fall within internal psycho-dynamic and external social responses which show some power to meet their own needs for inner and social wellbeing and also meet their physical requirements.

There was, however, a small group of informants whose experience of life with disability was unhappy. They often reported perceptions that were different from that of the main sample. The significance of this phenomenon and how their experiences formed any coherent picture in contrast to the main findings is discussed in Chapter Six.

5.9.1 Choosing to embrace the disability experience

Most informants saw their lives as difficult but also as worthwhile. They experienced a big difference between life before and after their injury and reported having “two lives”. Irritations, frustrations and disadvantages were part of their daily life but they had a level of acceptance of their disability as a fait accompli. This acceptance assisted them to live a rewarding life, aided by good care and support. Many informants made a conscious personal choice in accepting the fact of disability in their lives. In contrast, some informants, who were among the few who preferred death to living with their disability, did not experience worthwhile lives. They experienced their lives as mere survival. For them the losses of independence and other characteristics of their first life were constantly felt.

Many informants reported having two lives, with noticeable differences between each.

I’ve got two lives, one pre accident and then the new one really. I’ve just started again.

I just did two different things. You know it’s gone. The past is completely different.

The second life was a life that they mostly saw as good, albeit one full of difficulties, which affected them on a regular basis.

I experience my life as difficult with many disadvantages. In spite of that I still find life worthwhile while … and can see the sun shine.
So while you lose on one you pick up on another, I guess at different times in your life everybody has to re-assess the positives and negatives and what they are and I see mine as a positive. I see myself as a lucky person in some respects.

Some experienced their present lives as very good or even better than they were prior to having quadriplegia.

As I said before, it’s better. It just gives you the opportunity to explore a whole new realm. Also, certainly extreme frustration and annoyance and that but it’s still very much a wonderful life.

Oh I think it’s good. I mean I really enjoy my life … I really enjoy what I do, I really enjoy the life.

There was a level of acceptance of their life, which needs to incorporate the fact of having disability. Informants perceived a need to make the best of things:

I try to be accepted in this world. I am X with a disability and not X without a disability.

Well, sometimes it’s the pits. It’s, um…, if you had your choice you wouldn’t want it this way. That covers it I think: it’s the pits. You know, if you could have things differently you would but it’s what you’ve got and you’ve got to accept it and just get on with it.

For many informants there had been a point of acceptance of their disability which had been a choice they had knowingly made. They had made such choices prompted by their early disability experiences in a very different life.

I had a moment where I realised how it was. I just sat in front of the mirror and said to myself: You’re stuffed, don’t whinge on because nothing further will change. So, don’t lose your time. Take that! Go for it! And that’s the way it is.

I’m really bloody lucky you know. (...) I think I have a very good quality of life but I’ve worked for it to make it better too.

I think [disability] forced me. There’s been a force somewhere that’s forced me to wake up and smell the daisies (sic). How can I explain how I feel this way, I just feel it.
But this acceptance was also fragile. The impacts of spinal cord injury were constantly present throughout many activities of life: “I don’t think you ever accept the disability but you learn to live with it”. Life was certainly more difficult since acquiring quadriplegia.

Well, just the actual physical side of it, I mean you’ve got spasms which gives you the shits, you’ve got to shove suppositories up your bum, you’ve got to wear a leg bag, your balance is – you’ve got to drag a chair in out of the car which I’m lucky to [be able] do, I’m not complaining about [it]. (…). And there are certain times where you’ve been out, all you want to do is drop your clothes as you’re heading towards the bed and crash – no, get your chair out of the car, into it, through the door, go and do your tapping [emptying bladder] – it just complicates things.

For most their difficulties were perceived as irritations and frustrations, overcome in large part by means of good relationships with others, and by having good support, themes that are more fully presented later.

I enjoy my life with my disability because that’s my life. I don’t have any, well, I don’t know of any issue I have there. I think the things that have made my life as enjoyable as I want it is having a good group of carers around me to get me onto it, you know.

I mean, there are people with a disability and people without a disability. There are people with blue eyes and people with brown eyes. The wheelchair for me is not really something like I could not live with it (sic).

In contrast, three informants saw their present lives as mostly bad, with their lives revolving around such issues as their care management and frustrations about dependency, relationships, sexuality; having to ask for many things; a loss of spontaneity and loss of an able body. They also thought that they would be better off being dead, by way of access to EPAS, than to live with their disability. For them there was an ongoing comparison with life as it was before the accident that caused quadriplegia. Their views and experiences provided strong contrasts to the themes that arose from the more positive life experiences that most informants described as shown in various themes throughout this chapter.

And so yeah, it makes it difficult for me – I’ve got two lives, one pre accident and than the new one really. I’ve just started again, there’s no
point in trying to incorporate any of that [life before disability]. It was pretty obvious once I was told I wasn’t going to walk that I knew straight away what it meant, that it was never going to be obviously, as you well know, you never know quite how much how bad it’s going to be at first but for me it doesn’t really get any better, it’s just the experience, I didn’t choose to do it it’s just choice, so I just tend to look at life for me – I find it’s too complicated for me.(…). [I]t’s pointless for me to pursue something that just because it’s something I can do doesn’t mean that it’s me, I prefer not to change.

Well the whole experience has been the worst thing, I mean there’s nothing positive to say about it really. To me personally I feel like the person that existed before the accident is no longer. Well, it’s not me. I’m just a shell of the person I was. … just being in a wheelchair. I’d like to change that … not being in the wheelchair covers it all.

(Leaders)

Confirming the grassroots’ perspective, some leaders believed that attitudes that people with disability held towards themselves could determine their life experience.

It is also to do with how people with disability see themselves. One is really disabled, the other is a citizen with a disability.

5.9.2 Shifting criteria of acceptance

“Shifting criteria of acceptance” is a theme that reveals a changing perception of the circumstances under which life is worth living. Before the onset of their own disability fears and ignorance of disability had led some participants to conclude that death is better than life in a wheelchair. Now most thought the opposite. They had ideas now about what kind of life was not worth supporting, notably when one had lost consciousness or cognition. At the same time they could relate to the relativity of such concepts by looking at times since the onset of disability when they had shifted those limits, or shifted their criteria of what constituted life worth living.

Perceptions of the ability to live with quadriplegia changed from pre- to post-accident. Some informants recalled specifically thinking about, or talking with others about, the undesirability of ever being in a wheelchair, prior to the onset of their quadriplegia. They then thought that death might be better under such circumstances.
I remember thinking, I don’t know if I could live like that. … I used to wonder how they coped and then again it used to be quite scary. … I used to think oh gosh, so you didn’t want to get too close in case they spasmed (sic) or something but now … you see it in a whole different light. … and I think that the deformity is a bit daunting to some but I find that’s not so bad these days.

One, an avid motorcycle enthusiast, who broke his neck in a road accident riding his bike, recalled having made a pact with a mate with whom he rode on trail bikes. They agreed to always “ride fast”, so that if they had an accident they’d be dead, because he had a “morbid fear” of ending up in a wheelchair. This particular informant was one of the few who reports such unsatisfactory life with disability that he would rather be dead. But most informants saw their present condition as one they could live with.

I know people say, oh look, I couldn’t do it. If I ended up in a chair I couldn’t handle it. I say well, you don’t know till you get there.

Some informants said that if changes could be made to improve their lives they would like a slightly lower level of quadriplegia to make their lives easier, or to regain hand or arm function, but, on reflection, also recognised that if that were possible such improvement would never suffice.

Well, to be a lower level of quadriplegia – a lower level of disability, like instead of being a quadriplegic I’d rather be a paraplegic. But then I suppose if I was a paraplegic I’d say why can’t I be one of these people that come into hospital, break their neck and walk out.

Informants gave scenarios in which they stated the limits of what they consider life worth supporting, such as permanent loss of consciousness, being artificially respirated or being bed-bound. At the same time they also recognised repeatedly shifting boundaries as to what they would accept as life worth living for themselves. For example, a woman who had developed further disabilities as a result of a car accident after acquiring quadriplegia said:

Of course, thinking of myself, where my limits are. That you are on a respirator. If you are in an iron lung or something. That is my limit. I have learned that your limits shift time and time again. As far as that is concerned I think; I don’t have to decide yet. When it comes to that time I will decide. I have just learned through life that you keep on going. Apparently a human being is always capable to go over another
limit and find some, yes some happiness. In any case to find some
contentment. Some equilibrium that’s what it is all about.

Many informants adopted a relative perspective towards their
disability: “There’s always someone worse off than yourself” was an
often-heard statement explaining how they managed to make the best
of their lives.

(Leaders)

Leaders did not have much to say about this theme but captured the essence of the
grassroots responses by saying:

[A] disability perspective forces you to think about the essence of
things. A disability perspective can make theoretical issues very
practical.

5.9.3 Intra-personal approaches to public attitudes

Most informants employed various strategies to not be affected too much by
negative attitudes towards them. Their own attitudes were key in this. They
understood why people displayed attitudes of rejection and curiosity towards them
but they did not condone this. Their understanding came from their own, similarly
negative attitudes towards people with disabilities, pre-quadriplegia. They perceived
that people with intellectual disability had greater public image problems than they
had. Leaders confirmed the importance of the disabled individual’s attitude in
shaping their life’s experience. They described underlying social trends that
contributed to negative attitudes, as the grassroots sample described. According to
leaders residual public paternalism in the Netherlands; in both countries a rising
individualism; as well as a growing concern with health and wealth, all lead to a
public questioning of the presence of people with disability in society. At the same
time there was a perception of a growing acceptance of people with disabilities
through implementation of a number of integrative policies. A hierarchy indicating
level of worth of people was apparent among the public and among people with
disabilities themselves.

Informants displayed a mixture of external and internal strategies of dealing
with incidences of negative public values that were directed at them. Sometimes they
acted directly in trying to assert themselves as human beings with full worth. At other times they judged between the relative importance of self-assertion and adjusting one’s own view of the world.

So I have made it my business … to go up to people and just let them know I’m here. I’m fine. Yes, I am sitting in a wheelchair but you can associate with me.

I used to get annoyed about all sorts of things – things not really pertinent to life – while now I can better judge things for their value and have learned what is important.

They recognised that their own attitudes towards others could change a negative situation into a more positive one.

I think it’s a case of breaking through that bit of having to ask people to do things … it’s not really a problem. It’s just an issue that I’ve got to get over and do something about.

I think sometimes it’s your attitude towards them … I mean if you’re rude and abrupt to them well naturally they’re going to be rude and abrupt back but I mean, you know, getting into places or asking for help, there’s not very many places that you know that if you ask somebody they usually help you, there’s never any moans and groans.

Some recognised negative attitudes towards people with disabilities in themselves before they acquired their disability and saw their own experiences as relatively benign by comparison with negative public attitudes people with intellectual disability faced. Indeed some Dutch informants elaborated on the situation that people with intellectual disabilities faced. In a number of these informants’ neighbourhoods there were large group homes and their residents faced teasing from the non-disabled residents. No Australians raised this as a community-based phenomenon.

They recognised that negative attitudes towards them often come from ignorance. This understanding arose from their own dual experience of life with and without disability and because of their experiences with people that knew them well, who did not display negative attitudes towards them. This understanding helped some informants in reducing the impact on them from negative attitudes from others.
I do feel categorized. Some people give the impression that if you are in a wheelchair you are different, you are not like us. I think that for people with intellectual disabilities that is worse than for us.

So, with strangers I have some unpleasant experiences. … they really think you are mad if you are in a wheelchair. And that’s normal. I recognise it in myself. Because … when I was not disabled, it is strange, if you don’t know anyone in a wheelchair, it’s not part of the way you see the world. At that moment that you are confronted with it, it gives a scare. I can understand that.

When things were very frustrating, some informants told of letting it “out of their system” after which problems could be seen in a relative light, as no more than “having a bad day”. Frequently informants repeated their use of the maxim: there is always somebody worse off than yourself, in getting them through.

Oh, there are days that I abuse and carry on, mostly with myself. By the time I get that out of my system and get on with it. You think, oh well, it’s a bad morning.

They did try to let go of their bad experiences, because “… if we remembered all the bad things in our life, we’d probably go and jump off the cliff anyway”. Again, ice-breaking through using humour and trying to be clear and direct about the assistance they needed, could succeed in minimising displays of negative attitudes towards them.

[Y]ou can make the situation what you like by either saying nothing or by making a joke out of it … I have to deal with it all the time.

In the case of those who were experiencing unsatisfactory lives and preferred death, the contribution of one’s own attitudes to the quality of one’s life appeared to play an important role also. They greatly focused on their past, non-disabled, body and the physical experiences they enjoyed prior to their disability. For them, nothing but a full reversal, or cure, of their disability would be sufficient to restore them to their former state of feeling like a real man, or regain their former sexual identity, physical powers and independence. This construction of their daily reality contributed to their negative experience of life and to their suffering. They had decided that their present lives were not worth living. Yet there was also a realisation that for any change to occur in their lives a change was needed in them. One
expressed regret at being unable to change. The following quotes were from speakers who acquired quadriplegia 16 and 13 years ago and who described the attitudes of carers towards them as very good. The first described the attitudes of two stepdaughters from a previous relationship as accepting of him but this did not change how he felt about himself.

[T]o them it was nothing, they never saw the wheelchair. They just saw me as most people do. It’s how I feel [about the situation that makes the difference]. (…). I don’t think the wheelchair has really changed anything. Only my conception of me in the wheelchair, let’s put it that way. I’ve still got to have somebody come in and dress me, I’ve still got to have somebody shower me, I’ve still got to have somebody help me with bowel treatment… So, just the anger and frustration of not being able to do what I used to do. Basically all the time, yeah.

I can’t stand how I’m still not comfortable with carers doing things – even though you pay them – doing things for me, I find it very difficult to be a taker.

(Leaders)

Leaders confirmed the existence of negative attitudes towards people with disabilities but related their views to a more global level. In both countries a predominant human service care-model towards the needs of people with disabilities had resulted in reduced attention to their needs for “participation, contribution and relationships”. They were still seen as “objects of care” and they could also be seen in a black and white light: “they are losers or heroes. Nothing in between really”.

Dutch leaders saw a kind of paternalism arising from the care model, which had always told people with disabilities that they could not work or study, so why bother. For example, a Dutch person with disability could be stopped in the street by a stranger and be asked what was wrong with them.

[T]hat curiosity has to be satisfied first before they will interact with you. If I’d say ‘I have MS’ then it’s done. … for them all is then clear. Then they will approach you like that …; that is the woman with MS, that is the MS’er.

A Dutch paternalistic attitude was seen as part of the culture.
So, yes there is some paternalism, a bit of caring which is embedded somewhat in the Dutch character I think.

Dutch leaders in particular emphasised their perception of a public attitude which questioned whether parents “would be allowed to put children with a disability into the world”. People with disabilities were often seen as bludgers by the public: “you hear more often that people say that scooters are provided from their tax money”. A leader with a congenital disability who had children who also had this condition spoke of a culture, which was against “choosing” to have a child who had a disability.

I have the idea, as somebody with a disability, you have children that in general people around you react with: how can you do that? You cannot do that to a child. You hear it via the neighbours. And maybe the neighbours say it themselves too.

Dutch leaders mentioned such factors as individualism, lack of physical access, over-emphasis on material wealth and health as tendencies that have adverse consequences for people with disabilities.

In the Netherlands individualism has grown enormously in the last few years. And so has a kind of health ideal. Many people in the Netherlands think a) they can buy health and b) that you can prevent certain things and if anything should happen then they fix you up. Well, in practice it shows that all that is only relative.

Although some saw a gradual improvement in terms of inclusion policies in work, accommodation and physical access, leaders confirmed the low position of people with intellectual disability in a public hierarchy of human worth. But people with disabilities, they said, also applied a hierarchy to themselves, where the use of an electric wheelchair for instance indicated less worth than if one used a pushchair. And people with physical disabilities “don’t want to identify with intellectual disability, and certainly not with people with psychiatric illness”.

There is a kind of social ladder. That is the first thing I learned with X [a peak disability group]. If you are blind, a woman and you work, you are at the top. If you’re alone and blind you’re below that. But still reasonably on top. And who has cerebral palsy and is incontinent, well you can forget it. With intellectual disability or mental illness you go right down the bottom as well. Formally all this is denied.
Some leaders saw an improvement in people with disabilities’ public image some did not. A Dutch leader who claimed that there was essentially no negative view of intellectual disability in his country, listed existing public prejudices against people with intellectual disability.

[T]hey are aggressive and dangerous; cannot talk with them; they are crazy; they always need full care; they cannot go to school and they cannot have a job.

5.9.4 Losing friends and forming new relationships

Many informants, Dutch and Australian, experienced the loss of friendships upon the injury that led to quadriplegia. Often relationships with wives and girlfriends terminated, though this was not always attributed to the disability. Many informants believed that their loss of friends was related to their changed bodies and status and because of the hospital and rehabilitation settings they were in “they [the friends] didn’t like the hospital and the sorts of accidents that surrounded them.

Well I regard it as two lives because the friends you had before your accident tend to have dropped off – they see you in a certain perspective – like you’re walking around, you’re doing things normally …, then suddenly you come along and you’ve got to get your chair out of the car and if there’s a step you need a hand up the step and those sorts of things and it’s just kinda different.

In fact quite a few people have distanced themselves in one way or another since the accident, not just friends but family as well. (…) Admittedly some went interstate and things like that which would have happened anyway but there were others that just excluded me from their life. I suppose you put it that way because, I don’t know, maybe it’s too hard to have a bloke in a wheelchair tagging along all the time if you know what I mean.

But for most new friends were made after these losses.

A lot of friends stayed away but most I still have. I even gained new friends.

I lost my limited friends. I still have four. I used to have more but they stayed away. Now I still have four real friends. They don’t visit everyday but I can ring them should I have any problems. … Like
Friday, we are going to modify my car … a friend then comes who says: “Oh I’ll come by”. Those sorts of things. They are real friends.

Indicating the importance of good relationships to them, when asked what was the best thing about their life with a disability, informants often stated that it was their close relationships, with family, friends and at work, which have added meaning and enjoyment to their lives.

I can say, in hindsight: well it is not meaningless what happened to me. I have been shaped by it. I have, like I said, deeper friendships. I value that greatly. I would not want to do without that. So, if you ask me, would you do without that in exchange for the ability to walk, I would say no. That may sound absurd but it is true. Would you like that and the ability to walk? I would say yes.

What’s important to me – OK, well I guess a lot of my life is actually centred around my work or what I’m involved with, and that’s working for the X … And other things that are important to me I guess is my marriage, my wife and the life we have together.

The importance of good relationships was also expressed through regret for missing, or less than perfect relationships. When asked if they wanted to change anything in their lives if they could, some informants referred to the primary importance of their relationships.

I think that I would like to have a relationship [with my partner], which is less complicated, with someone who is a bit easier about things.

I mean sometimes I think I’ve got a good life, but then you have days where you think it’s the pits – but not that many, not that many. It’s no use, I mean there’s nothing you can do about it, you can only sit and sulk. … [O]h, I guess in some ways – there’s the partner leaving, that sort of gets on your goat a bit, that sort of gets you a bit emotional …, and that’s when it sort of hits home, you think life might have been different, but then it may not have been different, you just, you don’t know.

Work was another factor that made for a good life. Four Australian and four Dutch informants were employed part-time or full-time. Opportunities for relationships at work were important to their wellbeing, with the financial rewards of employment seen as of lesser importance.
There are customers that ask where I am when I am not at work because they need something or other done. I like that.

There are daily frustrations associated with a disability. But I do do many things. And I make something of it. I have a nice job, I have very nice colleagues, very nice friends. I have a lot of people around me through whom I can just too many, many things.

Then I think, what’s it all about in life? To be healthy and to have good relationships and just be satisfied with a little less money or no car. I don’t get worried about small things. I think the quadriplegia has a lot to do with that.

Those informants who reported a bad life and would prefer death described more detached relationships. They preferred not to get involved with others, saw human nature as essentially bad or voiced disappointment with the way others related to them.

There’s a couple [carers] like I say have been here a long time but I haven’t actually, I don’t think, formed – you know … Although they’re caring people and you get to know them, … I tend to not get involved, the same as I do with all, with the rest of life. … most of them care but I tend not to take them up on the offer most of the time, I just don’t…..

Another man from that group who described his life as “heavy shit” (“zwaar kloten”), said that “people have become my greatest disappointment in life”.

5.9.5 Enrichment of relationships

Whereas many informants had lost friends upon acquiring their disability a greater depth of relationship was now experienced with family and friends and in new relationships. Rich relationships were also experienced with carers who often confided in informants in relation to their own personal issues. Informants described contributing to their carers’ and friends’ wellbeing by being approached by them to talk through their personal issues.

Some described having close relationships prior to their accidents and reported no loss of friends at all. These informants were in the very small sub-sample of those at the very highest end of a continuum in rating their lives as good.
However, these informants also experienced a further enrichment of their existing relationships with family and friends.

A good experience with quadriplegia, I think, is that because with my family but also with my friends we went through a very emotional time that you get much closer with each other. … You get closer connections to those around you. When you go through the suffering together, certainly in the first stages, you have a lot to process – and still now of course. When you have problems you have to work through them. You learn then whom you can rely upon.

Relationships with paid and unpaid carers also took on a certain richness. Paid carers often found a listening ear from the person they cared for when airing their own personal problems. It made no difference whether the informant was male or female. They were happy to fulfil such roles. Informants thus made a contribution in a reciprocal relationship where they were not just recipients of others’ friendships.

I am practically a counsellor. Because I look so much deeper and think more clearly on the human side of life, you could virtually call me a counsellor to my carers.

Especially carers do [talk with him about their problems]. I think what they do. What they did was use me as a release. You know, they’ve got something eating at them – you know they’ve got it on their chest and it’s just a release to talk to someone and let go.

Friends also used informants more in this sense of ‘personal counsellor’.

Sometimes I feel like a psychologist. Maybe that sounds crazy. But the stuff that has been discussed at this table, you cannot imagine. I have friends that raise things you wouldn’t believe. But it is interesting. They think L. has experienced so much already, he will have some wise counsel.

5.9.6 Conscious relationship building

Enriching relationships did not appear to happen in any automatic process following injury and disability. There is a theme of conscious efforts to achieve relationships with others, and informants used various strategies to this end. These efforts were made for inherent benefits of informants’ wellbeing as well as for feelings of security but at times in contexts where they felt that they needed to
maximise the quality of care that they received. The Dutch were most emphatic about the use of direct, open communication. Leaders confirmed the importance of relationships.

Informants set out consciously to build good relationships with others, including at times in medical settings. In the first instance this was seen to be a matter of necessity in ensuring good care. This was perceived to be in their own interest besides the inherent benefit derived from a good relationship. A practical Dutchman for example described the reaching out he does whenever he enters hospital in order to maximise his wellbeing there.

And I see sometimes how they relate to you. In hospital you are but a number. At least to start off with. Then I take care that they start to like me, so that they go that extra mile, that they know you. And that I know them. I ask them: how many children do you have, where do you come from, you are looking nice today. That’s how you ensure that people get to know you and you them, so that they take that extra bit of care. So you know, whatever decision they make, it is in your interest. Is he allowed to go home? Is he not allowed to go home?

I’ve learnt the importance of keeping everyone as a friend. You never know what you need it for. I’m not sucking up to people or something but I think it’s important to have good relationships with everyone with whom I am in contact – who I am working with. I know for sure that if you are nice to them, that you get treated better than if you were not.

Another informant who had realised his vulnerability before returning home from rehabilitation, reached out by inviting local ‘huis artsen’ (general practitioners) to his home when he first returned from rehabilitation. He then explained his condition to them and set out what he might need from them in future, laying the basis for a professional and personal relationship that might safeguard his physical safety and wellbeing.

Informants used a variety of ways to enhance their relationships. These included breaking the ice with strangers and the use of humour to cope with difficult situations. Some said that they used humour between them and their partners when the circumstances were particularly frustrating. It was also used to deflect others’ embarrassment about disability.
Luckily I have a personality where I break the ice a little, just with a joke, so that they feel at ease a bit quicker. I don’t mind really to give people who feel unsure about this [disability] to give some instructions how I best like things to be done, and for them of course that makes it a quite lot easier.

Another informant for example broke the ice in a typically Australian way by organising an annual barbecue in his garden so neighbours could get to know him.

Reaching out to help and understand others, having a diverse social network, being involved in wheelchair sport and doing volunteer and paid work all facilitated relationships. Unique to the Dutch sample was the use of direct, open communication to get things done.

Be clear, be open, be honest. Those are the three things. And you can apply them anywhere. Because when something goes wrong another will then show understanding.

You have to be super clear on what you want and what you don’t want. If you don’t they’ll all take advantage of you.

Among those informants who saw death as preferable to their life with disability, one was very “conscious of his appearance” and dressed neatly so that “people notice me more than the wheelchair”. He did not describe any other social strategies towards his inclusion. Of the others, one has a belief that human nature is predominantly bad, leading him to observe people, to not trust them and to not get involved. Another had lost all faith in human relationships:

The manner in which we relate to each other, that is the biggest reason to keep thinking about euthanasia, about how do we live together. I always say that humans have become my biggest disappointment.

But for most informants the dominant theme was one of a need for relationships for one’s own feelings of wellbeing and development.

What is important to me is interacting with people because when I interact with people I’m coming to understand myself.

You need to be able to bounce off people. Everybody does. And it’s only the people around you that you bounce of that provide that feedback to you. Then they assist you but not in a condescending fashion, but [they] are just as normal with you as they can be.
Australian leaders made more direct reference to and put more emphasis on the value of relationships than Dutch leaders did. They did not only see relationships as important to people with disabilities but some described them as part of a full life.

No-one ever has a perfect life and I mean relationships are often part of the non-perfect part, but still, it’s the fabric of life.

Dutch leaders tended to refer to issues such as the need for people with disabilities to work and be educated in the mainstream, as well as to the need for improved physical access and transport. They also referred to new developments in integration in education and individual funding for personal assistance to people with disabilities who lived in the community. Australians directly named relationships as important to people with disabilities. The Dutch did so indirectly because their technology of integration and individual funding was aimed at the inclusion of people with disabilities in community, which inevitably involves relationships.

Government policies in both countries were less cognisant of the importance of facilitating relationships than on welfare or care.

But for me it’s the interaction or the relationship issues that are important to me in that people with disabilities – some people have such limited opportunities to have relationships. I guess the issues that I’m more interested in are those relationship issues, other human rights issues that aren’t as sexy to look at … . So I tend to be more interested in those sorts of issues than housing, employment, more I guess traditional type issues.

Australian government programs were not being built around a community vision but are designed around a welfare model: “the general community, whoever that is, often puts people with disabilities in a welfare context“ . This was preventing the facilitation of people with disabilities’ inclusion in community.

The system of how people live in Australia is what is preventing me from inclusion in community. It could include relationships with the local community, it could include government programs and how they’re designed. I think they’ve been designed on keeping people with disabilities in a welfare model.
In the Netherlands lives of people with disabilities were seen as controlled by the medical profession and service providers, within a care model.

5.9.7 Sense of meaning

A sense of personal contribution arises from engagement in positive human relationships. But there is also a sense of a contribution to the wider community. This sense of contribution, in turn led to a sense of meaning in life for most informants. But meaning was a fragile concept and others should not assume meaning to be necessarily associated with life with disability.

A sense of personal contribution and meaning arose from informants’ reciprocal and deep relationships. For instance an Australian woman with a high level of paralysis and dependency on others described her sense of purpose and meaning.

When you try and search and see what is the purpose for all this, what is, why, how. What is my role in the world now. And then gradually as the years have unfolded …, it just becomes clearer to me every time, and then I pass it on to them [her carers]. And it becomes clearer to them. And then eventually they’ve grown enough and they move on. Now, after what I’ve been through, after exchanging of thoughts, after more and more experiences with people rather than just with money and me, I can be here for them and listen to them.

This sense of contribution was not confined to the immediate private sphere. Informants saw the ways in which they lead their lives as a contribution to the wider community also. There were lessons to be learned from disability experiences. A Dutch informant for example, returned to the rehabilitation centre after some years in order to update his skills and experienced a culture shock between the very basic needs of some people there and the more trivial issues that occupied people at his work.

Then I thought, if everyone could have a look for a week in a rehabilitation centre [to see] what life’s all about… whether you can move your own wheelchair. Whether you can comb your hair.

He believed that there is a contribution to be made to others through such experiences.
Well, I think that I had this quadriplegia, I think that that has been, for me, and my surroundings, very meaningful. That sounds odd of course, but because of that you experience things, that you know what it’s about in life. I can get quite upset when people get angry for trivial reasons.

People at work were unsure about him at first but had later confirmed to him a contribution to their thinking through his presence. His co-workers said things like:

Wow, so much is possible. I have started to look at things differently. And I think that that’s important that people [with disabilities] are out in public. And that people see what is possible.

Yet, as a contrasting theme, meaning in life with disability was rejected when disability was inappropriately glorified by others assuming it to be there. Meaning was seen as something ephemeral and personal. It was not something anyone else should a priori ascribe to anyone’s life with a disability.

[Y]ou should not see my disability as meaningful. I will do that myself, because I am the only one that can do that. I get quite pissed off when people [do this].

I would not like to say that everything [has meaning]. There are people who say sometimes: well, it will be good for something, it has to be like this. Those are expressions that I don’t like very much, to be honest. I can, when I look back, say: well, it is not meaningless what happened to me. That is something else.

Meaning is personal and sometimes only a glimpse of it can be had. There can also be a lot of “non-sense” in life:

At most I can say that, through these experiences in my life, I discovered a small piece of meaning, or experienced it. And I want to be very careful with that, because I’ve experienced it sometimes … and sometimes I don’t. It is very fragile. It is something that you are given. I am always very cautious in describing it.

For informants for whom life was not experienced as “good” and who preferred death, meaning seemed not to play a big part in their lives. There was more of a focus on their life prior to their disability.

[It] doesn’t mean I’m depressed or anything like that. It’s just you know, I’ve given it a go, I’ve had my good times.
5.9.8 Loss of dignity and regaining it

The theme “Loss of dignity and regaining it” shows that the perception of dignity is very much associated with the kind of attitudes others expressed towards the informants. It was also connected with some blunting of a perception of lost dignity with the passage of time. Dignity was affected immediately after the onset of the informants’ quadriplegia as well as during hospitalisation. Loss of dignity in accepting their “new” body’s need for intimate care became much less of an issue later through their positive experiences with carers whom they knew and who gave effective assistance. The passage of time also eroded some feelings of indignity. A few informants maintained a high level of unease with incontinence, which affected their perception of their dignity. Negative attitudes from others that caused loss of dignity particularly occurred in care settings.

Informants’ dignity was particularly affronted in the time immediately after the onset of disability when strangers had to minister to normally private tasks like their toileting, showering and dressing. Over time most informants no longer saw this type of assistance as a loss of their dignity. This was because of their familiarity with helpers, good quality assistance, which helped in minimising incontinence problems. Time had eroded much of their sense of embarrassment.

Well, I used to get embarrassed when I had my accident and I still get embarrassed at certain points, especially when we’re training a new carer because you never know how they’re going to react. On the whole, with the old carers there’s no problems at all. … [B]ut I still get embarrassed if I wet myself or if I mess myself. I haven’t done that for years because the carers do their job properly.

I have had it now for seven years, and in the beginning you have to get used to it, but luckily I am rather cool in such things. Yes, it has to be done, I can leave it too but then I will come to die from that so, that makes it easy, I did not want that. Generally that goes well. It does not frustrate me to the extent that I would not want to live because of that. I urinate and get help to empty my bowels well. And sometimes that means problems, but after it’s over, there’s a new day and the sun shines. And the birds sing again. I have a lot of those things from which I get motivation to live. I do not, at least not till now, let that get obscured by bowel or bladder problems.

Even when carers were not well known, informants became less worried about accepting intimate care over time. This took longer for some than for others.
but most had gained a level of acceptance of their need for intimate care by the time they were discharged from rehabilitation, a period between ten months and two years.

Well, to start with you think, pheww. But you know what it is? You’ve had so many people at your body. Then you just think, well why not, just let them. In the beginning you have this [attitude] like strange girls and intimate issues, how do you say it? Privacy. … you constantly get someone else. You just have to not worry about that, so to speak.

How could you put it? Is it loss of self-esteem or development of self-esteem? The point where you’re naked so often in front of people, it doesn’t matter any more. I mean, for years I wouldn’t have X [community care agency] come in, but now it’s, you know, I don’t have a problem. If someone new fronts up, OK, that’s what you’ve gotta do – bam, bam, bam, bam. I could never do that before. I’d break a leg before I’d let someone into my bathroom. So it is, it’s desensitising.

A few informants still felt their incontinence as a major problem and as something that was degrading. They were among those who reported bad or very difficult lives. For example, a Dutch informant always worried about incontinence problems and resented paternalistic attitudes towards her from some of her assistants.

I feel devalued by it. I think it is inhumane. It is. I now got my assistants not call out any more: ‘do you need a nappy?’ Those things, they drove me crazy. Then I thought: well, well, well. I said: babies wear nappies here. I find it very annoying and feel very unhappy with this. I am always thinking: oh dear, it’s not going wrong or is it going O.K.? My catheter, is it sitting right … . Misery, misery. Then it goes well for a time, and it gets better. But, always watchful, always checking.

Informants had experience of lost dignity in relation to care issues in the early hospitalisation days. Dignity could be preserved or regained by attentive, respectful care.

I think the only time I lost my dignity and felt sort of confronted by it was when you get pushed on to the commode chair and go to the communal showers and toilets. That’s a bit of a hard… when you’re sitting on a loo and someone says, come on hurry up … there’s a real dignity issue there yeah and for the first week its terribly confronting.
Institutional staff attitudes could also destroy a person’s dignity. A man who lived in a residential care facility for some time had his dignity assaulted by staff attitudes and service routines.

Q: Did you feel that you were being treated as a human being in (institution)? A: No, no, I was a resident. Q: And that’s not the same as a human being? A: No, no because to treat a person as a human being is to treat them with dignity. They didn’t have any … I mean one thing I hated was bowel treatment day because if you didn’t do it … well they’d give you your bombs as they call them, suppositories, at four o’clock in the morning, whether you was [sic] ready or not. And if you went in the bed, so you went in the bed … well how undignified can you get. I haven’t done that once here because I have well, a different type of living. And in fact it was better for them because if I did it in the bed it meant that I didn’t have to go on the toilet. They could put me straight in the shower and shower me.

In essence dignity arose from interactions with others, from the nature of the informants’ relationships. For one informant this included his relationship with God, with health and material comforts playing minor roles.

For me, life has worth, in the first place, because I know that it has been given by God. That determines the value. The second thing that determines the dignity of life for me is the relationship that I have with other people. That determines the dignity of my life. Number three, then perhaps your health. That is also important. Of course I’d rather be fully healthy than sit in a wheelchair. I don’t want to be unclear about that. But that’s not last. Number four is, you could think about material goods.

5.9.9 Loss of independence, gaining a sense of interdependence

Informants initially experienced their dependency as bad. Dependency arose from the nature of their disability. It was affected by physical and social environments and by having to continually ask for many things. Over time, through reaching out to others, long-term relationships developed which helped in outgrowing their most negative experiences of dependency. Dependency could then sometimes be perceived as interdependence, a fact of life to be lived with. Negative feelings about dependency never disappeared altogether but the great majority of informants had learned to live with this. A feeling of independence arose from receiving adequate assistance in order to engage in daily activities, within a good
relational context. Interdependence was understood as the reality of their lives, a framework in which dependence and independence blur. Interdependence was also described as being the nature of the world for any human being, disabled or not. A small minority did not feel anything much positive about their dependency and had not experienced a reduction in their feelings about this issue over time.

Both Dutch and Australian informants saw dependence as the most noticeable and worst change in their lives after the injury that caused their quadriplegia.

The worst thing is just that dependence on people. I don’t have to think about that one.

The biggest difference is the dependency. While before that time you were absolutely not dependent, now you are with so many things. You don’t want it but it is so. The biggest difference is, I think its very logical, things you really cannot do. To just go on holidays, everything is a problem.

It was frustrating, and problematic to some, to have to rely on others for help with many tasks and to have to ask for many things and to have lost a degree of spontaneity in one’s life because of this. In the familiar, more accessible home environment dependence was experienced as less of a problem than in the wider environment. Yet many informants felt quite independent, despite significant physical limitations.

At home I am quite independent. I cannot just go anywhere. I cannot go to the toilet just anywhere. My freedom has been reigned in because of the spinal injury. That bothers me a lot.

Well to me it’s as big a circle as you want to draw. It depends on how wide you want to make it. If you want a little closed circle, then you’re independent but if you’re more adventurous and you want to go out and do things like go camping, … then you become a little bit more dependent on somebody.

All negative feelings of dependence had not disappeared but most informants had learned to live with it to a point where it was mostly no more than a nuisance or seen as “a fact of life” and “just having to get on with it”. Help from others with some tasks was mostly seen as an act of enablement to a level of independence, not as an affront, including for those informants with the most physically restrictive
impairments. Help became “a social occasion”. The relationship between carer and themselves could thus dissolve feelings of dependency.

It’s a fact of life. I mean, I am dependent on my carers to get me up in the morning so that I can become independent – put my spoon on so that I can feed myself, so that I can get to my water and tea and stuff – but I cannot prepare a meal, but they can do that and we can sit down together and have breakfast together like a normal family would do. Sure, it’s not a family situation, but it’s still a family to me.

There is a Dutch saying: ‘when in trouble you learn who your friends are’. That came true. And I did not lose any friends. Those who were have become closer friends. Look, it’s easy and nice to have a few drinks in a bar with people. And then to say at 2 am: O.K. guys see you later. But those who go on holidays with you, put you in the shower all week and give you suppositories and manually remove your faeces when things won’t work well – those are different friends than those you see in a bar sometimes. For me that is very valuable. So there good things and frustrating ones attached to that dependency at the same time. Yes, that dependency gives a very deep relationship with people around you. At the same time it is also fantastic to be able to be independent.

This state of acceptance of one’s dependency occurred within a context of an accepted need for assistance, which was seen as necessary to give informants a degree of independent functioning, that is to enable them to a degree of independence. This applied in many situations, such as help to get behind the wheel of a car, having an eating utensil put in a splint, getting up and ready in the morning to get to work, study or other pursuits.

As presented above, informants often reached out to carers and others. This enabled the kind of long-term relationships where feelings of dependence were reduced because of the reciprocity in giving and taking. Knowing each other as persons and not being made to feel a burden reduced feelings of dependency.

We can do a lot to make something of it. It does limit you and you don’t easily become a millionaire of course. But you can be nice to people. You cannot for instance afford to hire someone to build you a ramp. But if you are just nice to your neighbour, he will build you one.

The carers that I have generally stay because you know, I treat them well. It’s a mutual arrangement and I try to get sort of people that like
this sort of work. And, you know, caring carers that are obviously not just in it for the money but also for the satisfaction of doing it.

This reaching out required an ongoing effort. Sometimes informants could only “just manage to keep up a smile for half an hour” with some paid carers and others said how they “worked hard” at keeping their relationships good. They also made an effort in selecting the ‘right’ carers in the first place, where they could.

Most of my friends and acquaintances can assist me. When you are dependent on other people I think that it is important that you yourself are an agreeable person in being helped. It is then that you notice that people meet you quite willingly. Then everything goes a bit easier.

I run an ad in the local paper …, for myself because I want to put the ad in the way I want to word it and that way I can interview them and see – I don’t want to go through a filtering agent like them to decide who I’m going to have, because they don’t know what sort of people I like.

A few informants did not accept their state of dependence at all. Again they were those who reported a preference to death rather than to live with quadriplegia. It could interfere with “feeling like a real man” and asking others continually for help made them feel continually dependent.

When I sit behind my computer I am independent, at least that’s what it feels like as if I am not dependent. But as soon as I am no longer behind the computer I feel terribly dependent. I cannot get away from that.

These differences in feeling about dependence and independence were not directly linked to the informants’ level of physical impairment. Some with the highest degree of paralysis were among those least bothered with dependency, felt independent and could see a broader pattern of interdependency for all people. Some of those with a lower level of spinal cord injury, and thus a higher level of physical functioning, were among those feeling most affected by feelings of dependency. Nor did length of time of having lived with quadriplegia seem a factor. Those who reported a ‘bad’ life and wanted to be dead had experienced quadriplegia between 13 and 16 years at the time of interview. On the other hand those who reported very ‘good’ lives had acquired quadriplegia less than 10 years ago. For the bad life sub-
group their “feeling” of “anger and frustration in just not being able to do what I used to be able to do” appeared to dominate their thinking.

Q: And is that anger and frustration with you all the time or only occasionally? A: Basically all the time, yeah. You know if I’m at home I can’t just automatically get up and go turn the TV over or turn the TV off and put a tape on. Or if I’m out somewhere I can’t just get up and walk over to somebody, you know especially if the terrain’s a bit unstable. You know, you’re always relying on somebody I suppose that’s what I’m trying to say.

For them dependency continued to be keenly felt: “I am daily worried about being dependent on others, always having to ask”. And they saw no way to change that. One informant “could not stand” still feeling uncomfortable with dependence on carers for intimate tasks: “I don’t enjoy having to have things done for me. I was always independent so I don’t like having to have someone come in …”. If they could change anything at all it would be the return to a fully functioning body. Another of those with a bad life thought that others still could relate to him as a person but how he saw himself changed the nature of his relationships.

I don’t think the wheelchair has really changed anything, only my conception of me in the wheelchair. (…) I know how I feel, and as I said, no amount of money would change that in my personal circumstances.

Many informants implied an interdependence between their social environment and themselves. For example, interdependence could be explained as “a fact of life” where “one hand has to wash the other” [a common Dutch saying], applicable to all people with quadriplegia as well as in general. Independence, dependence and interdependence were interwoven concepts in the lives of most informants.

It has to do with the one hand washes the other. That’s how it is in life. Even if you do not have a disability, you always need other people – sooner or later. And people who do not think so, they really get into trouble if it does happen at some point [become disabled]. Really I believe that you always need somebody. My motto is: It’s not who you are but who you know.
But it was a small subsection of some three informants who reported their lives as very good, or even better, than before their disability who were explicit in asserting interdependence as part of the human condition.

Interdependency is one of the basic concepts of humanity. It’s the ability to share, grow, assist and love other people. What greater joy do we have? It depends upon that important ingredient independence … having the necessary skills, choices and attitudes in order to be able to work with and assist others.

Q: So in all of that, do you feel dependent or independent or in-between, or how do you feel? A: No, isn’t the new word intra, intra-dependence is the new terminology, intra-dependence. Yeah I see myself as a very independent person because I mean I’ve got that ability, had that opportunity, had very much that opportunity to be able to contribute to society, to be able to give back just as much or even more than I’m actually receiving. So yeah, that’s what part of being independent is.

(Leaders)

Leaders in both countries agreed that dependency is “a fact of life” and could be overcome by seeing it in a universal light. A Dutch leader with disability for example agreed.

In the view of many people dependency is about the worst thing that can happen to you. And I think that that is true. Until you can balance that. There has to be an exchange. I am dependent on the greengrocer, my wife too [who does not have a disability]. Dependency in itself is not so bad, as long as it is not only that. I know people without arm or leg function, who can only nod their heads, upon whom I am at times dependent [for their advice]. I think that everyone is dependent on everybody else. It is just that nobody thinks that this is so anymore.

Independence was seen as about developing people’s potential, with care being a normal part of that, not as extraordinary. They also held that dependence is caused by the disability itself, by society and by one’s own attitudes. Interdependence was raised as “the real issue” rather than looking at dependence and independence as a mutually exclusive construct. Some people would never be independent and would be left out of community if they had to earn their way in through first gaining independence. As an Australian leader who did not have a disability said:
I think it’s more, how do we look at things like interdependence, that are the bigger issue. Because it doesn’t matter how dependent or independent you are if you have people around you and you are part of what’s happening and contributing to that then whether you can do it on your own isn’t the issue. We don’t talk about children as not being part of our community and yet they are not as independent as adults. It’s the same issue with people with disabilities, that it’s not an issue of independence. It’s although, the way that we currently deal with that means that it is almost on a continuum, that people have to earn their way back to community by becoming more independent. Some people will never become independent – that’s not the issue.

And her Dutch counterparts saw it similarly. For them the attitude of the person with disability also played a role. People with disabilities must also take responsibility themselves. Asking is difficult and must be learnt. In reaching out to others relationships would form and dependency would be less felt.

If people are able to not be swallowed up by their dependency, then usually relationships are formed between people. If at a certain point you have the feeling that you don’t have the control over your own life anymore then you can go the other way. Then you are in fact a kind of a zombie in the hands of the one that has to help you. And I think myself that people with a disability … they have to literally learn that they can also pour a cup of coffee. Within people with disabilities themselves change has to occur too.

On one hand it has to do with society itself, how society views people with disabilities, because that makes the disability. … But it’s also in your head.

And dependency was seen as universally applicable, not only to people with disabilities:

You can become chronically ill, you can get old and frail. All sorts of things. But one normally thinks only in very short terms. People do not look at the future nor do they look at the past. Everything is focussed on now.

5.10 Value change and personal growth

Most grassroots informants told of a positive change that had occurred in how they relate to others, compared to before they acquired quadriplegia. Through their disability experience they had developed qualities such as a listening ear, greater
assertiveness, patience, direct and open communication, acceptance of life’s unpredictability, equanimity, kindness and tolerance. Their experiences and their inner growth towards such qualities helped others grow and mature too. They themselves perceived this as personal growth, which enabled them to see the world and themselves in a different light. Yet, in important ways, they emphasised too that they were the same person as before their accident. They were aware of a contribution they were making to themselves and others through their inner change. Those who were among those at either end of a scale of good life, that is very bad or very good, appeared to experience a less perceptible change in values or the kind of growth that other informants described.

In some sense people were the same they were prior to their accidents.

I guess in some ways, deep down it doesn’t change your nature. I mean if you’re a dickhead before you’re still a dickhead afterwards.

[M]y thinking has not changed. If I could walk now, I would do exactly the same things like I did then. (…). My way of life has changed, I think because of the restrictions.

### 5.10.1 Being more social

Whereas in some sense informants felt no inner change as to who they were, many informants had experienced a personal change within themselves since having quadriplegia. Those who were previously impatient or easily angered, or were more materially oriented, felt they were less so now. They had undergone a personal value change and thought that they had inwardly grown into more sensitive and social persons.

Because I used to be a rather impatient type, and that’s going a lot better. For instance, if you have ever sat on the toilet for two hours … counting tiles and discovering patterns and trying to think of a mathematical formula about some patterns. Then you learn. You exercise patience.

I have become more agreeable (“liever”). I have changed, become more of a social person. I used to be rather a-social, if I look back. I have to laugh about it now but I mean, I needed no-one then. And perhaps that is a healthy way to be but when I arrived in the rehabilitation centre I experienced great difficulties in working with
people that I needed. Before, that did not play a role – you had your own life. And I guess that is healthy but this is healthier.

People had commented on the change in an informant, who had had a rough upbringing and who went into the army at 15 in the UK. He now had heart-to-hearts with his carers about their issues.

Before my accident, well people didn’t trouble me with their problems anyway, but even if they did I would have most likely turned around – I would have probably turned around and said: well look, I’ve got enough problems of my own. I don’t need yours on top of mine.

And such inner ‘growth’ was not confined to the person with quadriplegia only. It touched those around them too.

Quadriplegia influences those around you in any case. You don’t have quadriplegia all by yourself. Life for your family, but also for your friends is never the same again.

Another informant who said that she used to be bombastic, critical and not giving much time to people she considered “weak”, claimed that she is now more patient and tolerant and developed into a listener for her carers. That change was not limited to herself but affected those around her too. And her disability experience was the catalyst. Most others felt similarly.

How can I explain how I feel this way? I just feel it. (…). I think before I was not a person who relied on anybody. I was always the one going around to my parents, doing her garden, going to my sister’s, lecturing her, taking her children, giving her a break. So I was always the big-mouth-up-front person and all of a sudden, and for X [husband], all of a sudden the roles had reversed and he had a lot of learning to do within himself and yet when I look now at the man I have, my bombastic attitude never really allowed him to show what he was made of. … a quiet achieving person – there’s been a person under there that I never knew I had – the depth of the person.

I have started to live more consciously. (…). I gained an awful lot of knowledge about how people are, after my disability. [I] can generate more understanding for more things. (…) you realise more about other peoples’ suffering. I will not easily say to someone, you are whingeing.
The longer I seem to be in the chair, the more patience I seem to have and more tolerance. So, for me, although I’ve lost certain ability, I’ve gained other ability.

This last quote is from an informant who said that before his accident he would never want to talk like this before his accident

Now I do just listen to it. I just learnt that in those two years [of rehabilitation].

5.10.2 Living in the moment: letting go of control

The difficulties of living with quadriplegia, including frequent health treatment for some, were in part bridged by informants’ personal change in attitude towards living a day at a time or living in the moment. There was a letting go of control of all situations. Paradoxically life became more enjoyable because there was an acceptance of the fact that life was uncertain and unpredictable. This kind of growth may in part account for the paradox of knowing themselves to be vulnerable but not feeling it. The enjoyment is in the interactions with others in the moment without worrying about what might come next:

Q: So it is a very different life for you? A: Yes but not less of a life. Certainly not. In spite of all the troubles I do have an enjoyable life. I do have to go to the hospital regularly. Every time again that’s like: you experience something. You meet some more people. I enjoy now. I do not enjoy tomorrow – no, I enjoy now.

And sometimes you’ve got to let the dust roll, so to speak. You know you’ve set something in place and you think oh I should have done this or I should have done that, but you’ve just got to let it roll. Q: Can’t control everything? A: Well, I’ve tried to interfere with it and all you do is end up creating more work than you really need for yourself. The result turns out to be the same and if it doesn’t well sometimes then you just deal with the end result and apologise or stuff it up or if it works out fine then think you know that’s good.

For some who worked, work was approached in a different style, reflecting some prioritising of life’s goods, as well as balancing physical demands with work. Work was integrated more into a way of life than being the means to an end. An Australian participant worked part-time, making sure he spent time driving past the
harbour and seeing the sights on his way to and from work, or to stop off for a coffee on a terrace. And a Dutchman did the same in his climate.

I used to be a career man and now I don’t really care. When I need some money I just build some more websites, or I draw some building designs. I don’t care about the rest of it. When it is good weather and I hear the birds sing I take the car and go. And I enjoy that. I used to not have time for anything. I like birds, I love storm. When there is a storm X. is by the water, then he goes to the Afsluitdijk [a long dyke connecting the northernmost provinces] with his car and lets the wind blow through. I love that. I never did that before. I could not. I had no time.

5.10.3 Greater assertiveness

Becoming more of a social person included, for some, the experience of becoming more assertive, straightforward or direct in dealing with others, where they were not before. For instance, an Australian woman, divorced after her accident because she says her husband could not deal with it, became a stronger person.

[I was not] not dominated by my ex but I just went along with whatever he wanted … I just fitted into his mould and I think [that] once I had quadriplegia I had no choice. I had to either, you know … [sink or swim], and it’s funny because I’ve grown 100per cent to what he is. He’s still the same. He hasn’t changed at all. I’m a lot stronger person I think. And I’m more forthright I suppose and I think I don’t let people walk all over me like I did before. If I’ve got something to say I’ll say it. I am not rude or anything don’t think but if I feel I’m in the right I’ll say well, hey!

A Dutch male said he had learned to deal with situations rather than leave them, while being accepting of other circumstances that he could not change.

[Y]ou start to think more simple and logical. That is a way of life. More often you find a simple solution. (…). I think I have changed, I have become harder, a bit more straightforward, don't quickly get so emotional…. Because emotionally you've grown stronger. (…). [M]y thinking did change with the spinal injury. You have to be more practical. And you have to accept things more easily. Before my accident I was like: if I don't like it I will just go away.
5.10.4 Value change and perception of wellbeing

Whereas no-one reported a personal change for the worse, a small proportion of informants said that they had not changed, or had changed in a very minor way only. These included all those who expressed the very worst and all those who expressed the very best of satisfaction with their present lives. Informants at either end of this life satisfaction scale said that they had similar attitudes to life, and towards others, before and after having quadriplegia. The majority of informants who reported a difficult and good life said they had changed a lot.

A few informants reported lives where, although at least some of their relationships were good, they seemed to be more in receipt of them than being involved in them on a reciprocal basis. They focussed on their physical body and wished for its return to how it once was. Not reaching out and an inability to trust others seemed to stop them from valuing and developing their relationships. They reported no personal change or growth.

… I think a lot of people have got the potential to be quite nasty. Q: So you haven’t changed in that respect? A: No, no and I’ve actually been proven right because I had a lot of acquaintances but one close friend and don’t see anybody now. I’ve been in a chair for just over 12 or 13 years and I don’t know one single person from my past now except for my best mate who, I actually said to him, look if you don’t feel like visiting don’t do it just because you haven’t seen me for a while – I don’t want you to come round …. We don’t have much in common any more and that’s unfortunate.

At the other end of the scale were those who said that they always were sociable and thinking of others and who described a very satisfactory quality of life. Some claimed to have even better lives now than before their injury. An Australian male, with a pre-injury physical labouring job and who was once a rock climber, described the change to having a disability as very traumatic but views the world as positive.

Q: …[T]hinking of other people in that way, is that something you used to do before your accident or not? A: Oh yeah, I guess so. I mean an accident doesn’t really change a person in what they are… I mean maybe it’s a gradual change. Time itself changes people. I guess I was a fairly considerate person always. I’ve always enjoyed people. I mean I’ve always enjoyed the company of people and communicating and working with them. Never done too well on my own. As I said
before it’s [life post injury] better. It just gives you the opportunity to
explore a whole new realm. Also, certainly extreme frustration and
annoyance and that but it’s still very much a wonderful life. I don’t
think there’s anything I’d change, no definitely not. No, I can’t think
of anything right now.

(Leaders)

Reflecting some of the grassroots’ experience, and drawing on their personal
experience, some leaders voiced a belief that a certain wisdom could be acquired
through disability which was of benefit to society.

I see how I have been able to help people from my own experience
and knowledge, of which I am very often not conscious myself, but
[know] through what people tell you afterwards.

It is possible that people will discover that particularly people with a
disability have gained a certain wisdom that society needs. (…) …
that you cannot create human beings; that people have to learn to live
with the unknown; with the fact that any moment of the day anything
can happen, whereby life is changed completely.

Like for grassroots informants, change and growth had also occurred in the
personal lives of leaders with disability. It is relevant to report it here as it seemed to
be confirmation of this theme, especially so as these leaders had different disabilities
to the grassroots sample.

Once you’ve found your identity as a disabled or ill woman then it
often shows that you experience a meaningful life within your
restrictions. Your indicators of a good life change.

In the last few years I have gained talents that I did not suspect in
myself and thanks to all this I’ve gained them.

The two non-disabled leaders also believed in the possibility of an inherent
social contribution arising from the disability experience and an ‘enrichment’ arising
from dealing with loss.

Through our work we make a real contribution to society. A society
where disability would be considered something that should not be
couraged, that should not happen, is a society in which I would not
want to live. Really not. I even think that I could say it is one in which
I would not be able to live…. Because in my own personality there are at least 87 characteristics that could also be eliminated

I believe that both the people who are experiencing or preparing for a loss can grow enormously as can the individual who is supporting those individuals. Such experiences expose us to a whole range of emotions and feelings that individuals need to explore in terms of their own value systems and this can be quite an enriching process for all involved. The very nature of helping and accepting support at these times can be a very positive experience that derives from a closeness and intimacy of working through difficulties associated with the loss.

5.11 Summary

In summary, grassroots informants experienced a heightened level of vulnerability arising from their disability-related health problems, others’ attitudes, and inadequate treatment and care. They described a socially declining society in which it appeared their vulnerability would grow while leaders of disability movements described their organisations a disinterested or unable to speak out on controversial bio-ethical issues, including EPAS. Nevertheless, most informants felt invulnerable. Partly because they had already been through difficult circumstances, and partly because they believed in society’s commitment to improving circumstances for people with disabilities. They did not think that this declining society, or a rising availability of EPAS, would be problematic because of their faith in strict safeguards. Although they did not name it autonomy, they accepted, for them, independence as a state that often depended on the assistance of others. This independence lessened negative feelings of dependency on others. They had been able to re-frame their initially keenly felt loss of independence and dignity through rich relationships with others. Initially they sought such relationships to safeguard their vulnerable situation. After some time these relationships, despite their difficult circumstances, grew to be the source of their feelings of wellbeing. A small subset of informants had contrary experiences. They continued to suffer from loss of independence and dependence on others. Their relationships were not rewarding like those of the main sample and they experienced their lives as unsatisfactory. Whereas the reciprocity involved in the relationships described by most informants implied interdependence between people, some in a small subset of those who had the best experience of their life with disability, identified interdependence as a fact of life.
Most informants described strong personal value changes in comparison between their pre- and post disability lives from being more self-interested then to being more social now. The small subsets of informants who experienced their lives with disability as unrewarding or as very rewarding reported little such change, the first continuing a predominantly individualistic view of life and the second a more social view.
CHAPTER SIX

DISCUSSION

6.1 Introduction

In this chapter the findings of this study are interpreted and compared in the light of the conceptual framework and the wider literature. The discussion is structured around my responses to the study’s four research questions. I argue that the main sample of grassroots informants predominantly used two different and opposing value frameworks in relation to the first two research questions. In relation to the first question, which enquires into their views on EPAS, they mostly used the socially dominant framework of individual autonomy, with its attendant rights to choose EPAS. Leaders in both countries applied a more relational concept of individual autonomy. However, in reference to the second research question, when grassroots informants discussed their disability experiences in relation to vulnerability, dependence, and independence they used an interdependence framework. The findings show that the latter value system was involved in most informants’ successful outgrowing of significant threats to their safety and wellbeing. These threats included losses of relationships, dignity, meaning and independence through multiple causes, such as from their physical impairment, inadequate health care, attitudes from others and wider societal trends. Informants described similar kinds of threats in terms of unbearable suffering, including loss of dignity, as sufficient reasons to allow EPAS for others. In addressing the third research question I discuss how these two responses may relate to each other. I then look at the fourth research question, which enquires about the cross-national significance of the study’s finding and proceed to my conclusions, including possible further research.
6.2 Research question 1

What is the knowledge, including the beliefs and assumptions, of Dutch and Australian people with quadriplegia and leaders in Dutch and Australian disability movements, on issues of euthanasia and assisted suicide?

Five main themes were found in analysing the data in response to this question: Conceptualising euthanasia and physician-assisted suicide; the primacy of rules as safeguards; death and dying as a distant experience; suffering and EPAS; and rights, choice and compassion. There are twenty-one sub-themes within these five main themes.

Conceptualising EPAS: Both Dutch and Australian informants, grassroots and leaders, showed some uncertainty about defining euthanasia or physician-assisted suicide. They used euthanasia and physician-assisted suicide interchangeably and did not make great distinctions between the two. Withdrawal and withholding of treatment (WOT) was often seen as the same thing as EPAS. They were essentially perceived as the same because they all had the same outcome, that is death. The different processes underlying these various life-ending procedures, including any differences between a medical doctor’s intention to actively kill the patient or to decide to stop futile treatment (Somerville, 1993) were not clearly understood by them. One significant effect of the blurred lines between these life-ending procedures is that in this view EPAS can be merely seen as a relatively innocuous extension of current medical practice, whereas the two life-ending practices are qualitatively different. This in turn may make it easier to adopt a positive mindset towards adoption of legalised EPAS practice. Dutch and American histories of public high-profile cases involving WOT appears to illustrate this trend to a gradually more positive public attitude towards legalised EPAS. However, Australian support has grown without such history, maybe because of an influence of these prior developments elsewhere. Informants appeared to demonstrate a low awareness of clear meanings of EPAS. Many informants were unaware of the term physician-assisted suicide; found it difficult to articulate the meaning of euthanasia; and their meanings of their perception of euthanasia and PAS were blurred. The support that most informants gave for allowing EPAS for others therefore must be viewed in this context of relative ignorance. In fact, several informants volunteered that they had little interest in the topic.
The basis for their information on EPAS is further qualified by the source of it. Several informants, including some of those who expressed little interest, gave examples for EPAS, for which the source was a recently watched television program, which used an extreme case. The literature suggests that this sort of unawareness of the meanings of euthanasia and physician-assisted suicide is not uncommon (Aranda and O’Connor, 1995; Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991; Meier, Emmons, Wallenstein, Quill, Morrison, & Cassell, 1998).

Dutch informants mostly, but some Australians also, closely identified advance directives with their concepts of EPAS. Such advance directives are contractual advance expressions of one’s wishes, indicating under what circumstances one would wish to have EPAS. However only one (Dutch) informant had formulated their own and that turned out to be about the nature of medical treatment, not EPAS. The literature confirms this finding as part of a wider trend: studies have found positive public attitudes towards advance directives while few people complete them (Emanuel, Barry, Stoeckle, Ettelson & Emanuel, 1991; Kastenbaum, 2001). My informants had not made advance directives for themselves, firstly because they felt their lives to be worthwhile. They had not turned their minds to any future scenarios where they might want to influence the nature of their medical treatment or indicate the use of EPAS. Secondly, upon acquiring quadriplegia, they had personally positively re-appraised the circumstances under which they could live a fulfilling life and some had done so repeatedly following further health problems. This apparently led them to conclude that it is difficult to know in advance what conditions one might still want to live with, despite earlier beliefs to the contrary. Thirdly, they did not have sufficient trust that their directives would be carried out by the medical profession. Studies confirm that their distrust is grounded in evidence of such unreliability of the implementation of advance directives (Pool, 1996). So, whereas they had their reasons not to have advance directives themselves, they still framed EPAS for others in this context of a technology of advance directives. In the light of their reasons not to have an advance directive document for themselves, it is interesting that they offered no caution about the use of advance directives by others. To the contrary, one informant told of apparent family coercion to have a terminally ill man act on his advance directive to have EPAS, but this informant showed no discomfort about this.
The primacy of rules as safeguards: Most informants supported EPAS while also insisting it be well safeguarded from abuse. They primarily insisted that strict rules be in place and EPAS be legalised to this end. Some showed an awareness that safeguarding everyone from all abuse is not always possible but most showed considerable faith in the workability of legal safeguards. Besides protection from abuse of EPAS another reason for legalisation was protection of doctors from prosecution. This was seen as necessary. Australian informants in particular were convinced that illegal EPAS occurred frequently. Indeed studies do confirm the presence of illegal EPAS and other medical life-ending practices in Australia (Baume & O’Malley, 1994; Kuhse, Singer, Baume, Clark, & Rickard, 1997; Kuhse & Singer, 1988, 1992; Magnusson, 2002; Stevens & Hassan, 1994). Dutch informants knew little about their country’s legally binding guidelines towards accountable practice of EPAS but most believed them to be operating well enough. Kennedy (2002) and Gomez (1991) have suggested that such unawareness of EPAS and how it operates is a wider trend among the Dutch. Informants who related their experiences of coerced EPAS; non-reporting of EPAS by doctors; or apparent EPAS of non-terminally ill people with quadriplegia, mostly expressed little or no discomfort about these. Informants still supported EPAS, in the knowledge of abuses of the strict safeguards they insisted upon. Abuses of Dutch rules such as reported by informants, including non-reporting of EPAS by doctors (Van der Maas, van Delden, & Pijnenborg, 1991; Van der Wal & van der Maas, 1996; van der Wal, van der Maas, Bosma, Onwuteaka-Philipsen, Willems, Haverkate & Kostense, 1996) and a slippery slope towards use of EPAS for people whose suffering was psychological, or non-somatic rather than physical, have also been claimed in the literature. Any abuse of euthanasia or physician-assisted suicide of people with quadriplegia, for reason of the disability, has not.

Doctors were seen by all informants who supported EPAS as needed in the operation and safeguarding of EPAS. Legal rules such as a demonstrated soundness of mind to make a decision about EPAS for oneself and assessment of the suffering underlying a request for EPAS require doctors to apply them. Informants also raised the need to involve family in the decision making involved in a request for EPAS. Although such involvement may in practice act as a safeguard, it was not often mentioned as a safeguard. Informants just liked to have their family involved in
decision making. Family involvement for purpose of care and support for the dying person was not raised. Dutch informants suggested that a safeguard might be to have open discussion about the decision to have EPAS in the context of *bespreekbaarheid*. *Bespreekbaarheid* is a Dutch phenomenon meaning open conversation of something that might be considered taboo, in this case, EPAS. One Dutch informant considered that opening frequent discussion of EPAS leads to normalising it towards a growing availability of it. Indeed, Kennedy (2002) in his study of the history of EPAS in the Netherlands, called "A well-considered death" ("Een weloverwogen dood"), discussed this open conversation or *bespreekbaarheid* as a typically Dutch approach. A taboo subject, or proposal, is, in the spirit of open enquiry, put on the agenda. This action then influences its inevitable, eventual acceptance, the longer public discussion is conducted. Open discussion of EPAS then, in the Netherlands, appears to be less of a safeguard than a preparation for acceptance of (having) EPAS.

Death and dying as a distant experience: Not many grassroots informants had had close experience with the dying of others with leaders having somewhat more experience. The literature confirms this finding as a wider social phenomenon (Aries, 1974, 1981; Becker, 1973; Borysenko, 1994; Gorer, 1955; Kastenbaum, 2000; MacNamara, 2001). Most informants saw death as relatively meaningless and many expressed agnosticism about any continued existence after death. Perhaps informants reflected something of Becker’s (1973) construct of repressed death in contemporary Western society when they said that they perceived most people as scared of death and dying. They themselves were not fearful. Those who did explain their non-fearfulness said that their experience with dying people had removed their fear or led them to live their life in an appreciative way. This difference between their private view of death and the public’s is reflected in literature, which shows a declining private fear of death the closer one is to the experience of it. (see Chochinov et al., 1995; Emanuel, Fairclough & Emanuel, 2000; Koenig, Wildman-Hanlon, & Schmader, 1996). Whereas most of my informants had little experience with the dying of others, they had of course had much experience with the “dying” of life with a whole physical body and had gone through dealing with and overcoming many of the significant losses this brought. In some sense they had already experienced *dying*, and this experience may have contributed to their lack of expressed fear of death. This analysis appears to be supported by the finding that

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some informants had overcome suicidal thoughts early in their transition from being able-bodied to being disabled and so did not see EPAS as applicable to themselves. Despite their own experience, they still supported EPAS for others and the Dutch described suicide or EPAS by others as courageous. At the same time informants acknowledged the emotional impact of suicide on family, friends and others. Those few informants who described their lives as essentially unsatisfactory, for reason of their experience with disability and who would prefer EPAS to end it, said that they had actually decided not to kill themselves for such apparently altruistic reason as an impact of such an act on others. I propose that these apparently contradictory private/public attitudes indicate a tension. On the one hand it involves a public view of death and dying which involves heroic projects as a mechanism to repress thoughts of them (Becker, 1997), thus attributing courage to killing oneself. For example, one informant illustrated public repression of the fear of death with his description of a Dutch advertising billboard, asking: “is there coffee after death?” trivialising a pervasive fear of death. On the other hand this tension involves a private experience of overcoming the dying, or losses, associated with quadriplegia and regaining these in the course of daily life, where this is not recognised as courageous, by themselves or by others. I will return to this theme in discussing the relationship between the informants’ views on EPAS and their daily life experience.

A sub-theme within “Death and dying as a distant experience”, which seems important to discuss separately was “A low knowledge of palliative care”: This sub-theme shows the informants as possessing little knowledge of the nature or availability of palliative care. This was more so for Dutch informants, but applies to both countries’ grassroots samples. Palliative care is an approach to medical practice practiced when people are close to death and curative treatment is futile. It also involves control of pain and engages with any of the dying person’s social, psychological and spiritual problems. It includes bereavement support. Palliative care is a holistic approach, encompassing patient, family and the community in its scope (World Health Organization, 1990). Half of the Dutch informants had never heard of palliative care (palliatieve zorg), probably as a result of the historically low availability of palliative care in their country (Fraeneke & Willems, 2000; Janssens, ten Have & Zylics, 1999; Zylics, 1998). Of those few Dutch informants, grassroots and leaders, who did know something about palliative care some indicated a poor
state of palliative care in their country but also saw it as improving. This understanding again reflects the literature on this point (Fraencke & Willems, 2000; Matthews, 1998; Zylics, 1998). In either country’s sample, of those who had heard of palliative care, few could well describe its principles or practice. Some perceived EPAS as an integral part of palliative care, allowing a choice as to the course one wanted to take at the end of life. Palliative care practitioners mostly exclude EPAS from their discipline (Enklaar, 1999; MacNamara, 2001). Leaders in both countries were better informed about palliative care. On the whole informants are probably reflecting a generally low public knowledge of palliative care in the Netherlands as well as in Australia (Enklaar, 1999; Zylics, 1998; Webster & Kristjanson, 2002). This is so despite an apparently high level of availability of palliative care in Australia (Palliative Care Australia, 2002) compared to the Netherlands. The informants’ low level of knowledge of the nature and availability of palliative care is probably closely associated with their distance from others’ dying experiences. However this would be less true of leader informants. Within the context of informants’ broad support for EPAS this low level of knowledge appears particularly significant, as various studies suggest that availability of palliative care is a factor which could reduce requests for EPAS (Enklaar, 1999; Ganzini, Nelson, Schmidt, Kraemer, Delorit & Lee, 2000; Waddell, Clarnette, Smith, Oldham, & Kellehear, 1996).

**Suffering and EPAS:** Most informants had no wish for EPAS themselves, least of all for reason of disability, although they could not always rule it out for the unforeseeable future. MacNamara (2001) also found that, in general, people are more likely to agree with the principle of euthanasia than to envisage themselves asking for assistance in ending their own lives (p. 21). Informants thought that unbearable suffering of various kinds are acceptable reasons for EPAS. The most often used phrase was “unbearable pain and suffering”. Physical pain was mentioned most often. Loss of dignity could also be a reason to have EPAS. Such loss included intrusive medical treatment, loss of quality of life or when “life [is] no longer being experienced as a dignified existence”, loss of cognition, bad quality of care, the meaningfulness of terminal illness, and fear of future pain or entering a nursing home. Fear of future suffering under conditions of terminal illness was also regarded as a valid reason to have EPAS. Terminal illness was sufficient reason in itself but
other conditions, which did not involve terminal illness, could also constitute enough reason to have EPAS. Leaders thought that public fear of dying, disability and illness and their equation with suffering was underlying the EPAS debate.

Depression was mostly not seen as a valid reason for EPAS because it was seen as a curable medical condition. However, virtually any other conditions, if judged unbearable by the sufferer, were seen as a valid reason to have EPAS. Unipolar major depression is now a globally widespread clinical condition, projected to become the leading cause of disease burden by 2020 (World Health Organization, 2003; Seligman, in Myers (1992, p. 145). Perhaps, in the minds of informants depression has thus been normalised as an acceptable part of the human condition, rather than as suffering. However depression is a major factor in requests for EPAS (Breitbart, Rosenfeld & Passik, 1996) and one study suggests that all terminally ill patients who expressed their desire for an assisted death had a major depressive disorder (Chochinov, Wilson, Enns, Mowchun, Lander, Levitt, and Clinch, 1995). The prevalence of depression and its role in requests for EPAS therefore make it very relevant to the discussion of EPAS. Physical pain, on the other hand, the most mentioned source of suffering by informants, does not often provide the sole major motivation for EPAS when dying (Breitbart, Rosenfeld, Pessin, Kaim, Funesti-Galietta, Nelson, et al., 2000; Chin, A.E., Hedberg, K., Higginson, G.K., & Fleming, D.W., 1999; Bascom & Tolle, 1996; Kissane, Street, & Nitschke, 1998; Lavery, 2001; Meier, Emmons, Wallenstein, Quill, Morrison & Cassell, 1998; Seale & Addington-Hall, 1994; Zylics, 1998). With good pain control, patients’ desire for EPAS declines (NIPO, 1996). Perhaps informants’ high rating of pain as a factor in EPAS requests is related to their low level of awareness of palliative care. Good palliative care is able to relieve much pain (Enklaar, 1999; MacNamara, 2001).

Informants often stated that “everything possible” ought to be done before EPAS is considered. But for most unbearable suffering was also an individually and subjectively constructed condition. This means that if a situation “is hopeless for yourself”, EPAS could be considered, which appears a position close to some of the Dutch policy on EPAS (Regionale Toetsings Commissies Euthanasie, 2002) and to criteria in the former Australian Rights for the Terminally Ill Act, 1995. Informants did not want to intrude into how others determined their own unbearable suffering. Despite most informants’ insistence that EPAS was not for them, especially not for
reason of their disability, some of the same informants who had asserted this would also allow EPAS for those whose experience of disability constituted unbearable suffering. Among those who were most absolute and adamant about the allowability of EPAS for anyone who had assessed for themselves that their suffering was unbearable were those who had assessed their own lives with disability as unbearable. But *unbearability* of suffering might be perceived differently by the person undergoing than how others might observe it. The example of one informants’ experience of extreme pain and suffering from burns and amputations in addition to his spinal cord injury, and a leader’s experience of absence of pain in a near-death experience, show the possibility of transformation of pain. In such transformation the pain is still there but is experienced differently as Wendell (1996, p. 179) described. And many informants had positively shifted their own ideas of what was unbearable suffering from disability such as quadriplegia.

Some informants wanted to reserve the allowability of EPAS for circumstances of extreme suffering only. But *extreme suffering* would be difficult to quantify. This would be more difficult in a culture which identifies unbearable suffering based on the report of the *patient*, as reflected in the Dutch approach (Regionale Toetsings Commissies Euthanasie, 2002), for example in the Chabot case, discussed in Chapter One (Griffiths, p. 80–82; Klozko & Chabot, 1998). The now redundant Australian euthanasia law, Northern Territory Rights of the Terminally Ill Act of 1995, allowed a subjective interpretation of unbearable suffering by the patient. Twenty three per cent of respondents to a Dutch survey (van der Maas, et al., 1991), cited *tiredness of life* as a valid reason for EPAS. Prominent Australian EPAS campaigner Dr. Philip Nitschke also appears to be getting public support in pursuing the allowability of EPAS along similar arguments (“Nitschke: Right-to-die civil disobedience”, 2002). Legal safeguards against abuse of EPAS are difficult to conceive of under these circumstances.

*Pain and suffering* are to a large degree socially constructed. Callahan (1993) confirms that pain is connected closely with psycho-dynamic as well as social factors. It is a highly complex phenomenon (Aldrich & Eccleston, 2000; Csordas, in Paterson & Hughes, 1999, p. 602) associated with losses of control, of dignity, and of meaning in life (Callahan; Paterson & Hughes, 1999). Suffering during dying is often connected to past unresolved issues (Enklaar, 1999). In other words the suffering that
my informants described, such as losses of dignity through inadequate care, undignified existence, meaninglessness of a terminal state, over-treatment and fears of future conditions, are real. A question arises whether there should be a public policy to medically “treat” this kind of suffering, much of which is socially constructed, by way of EPAS, as my informants appear to suggest. For one informant the answer was that this would be morally suspect but she could still not stand in the way of someone who wanted EPAS for such social reasons as inadequate care. Wendell (1996) says that a public notion that disabled lives are not worth living “lies at the heart of much theorising about abortion, euthanasia and health care reform, putting the welfare and security, and the social acceptance, of people with disabilities in jeopardy”. On the other hand she says that people with disabilities, with their extensive experiences of the limitations of medical treatment “are unlikely to support an ethic of life at any cost, or a reduction of individual’s rights to choose death” (p. 151). Ann McDonald, a person with an awful experience of growing up in an Australian institution (Crossley & McDonald, 1984) said that only when we improve the quality of the lives of people will we be able to ascertain whether they want euthanasia because “they think life with a disability is worthless or because they think it is awful” (Parsons & Newell, 1996, p. 54). The case of MacAfee (Gill, 1992), as that of others, has shown that it is the latter. When conditions improved they thrived as people.

The Dutch doctrine of force majeure, or defence of necessity, in justification of a doctor’s medical killing in the face of otherwise unrelievable suffering, is interesting to contemplate in this context. Inevitably the doctor’s perception of a person’s suffering from disability as arising from their impairment depends on their view of disability as belonging predominantly within a medical model or a social model. A doctor may not be able to change much about the level and nature of social support of a disabled patient. But if EPAS were allowed based upon individually and subjectively assessed unbearable suffering he or she may be able to “help” the “patient” in their medical capacity to have EPAS. A generally negative orientation of doctors towards people with disability (Gill, 2000) would suggest the medical model approach towards socially constructed suffering may often prevail. And of those issues that characterise the disability experience, that is dependency and vulnerability (MacIntyre, 1999), dependence on others is a major factor in requests for EPAS by
anyone, disabled or not (Van der Maas, van Delden, & Pijnenborg, 1991). It appears then, that whether or not EPAS could be quarantined to those judged capable of exercising their choice for having EPAS, that the complex nature of pain and suffering would make it difficult to judge which kind of suffering justifies access to EPAS. The general reliance on the medical role of doctors in assessing unbearable suffering therefore is questionable as much suffering presented as physical or mental pain is connected with social factors. This situation is further complicated by findings that suggest that treatment decisions at end of life were more significantly determined by the doctor’s individual characteristics, their medical training and socio-demographic background, than by the nature of the medical problem (Waddell, Clarnette, Smith, Oldham & Kellehear, 1996). Others have made similar findings (DiPasquale and Gluck, 2001; Pool, 1996). Such findings suggest that social factors do not only influence pain and suffering but also determine how that suffering is perceived by doctors who are those empowered to implement EPAS. In this social context, it is again difficult to see, despite the best intentions of those operating within the empirical-analytical paradigm in which EPAS is embedded, how application of rational rules and monitoring as safeguards can be effective.

Informants also suggested that sometimes EPAS was allowable to help the bystanders of a suffering person out of their suffering, either caused by the pain of seeing another’s suffering or by the burden of care. As the earlier example of apparent coercion to act on earlier expressed intentions for EPAS shows such bystanders may often be in a role of “advising” a family member on having EPAS. The dual meaning of care is that it involves both loving attention and a burden of cares. If not consciously, it is probable that one’s own interpretations of the suffering of another are conflated with one’s own burden, either from the difficulty of seeing another suffer meaninglessly or from a burden of care in anyone’s thinking from time to time. The importance and degree to which this dynamic would be present in any EPAS decision making would be difficult to discern and it is difficult to conceive of legal safeguards against it.

As pain and suffering are largely socially determined, the appropriateness of the multi-dimensional nature of palliative care as physical, psychological, social, and spiritual, in response to the pain and suffering of dying people, is clear. The same dimensions of suffering are at play during life as when we are close to death and
suffering at the time of death is influenced by how we dealt with suffering over the course of a whole life (Enklaar, 1999). A multi-dimensional response to suffering at any time seems therefore an appropriate response. Therefore palliative care should not be seen as the only assistance to live well towards life’s end. If we really wanted to ensure that “everything possible were done first”, as my informants insisted, to relieve any suffering before allowing a request for EPAS, a society should also invest in social responses to causes of suffering such as that would not allow the circumstances that justified Ann MacDonald’s and MacAfee’s claim to a right to be killed for reason of their socially constructed awful lives. As the psycho-dynamic and social dimensions of suffering indicate, its amelioration requires both individual and public responses.

Informants often raised examples of extreme suffering based on media reports. When asked whether their disability experience had influenced their views on EPAS, most said it had not. Where it had, the main reason was that it had given informants insight that there were sometimes circumstances under which some people did not want to live. This response seems consistent with their view that they supported EPAS for others but did not see it as very relevant to themselves. After all they had overcome significant losses already. However it did not seem consistent with their experience of overcoming significant threats to their wellbeing, in a different response to suffering than is EPAS. Later this apparent inconsistency will be explored further.

Rights, choice and compassion: Informants believed that suffering persons had a right to choose the way they would end their lives. For some informants a right to end it by EPAS was an expression of compassion towards that person in “helping” them out of their suffering. But most informants did not talk about compassion in the context of EPAS at all. Their view was that everything possible to ease suffering should be done but it was the person’s choice to say when they had had enough. Within the grassroots sample the small group of those who experienced an unsatisfactory life and who would prefer EPAS for themselves placed a high emphasis on others’ rights to choose for EPAS regardless of the type of suffering. An example given by one informant from this sub-set was that it was a “compassionate” act to “put down” his suffering aunt who was not capable of choosing. In the sub-set of those with a very high fulfilment in life the emphasis was on care as a
compassionate act in relieving the suffering and to reserve EPAS for “extreme suffering” only. However both groups deferred to a person’s right to make their decision, like most of the rest of the sample. Clearly compassion for the first group was not thought of as *suffering with*, the meaning of compassion, whereas for the second group it was. But *care* necessarily involves an active engagement with the suffering person and compassion in relation to EPAS necessitates engagement with the full range of its psycho-social issues (Gill, 1992). The theme for most of the sample is to give the necessary care but, in the final instance, accord to the individual a right to choose EPAS regardless of their type of suffering or whether it can otherwise be ameliorated.

In contrast with the grassroots sample’s theme of a right to individual choice to EPAS, both countries’ leader samples saw self-determination as limited by a context of relationships to others. Australian leaders showed opposition to EPAS policy, as for them individual autonomy was not a sufficient reason to allow it. They perceived that people with disabilities would be vulnerable to abuse of EPAS. However, grassroots informants also understood that the exercise of rights involves others and is not a purely individual pursuit. But a certain interpersonal distance was involved in allowing others to exercise their rights. This distance allowed others to tend to “their business”, meaning their choice of EPAS or otherwise. The informants recognised an emotional impact on others arising from anyone’s choice to have EPAS. As mentioned earlier some of those who experienced their lives as essentially bad had decided against their suicide in order not to upset others. EPAS was considered less impactful. But here doctors could face legal prosecution, a point raised by both Australian and Dutch informants, and they had to bear the administrative burden associated with reporting EPAS, a point raised exclusively by Dutch informants. These were given as reasons why doctors should have a *choice* whether or not to engage in EPAS. Some thought it best that, in order to minimise an emotional impact on doctors and on the recipient of EPAS, *professionals* such as *euthanasia specialists* could be employed who would be relatively detached from the person receiving EPAS. As far as impacts on family was concerned, EPAS was thought to be less emotionally impactful than suicide and the impact would be further reduced by the professional participation of a physician. There was some suggestion in the Dutch leader sample that a doctor’s non-reporting of EPAS would also lessen
the emotional impact on the family by keeping it a private affair. Physicians were needed for their professional medical skill, an instrumental role, and also to give the act of EPAS a certain professional legitimacy. Some contrary views existed about the doctor’s participation in EPAS, which can be seen as a natural part of his medical role or as compromising her role as healer. The latter view could lead to the view that a ‘distanced doctor’ should carry out EPAS: “Let it please be done by people who have no other role to play, in a kind of anonymity”. Indeed such independent and distanced physicians appear now to have been established with the Dutch initiative of physicians trained in giving second opinions on EPAS (“Landelijke dekking SCEN”, 2003). But doctors, the informants said, should not be the only decision-makers on EPAS. Family should be involved also in the decision because doctors were “not necessarily an expert on quality of life”. Exercising one’s right to have EPAS thus appeared to be characterised by detached relationships which revolved around decision-making; some distrust of doctors’ capabilities of assessment; privacy; minimising adverse impacts on those other than the person receiving EPAS; and legitimisation of the act of EPAS.

In the sub-theme “Non-autonomy: Complexity and confusion”, within the main theme of “Rights, choice and compassion”, Suffering was thought to be included in the experience of some people who have developmental disabilities and mental illness or who are in a vegetative state. There was some support to extend the right to choose EPAS to these groups although others expressed concerns and opposed this. Reasons for their suffering appeared to include any medical conditions but for some also the condition of their disability itself. Some drew comparisons with the Nazi euthanasia program and leaders drew attention to unequal power relationships between people with intellectual disability and doctors. Some leaders cautioned that EPAS was a highly complex matter and societal motives underlying it may be “suspect”. For those who supported giving at least some people in these categories a right to choose EPAS, doing this was a source of uncertainty and confusion. They did not seem to want to deny the right to choice to them. They might be suffering but the question of who decides for EPAS in situations of unclear mental capacity confused them. A proposed solution was to let ‘parents’, in concert with doctors, as a private act, make the decision, because they knew their “child” best. Some suggested that the legitimacy of such acts of EPAS might come from the
current legal right to abortion, true for the Netherlands and for Western Australia. They were “glad” not to have to make decisions in such circumstances. In addition, the grassroots sample raised none of the concerns about a limited physician ability to make assessments of suffering for this group whereas they had for others. This might indicate that notions of a low valuation of people with cognitive impairments and confirmation of the high social valuation of intelligence and rationality (Goleman, 1996; Saul, 1992) were present in informants. In fact leaders pointed to the presence of a disability hierarchy where those with cognitive and mental impairments were ranked low. The support that most informants gave EPAS has to be qualified by a sense of the complexity of the issues some of which they had no answers for. Some of the answers that some did propose appear to be based on negative social stereotypes of intellectual disability. It is difficult to see how legal safeguards would apply other than to prohibit EPAS for those who are not capable to make such decisions. But medically assessing capacity for anyone is problematic, as has already been pointed out.

In summary, most informants’ views of EPAS seem close to mainstream Western views on the issue. They are supportive of legal, safeguarded EPAS as an individual choice in response to unbearable suffering, defined by the suffering individual. However their concepts of euthanasia and physician-assisted suicide are mostly unclear and they know little about their safeguards. Most have little experience about the realities of dying, including palliative care. These findings suggest a personal distance from dying and end-of-life decision making issues, which is emphasised by their support for EPAS for other but mostly not for themselves. All these elements of their background knowledge to their views on EPAS are also true for the general public. Their construction of EPAS appears inherently problematic in its ability to control abuse of it. The lack of notable differences between Dutch and Australian views suggests they are influenced by factors that go beyond any regional preferences. Their view of EPAS as predominantly reliant on the mechanism of individual choice appears related to the dominant Western values of individualism. This suggestion is consistent with literature which argues the strong role of individual autonomy in EPAS (Autonomy, 2002; Batavia, 1991, 1997; Dworkin, 1995; Dworkin, Nagel, Nozick, Rawls, Scanlon, Thomson, 1996; Enklaar, 1999; Griffith, Bood & Weyers, 1998; Pijnenburg, 1998; Sobsey, 1994) and that which
suggests that dominant Western individualist values underlie much of the interest in EPAS (Callahan, 1994; Callahan & Hanson, 1998; Griffiths, Bood & Weyers, 1998; Griffiths, Bood & Weyers, 1998; Magnusson, 2002; Mann, 1998; ten Have, 1998).

The low awareness that informants had on the nature and practice of EPAS or of palliative care and little direct experience with the dying of others, suggests that the rights to choose EPAS that they believe (ought to) exist, are not well founded. This finding indicates that an important criterion in the normal choosers exercise of individual autonomy was not met: that is to act with understanding (Beauchamp & Childress, 2001). Understanding is enhanced by being well informed but my informants were not.

Most informants supported EPAS for others, if strictly safeguarded, primarily by legal rules but their construct of suffering and regard for an over-riding importance of individual choice negated their stated intention of containing abuse of EPAS. Their support for strict safeguards occurred against a background of their lack of clear concepts of euthanasia and physician-assisted suicide; their low level of close experience with the dying of others; their low level of knowledge of palliative care; and a construction of subjectively defined unbearable suffering and individual rights to choose EPAS. As Newell (Newell, 1996; Parsons & Newell, 1996) indicated, restricting EPAS to the competent only is problematic because, if we thought that EPAS was a legitimate answer to suffering, only the competent could be assisted in this way. Further, Newell thought that the subjectivity of suffering made regulation of it difficult, as my findings also illustrate. Clearly, internal inconsistencies, such as the tension between individual autonomy to choose EPAS and subjectively defined suffering, exist within my findings. Ewin (2002, pp. 146–147) noted this sort of problem when he suggested that autonomy and compassion to relieve suffering work in different directions. In this view emphasis on compassion might lead to relieving suffering by means of EPAS, including of those who do not have the rational agency to decide for themselves. Emphasis on autonomy may lead to EPAS in absence of great suffering to be overcome. This would make it difficult to regulate against abuse. Therefore he insisted on the necessity of limiting EPAS to those who are competent. But if the limits to a right to EPAS are indeed socially decided (Ewin), then according to my findings there are no limits. This is because my informants emphasised the right to choose based on self-assessed subjective
suffering which over-ruled the strict safeguards they insisted on. Some believed that some people with intellectual disability could exercise a right to their individual autonomy in deciding to have EPAS if they were suffering. EPAS could also be performed on those not judged to be capable themselves, in order to relieve their subjectively determined suffering because “everyone has that right” in “a free world”. Such reasoning might be a misuse of the concept of individual autonomy in a similar way to that described by Dutch physician Pijnenburg (1998). She stated that the one-dimensional-focus on autonomous choice had led to growing attention being paid to the “entitlement” of those who are not competent and autonomous to “receive an end to their life because of the presence – in the view of others – of unbearable and hopeless suffering” (p. 246). Such misapplication also appears reflected in Gomez’s (1991, p. 137) feeling that in the Dutch EPAS practice something more than “an argument from autonomy was at work”. He perceived a sentiment that certain patients were better off dead and that it was humane to kill them. To further complicate matters, it appears that for most informants compassion played a very limited role in EPAS decision-making, as the EPAS process depends on detached relationships. The nature of compassion requires an active engagement with the suffering of another but the nature of EPAS emphasises individual agency to exercise a right to the outcome of death as a means to escape suffering and on the regulatory mechanisms that establish and implement such a right. As one Dutch leader said, for most people EPAS is a technical issue of “protocol” and “euthanasia guidelines”, but “not the existential subjects that it turns around”. The social phenomenon of an emphasis on rational, technological solutions (Goleman, 1996; Saul, 1992; Taylor, 1992), and a de-emphasis on the “personal, social and spiritual relationships that give our lives a moral texture and a sense of meaning – of self-worth, belonging, identity, purpose and hope” (Headey & Wearing, cited in Eckersley, p. 9) is not limited to EPAS but is a wider social trend. In relation to EPAS, this dynamic appears to leave little room for true compassion and care as it is one that operates outside deeper relational contexts. The dynamics of EPAS in these findings involve not only the individualistic normal chooser on behalf of themselves but on behalf of incompetent others too. This increases the vulnerability of the latter (Ells, 2001; Reinders, 2000) to a “definitive answer” (Reinders, p. 205) to their suffering: EPAS. These appear to constitute exactly those reasons why Hendin (1997) argued the impossibility of devising workable guidelines as safeguards for EPAS because “they fail to address
the inter-active nature of the decision-making process that is at the heart of euthanasia and its abuse” (p. 1491). In Gill’s (1992) terms, my informants’ engagement with the full range of individual and social issues in their responses about EPAS appears lacking. If good reasons for autonomous agents’ moral choices are indeed those that do not contain internal inconsistencies and if good (moral) choices ought to be universalisable (Kant, cited in Kerner, 1990), then my findings seem to offer little support for EPAS on either criterion, on the basis of a rationalist analysis.

In conclusion, my grassroots informants based their support for EPAS on limited, indirect knowledge of key concepts. An individual’s subjectively defined suffering as unbearable should be eased if possible but ultimately it depends on the individual’s choice whether they have EPAS in order to deliver them from suffering. According to them, the EPAS process must be safeguarded with regulation and involves personal detachment between patient and doctor. This construction of support for EPAS is internally inconsistent. It appears to pose vulnerability to abuse of EPAS through a tension between acceptance of individually assessed unbearable suffering and application of a misplaced concept of non-relational individual autonomy in choosing EPAS. This tension appears not to allow effective application of regulation of EPAS. Personal detachment between patient and doctor may be a barrier to receiving the care one needs to relieve one’s suffering.

6.3 Research question 2

What are the life experiences and views of Dutch and Australian people with quadriplegia and leaders in Dutch and Australian disability movements, with regard to issues of vulnerability, autonomy, dependency, interdependence and independence?

Three main themes emerged in response to this research question: ”Vulnerability: Physical, psychological and social factors, threats to wellbeing”; “A good, difficult life, responses to threats to wellbeing”; and “Value change and personal growth”. In turn these contain thirty-one sub-themes.

All informants had experienced a significant threat to their physical integrity and their psychological and social wellbeing from their acquired disability, quadriplegia. Their immediate disability experience was also characterised by many
deeply felt losses. The differences between their life prior to disability and their life since were so stark that they often described it as one of having had “two lives”. Murphy (1990), an anthropologist who described his own experience of progressive paralysis, applied exactly this phrase to his experience of life with and without disability. But most informants had overcome, or outgrown, many of these threats and losses and transformed their experience into one of a fulfilment or wellbeing.

Vulnerability: physical, psychological and social factors – threats to wellbeing: Threats to informants’ wellbeing came from informants’ health problems, inadequate health care and human services, negative public attitudes and wider social trends. These individual and social levels of threats to wellbeing appear to match Cocks & Duffy’s (1993) theory of heightened vulnerability of people who have disabilities, of a social theory of disability (Wendell, 1996) and of the joint personal and social nature of human suffering in general (Cassell, 1991). Many informants had experienced severe health problems arising from quadriplegia. At times these had been exacerbated by mistakes made by health carers or doctors. The effects of health problems such as pressure sores (decubitis) can lead to long periods in bed which in turn can make a person more vulnerable to further health problems, iatrogenic or other when in hospital, and to social isolation. Many Australian informants complained of a lack of attention to their psychological wellbeing when in rehabilitation and of inadequate or inappropriate attention paid to their relationships by rehabilitation professionals. On the other hand some Dutch informants expressed that they especially enjoyed their rehabilitation time because of the close relationships they had experienced. Both views thus appear to indicate the importance of relationships in human wellbeing. Whereas some had good relationships with general practitioners post-rehabilitation, many described an ambivalent or off-hand attitude from their doctors. They described negative public attitudes, which suggested that their disability projected an image of mental incompetence and of being an oddity in the minds of others. Also, leaders said that people with disabilities were often treated as care objects rather than as people welcomed in their communities. Of course as soon as one is seen as different to the social norm or as less than human, one generally becomes more vulnerable to ill-treatment, including in health services, support services and even to having one’s life shortened by death-making practices (Wolfensberger, 1990, 1992, 1998). In my
informants’ experience, state bureaucracy and inflexible attitudes in accommodation support services had an adverse impact on obtaining needed aids, appliances, and housing and on the flexibility of care arrangements.

Informants described an overall negative view of society presented in the sub-theme “Vulnerability within a context of social decline”. They spoke of a social and environmental decline, characterised by social estrangement, and an over-emphasis on technology with associated threats from new bio-technologies. Some leaders suggested that a value-vacuum had occurred after people had turned from religion. Dominant social values of individualism, materialism, progressivism and a fast pace of change had filled this vacuum and appeared to underlie these trends. They have been identified as current, wider social developments (Capra, 1982, 1996; Cocks, 1994; Eckersley, 1998; Goleman, 1996; Popenoe, 1994). These dominant social beliefs and trends have been identified as increasing the vulnerability of people who have disabilities (Cocks, 1994, 1998; Cocks, & Duffy, 1993; Wolfensberger, 1998) as they have been identified as underlying value systems of current social and environmental decline (Capra, 1982, 1996; Cocks, 1994; Eckersley, 1998; Goleman, 1996; Popenoe, 1994; Taylor, 1992).

Within this social decline, informants simultaneously saw an upward trend in societal support for people with disabilities. But this trend was mainly associated with better physical access, in other words with the technology of disability issues rather than with the substance of relationships. Some leaders confirmed that the disability movement was more interested in the pursuit of structural change, such as in access to employment, education, transport and the built environment than in strategies to facilitate good relationships. Again, these findings may find a parallel in social trends that emphasise technological approaches to problems as part of the Western ideology of progressivism (Eckersley, 1998; Taylor, 1992). But it may also be related to the discrepancy between personal wellbeing and a negative view of society’s future trend. That is, personal wellbeing is relatively independent of material circumstances but not of social relationships (Eckersley, 1998).

Informants saw EPAS becoming more widely available as part of a growing social tolerance towards social phenomena such as abortion and drug use. This view is consistent with the informants’ stance on EPAS, which was that it was a legitimate choice for individuals to make, should they wish to do so: apparently a stance of
tolerance of individual choice. The Dutch historical development of a growing acceptance and adoption of EPAS has indeed been identified by the well-known Dutch policies of tolerance towards drugs, abortion, and sexuality (Kennedy, 2002). Griffith, Bood & Weyers (1998), in discussing EPAS, actually dubbed a neutrality of government with regard to private morals and the values that they are based on a principle of tolerance. Both Dutch and Australian informants referred to ‘tolerance’ in explaining a growing acceptance of EPAS, indicating perhaps that the mechanism of individual choice is part of a universal liberalism, rather than exclusively part of a Dutch national culture. A few informants saw the probable wider availability of EPAS as associated with a lack of a sense of care towards one another, described as easy going.

However, most informants, apart from some Australian leaders, drew no negative conclusions from the two scenarios they painted. They did not see any dangers in a rising acceptance of EPAS and a simultaneously declining society although leaders also expressed some uncertainty. They referred to their faith in strict safeguards with EPAS. Some informants saw EPAS as an issue that was peripheral to broader social trends. The Dutch, in addition, relied on the safeguard of ongoing public discussion. In general, informants were disbelieving about the possibility of abuse of EPAS. Only one grassroots informant drew a connection between the spirit of the times and implementation of the strict safeguards that were needed in any implementation of EPAS policy. I suggest that Reinders’ analysis which he bases on Nagel (in Reinders’, 2000, pp. 179–180) and which he applied to family-carers of people with intellectual disability, might explain this apparent paradox. Many people with quadriplegia would have experienced some improvements with regard to physical access to public areas and have relatively better access to employment and education than people with cognitive impairments for instance. A notion that things are getting better therefore appears logical. Despite their beliefs about a decline in the public area, they build their belief on improvement in their personal case on private experience. To do otherwise is to live with too much doubt about their rationale for existence and hopes for a continued good but difficult life. This explanation fits with Reinders’ (2000) suggestion that people are unable to simultaneously hold an objective and a subjective view of oneself because the objective, detached view devalues their private experience.
Some informants suggested that factors such as pressures on health care and cost–benefit analyses of care might contribute to a wider adoption of EPAS in the future, and such concerns have been raised elsewhere. Given the devalued social status of people with disabilities one would think that these would be legitimate issues for disability movements to take up. However leader-informants indicated there was little interest within disability movements to do so. The diverse positions taken on EPAS within the membership of disability movements; the perceived impracticability of the issue, and its complexity; and a fear of opening up a Pandora’s box with regard to the legitimacy of life with disability, have resulted in inaction. The first reason might be an illustration of the Western socially normative situation of an absence of a “guiding story” (Hugh Mackay, in Eckersley, 1998: 11). The dominant social value culture is one of respect for individual choice, and, in a vindication of Reinders’ (2000) concept of narrow morality, the debate was stalled. No collective action could be undertaken. The second reason of impracticability seems to once again relate to the tendency of our times to value the technological, or the material, in this case action on structural change, over those things which give our lives a moral texture and meaning (Headey & Wearing, cited in Eckersley, p. 9). The third reason reveals the fragile social position of people with disability and the difficulties of advancing the interests of the devalued.

A good, difficult life: responses to threats to wellbeing: Informants had made conscious efforts to reduce threats to their wellbeing. A discussion of their responses gives a context to their outgrowing of feelings of dependency and to reduction of their vulnerability. Threats to the informants’ wellbeing have been discussed above and included physical, psychological, and social dimensions. Most regarded their present life with disability as good. Some perceived their lives as even better than it had been pre-disability. Such findings are confirmed in many studies involving people with disability, including quadriplegia (Cameron, Titus, Kosti & , Kostin, 1973; Eisenberg & Salz, 1991; Fine & Asch, 1988; Ray & West, 1984; Stensman, 1985; Titley, 1996;Wacker, Harper, Powell & Healey, 1983; Weinberg, 1984; Yerxa & Baum 1968). Many informants pointed out that their good life had not arrived without their ongoing effort to make it so. The first thing that had happened post-injury was a period of grief over the significant losses that they had suffered. But
there was a point where they chose to embrace and accept their new circumstances and, as they said, “get on with it”.

A process of shifting their criteria about what kind of life was acceptable seemed to play a role in this choice. This acceptance was not an attitude which had removed all disability-related frustration from their lives but was an acceptance of the fact of their impairment: that it was so. Some expressed their thought, previous to their disability, that death might be preferable to life in a wheelchair. But the experience of disability, and of subsequent health problems, had moved most informants’ internal limits of what might be levels of suffering they could live with. Nevertheless further limits they now set were loss of cognition, artificial respiration or being restricted to bed. Those who described their life as bad did not appear to have shifted their limits. Again this phenomenon of choosing how to regard one’s own suffering has for example been described in parent-carers of children with developmental disability (Reinders, 2000, p. 204) as it has for others (Luke, 1987; Wendell, 1996, p. 179). Those who described their lives as bad and for this reason desired EPAS for themselves appeared resistant to making such a choice. They preferred not to change.

Most informants understood the expression of negative public attitudes towards them because they recognised these in themselves prior to acquiring quadriplegia. They also recognised that people with a cognitive impairment receive less public acceptance than they did, and that among people with disability a hierarchy of human worth, relative to types of disability, appears to be present. The dominant social value of rationality would seem to be involved in such ranking, raising one’s vulnerability with one’s level of perceived lower intelligence. This ranking process appears to be deep-seated as it was found both among people with disability who had experienced a shift in their own thinking about what kind of life was worth living and among the general public. As I will discuss below these attitudes are relevant in discussing the informants’ attitudes to EPAS.

Informants were successful in using strategies to deflect negative public attitudes away from them. These ranged from ignoring them to active verbal riposte. In between those were responses that demonstrated their shared humanity to others, including ice-breaking, being clear and direct about one’s needs, and the use of humour. Those who were not able to achieve an acceptance of the fact of their
impairment and, as a result, did not feel good about themselves, found it difficult to accept being accepted, as they were, by others.

Informants had suffered significant losses as a result of acquiring quadriplegia but had overcome many of them. After losing friends and partners they had found new friends and sometimes, partners in a context of deeper, more meaningful relationships than they had had before. Relationships were key to informants’ wellbeing. They added self-worth and meaning to their lives as they were able to receive support and to contribute in such relationships. The significant threat that their impairment had caused to their physical and social wellbeing had initially prompted them to consciously reach out to others, as a means to an end of support and security. But the resulting relationships represented the substance of their wellbeing, a flourishing, which was more than support or security. Good, supportive relationships had enabled informants to overcome feelings of indignity caused by their losses of personal control over basic bodily functions and by dependency on others. This dependency on others was particularly undignified when assistance to them was given in an uncaring manner. But loss of independence and dependence on others were, for a time after they acquired their impairment, inherently experienced as the worst effects on their dignity. This is not surprising in a Western society which values individual independence and where the dependency of disability, that is needing others for very basic personal tasks, is seen as humiliating (Wendell, 1996). Now, the quality of their relationships had enabled them to reframe their independence as that personal freedom they received through the care and assistance from others. There was no humiliation in this kind of relationship. The effort required in living in dependency and in interdependence in these ways was an ongoing process where this effort constituted much of the rewarding relationship dynamic they were in. Therefore the effort was part of the essence of their wellbeing. However, those who experienced their lives as bad had not overcome their feelings of dependency on others. There was some acknowledgement by them that this was at least in part due to their own attitudes towards their disability and their non-acceptance of the fact of it.

In discussing EPAS informants did not talk about autonomy but applied an approach to suffering which incorporated an overly individualistic emphasis on one’s rights to choose EPAS. No themes emerged of choice, or (disability) rights in
responding to this second research question, at least not in the sense that they used these concepts in characterising their views on EPAS. As mentioned above, they had reframed their sense of independence (as a concept that is close to autonomy as self-rule) in relational terms. The types of committed personal relationships that were required to enable them to do this reframing are, as MacIntyre (1999) argues, at odds with “widely influential conceptions of practical reasoning” (p. 113). In the more general conception, he says, the question of commitment to others is left open because there is no concept of a debt to apparently unconnected others in a non-voluntarily undertaken relationship or transaction. On the other hand, within my informants’ view of interdependence, they knew that “one hand has to wash the other” and that “anything can happen to you”, meaning that independence and therefore unconnectedness and non-commitment to others are not reflective of reality. Arising from it are two types of relationships. One kind is “designed for and justified by the advantages of the parties to the relationship” which are “governed by the precepts of rational choice”. The other is “those relationships that are the outcome of sympathy, of affective engagements that are voluntarily undertaken”. The crucial difference between the two, he says, is that the demands of sympathy and those of rational choice are distinct and confusion results from combining the two. “The moral requirements imposed by rational choice extend only to those who are or may be our partners in cooperative bargaining”. Thus many people who lack the cognitive wherewithal to be such partners fall outside such a mutual relationship. Commitment to them therefore becomes optional if rational choice is the only guide. My informants did not apply such rationality to the relationships that sustained them. To the contrary, most treated their contracted carers as trusted family. But they also identified people with cognitive or developmental impairments as more vulnerable than them. And a hierarchy of a sliding scale of human worth related to types of disability existed among people who had disabilities themselves, suggesting a deep-seated sentiment in the human psyche of some people being less than fully human.

Value change and personal growth: Changes in the informants’ attitude towards their own impairment had resulted from their reaching out to others in response to significant threats to their physical and social survival and wellbeing. As presented in the third main theme, “Value change and personal growth”, these changes in attitude amounted to a change of worldview, a personal value change.
Informants’ perceptions of their world as more social, as involving a degree of trust and letting go of personal control and as involving a greater degree of candidness have changed the way their social world operated, and for the better. This finding of positive value change confirms earlier studies involving people with disability, including those with quadriplegia (Bach & McDaniel, 1993; Crewe, 1996; Keaney & Glueckauf, 1993).

As Crewe (1996) has also found, most of my informants signalled a sense of personal growth as they became aware of their changed values pre- and post-disability onset. Indeed my informants reflected the changes in values, priorities and self-understanding that various studies have found (Crewe, 1996; Keaney & Glueckauf, 1993; Stensman, 1985; Watson, Cunningham-Burley, Watson & Milburn, 1996) found. Those informants who reported no personal value change were those who had chosen not to change and who reported an unsatisfactory life. Most informants, who also reported a sense of wellbeing, did report personal value changes pre- and post-disability. Some had consciously adopted a view of the social world as interdependent. Those who reported very good or better lives compared to before they had quadriplegia, reported little value change but experienced ongoing personal growth. This was because their values pre-disability already closely matched those that the main sample had acquired post-disability experience. This finding appears to confirm previous studies which underlined that, as well as social support, one’s personality pre-spinal cord injury plays an important role in adjustment to quadriplegia (Bracken & Shepard, 1980). Of course, human flourishing in interdependence is possible, whether or not one has a disability, or whether one experiences the significant threats to one’s physical, mental and social integrity such as presented by old age (Vaillant, 2002) or when dying (Byock, 1996; Thomas, 2001). This is because it is a personal choice to live life in ways which may or may not lead to flourishing, as my informants experienced, a choice Reinders (2000, p. 204) also referred to in relation to family carers of their children with intellectual disability. However, a significant threat to one’s integrity, such as the onset of quadriplegia represents, is a powerful stimulus to act sociably, and provides an initially unintended route to flourishing. Experience of a significant disability, especially when projected to last for one’s lifetime, probably merely magnifies the more normative perception of the human condition of life without such disability.
The effects of informants’ personal value change, arising from their practised interdependence and sociability, were two-fold. Firstly, they enabled them to outgrow (Cassell, 1991; Jung, in, Wilhelm, 1962) or transcend (Wendell, 1996) the significantly felt problems of dependency, loss of independence and indignities arising from this situation. Secondly, they had begun to flourish as individuals within community with others. Within their private life most informants came to exhibit what MacIntyre (1999) calls prerequisites of independent practical reasoning. They also exhibited a resulting flourishing, where flourishing is acting virtuously arising from their engagement with the commonly unacknowledged aspects of themselves: dependency and vulnerability. MacIntyre proposes that virtues include acts of compassion, justice, courage, candidness, generosity, and temperateness. Independent practical reasoning involves the development and application of virtues as well as self-knowledge arising from “participation in a set of relationships to certain particular others who are able to give us what we need” (p. 99). These are prerequisites to an ability to choose possible, realistic personal futures for oneself. According to MacIntyre, a human being’s life flourishes “as a whole”, when an individual learns through “experience about the places both of independence and of dependence on others in the different stages of a flourishing life” (p. 113). The learning of a practical reasoner is that of “find[ing] one’s place within a network of givers and receivers in which the achievement of one’s individual good is understood to be inseparable from the achievement of the common good” (p. 113). My informants did exhibit such virtues as courage, patience, humour, trust and empathy for others. They also showed the social skills necessary to initiate and maintain their relationships. They showed an awareness of their states of perceived independence resting upon the assistance received from others in states of dependency, when they spoke of their independence within the disability experience. They understood their wellbeing as being closely associated with that of others and showed it in their actions.

Informants were able to outgrow their initial problems of their dignity being adversely affected by loss of independence and dependence on others because they chose to acknowledge their own states of vulnerability and dependence as a necessary part of a process and which also incorporated independence. Their integration of dependence and attendant vulnerability thus lead to living their lives
as, what MacIntyre calls, “life as a whole” (p. 113). Thus, a flourishing life occurs within a context of polarities, such as independence and dependence, necessarily involving tensions and change. Practical reasoners use their knowledge to make judgements about what parts of life are best accepted and which not. These judgements must involve both sides of the polarities, such as dependence and independence. Ignoring one side leads to a life with little personal growth, as those informants who experienced their lives as unacceptably bad appeared to demonstrate. They felt unable to choose to accept dependence as part of (their) life and continued to crave for their lost independence. As a result they could not flourish within their poor relational context. Paradox, acceptance of it, and personal growth are thus inseparably connected. In other words the nature of the human condition, or suffering, is paradoxical and involves entropy, expressed in our inevitably fragile and decaying bodies. A significant threat to survival or wellbeing, such as quadriplegia represents, can prompt one to see this and act on this reality. It is by embracing that reality that, in the continued presence of some of the outer phenomena of difficult circumstances that tend to give rise to suffering, informants outgrew the perception of their suffering and attained a level of personal wellbeing or fulfilment. Such individual growth, or “transformation experience” (Reinders, p. 176), within community, as experienced by my informants, was the essence of their human wellbeing, as also described by MacIntyre and others (Byock, 1996, 1997; Luke, 1987). Indeed Reinders (2000, p. 166) indicated that the enrichment one receives from such growth lies in the experience of making the effort rather than a goal itself. The outer phenomena of suffering are thus still there but in acknowledging and living with the paradox of life, life is perceived differently.

Much of MacIntyre’s interdependence framework seems reflected in the private experience of most of my informants. Where not, their negative experiences of life may be further evidence of the validity of MacIntyre’s theory. His theory, which draws on a holistic concept of our human nature, in the light of this study, appears as a practical, productive and sustainable response to the human condition. MacIntyre’s concept of flourishing is further expanded and supported by Jung’s theory of outgrowing insoluble and fundamental problems of life as it is by Byock’s (1994) and Cassell’s notions of suffering, namely as individuals’ enlargement in outgrowing suffering.
In conclusion, my informants’ private experience of human flourishing through their responses to great threats to their wellbeing closely reflects MacIntyre’s theory of the possibility of flourishing through one’s acknowledgement of both human dependence and independence as part of the human condition. The next section will compare how the informants’ responses to research questions 1 and 2 may relate to each other.

6.4 Research question 3

What relationship may exist between the experiences of, and views on, autonomy, independence, dependence, vulnerability and interdependence and the informants’ views on euthanasia and physician-assisted suicide?

Dutch and Australian grassroots informants commonly used two fundamentally different value frameworks in answering research questions 1 and 2. They used the interdependence framework in describing their experience of vulnerability, dependence, independence (autonomy) and interdependence. They used that of individual autonomy in describing their perspectives on EPAS. In the interdependence framework they found personal enrichment in the experience of making a social effort and of developing individual phronesis, or practical wisdom. In the individual autonomy paradigm they pursued the goal of elimination of suffering through EPAS.

The significance about these different responses to the two questions is that each describes the use of different values in approaching very similar questions of suffering. In the disability experience informants applied the values of the interdependence paradigm to the keenly felt losses of independence and indignities arising from it, including others’ attitudes towards them and inadequate care. Good relationships and their ongoing efforts towards these, were key to overcoming their losses. Their efforts required psycho-dynamic changes which resulted in a personal value change, culminating in outgrowing their initial problems and their gaining of personal meaning, wellbeing, or flourishing. In giving their perspectives on EPAS, informants approached suffering, such as from losses of dignity from physical and mental conditions, loss of meaning, inadequate care and medical treatment, by allowing an individual choice to be medically killed. They did also want to do
**everything possible first** to alleviate suffering but such actions related mostly to medical treatment which did not involve the same relational dynamics of personal engagement that they used in their private lives.

One might suggest that the two questions are about two fundamentally different issues where one is about how one lives daily life and another about what to do about unbearable suffering when dying. Therefore no meaningful comparison could be made between the responses to the two questions. This appears an incorrect proposal, as most informants did not limit kinds of suffering, which legitimised requests for EPAS, to a terminal condition. Nor did they circumscribe *unbearable suffering* by some objective limits, as they mostly left its assessment to individual, subjective judgement. The kinds of suffering encountered differently in each situation are comparable.

The similarities in the kinds of suffering that informants outgrew in their private experience of disability and also tried to address through a public, legal policy of EPAS, become more apparent when considered in Chochinov, Hack, McClement, Kristjanson & Harlos’ (2002) analysis of *dignity*. Their three elements of dignity include *illness-related concerns*, including symptom management and preservation of independence; a *dignity-conserving repertoire*, involving the way one looks at one’s own situation and personal actions that bolster one’s dignity; and a *social dignity inventory*, referring to “social concerns or relationship dynamics that enhance or detract from a patient’s sense of dignity” (p. 439). All three dimensions were present in the suffering that my informants described in their responses to each research question. In informants’ daily lives they had experienced effects of their impairment and associated health problems. They had changed the experience of suffering from these conditions and from others’ attitudes and care, by changing their perceptions of them through taking associated personal actions, including in their social relations. The dimensions were also present in the suffering that they described which might motivate requests for EPAS. Pain and mental suffering, themselves largely determined by psycho-dynamic and social dynamics (Aldrich & Eccleston, 2000; Callahan, 1993; Csordas, in Paterson & Hughes, 1999, p. 602; Enklaar, 1999); loss of meaning; inadequate care and medical treatment involve these three dimensions. Certainly the shared social relations dimension of dignity and human worth in dying (Kass & Land, 1996; Pollard, 1994) and in living daily life were
underscored by those few informants who desired EPAS against a background of their own poor relationships, with one explicitly citing this fact as his reason to want EPAS.

The informants’ two paradigms are qualitatively different in many respects. Their interdependence view values the trust and meaning found in deep relationships where independence may depend on assistance from others. It involves processes of value changes, instrumental in outgrowing of perceptions of suffering and to wellbeing and flourishing. There is an acceptance of disability where its experience is changed by changing one’s view of it. Discernment of what one should attempt to control or chooses to accept is part of this flourishing. Relationships began as a means to an end of reducing the threats to one’s integrity but their experience of interactive relationships became the most important and fulfilling part of their lives and added meaning. The interdependence view values the care and assistance that arises from these relationships as preserving one’s independence and dignity, as Chochinov, Hack, McClement, Kristjanson & Harlos’ (2002) work also shows it can. The interdependence framework requires engagement with one’s whole life, that is aspects of both independence and dependence, and vulnerability. This requires the development and application of private values. This paradigm is based on private and social experience and operates both in the private and public sphere of community.

The informants’ individual autonomy paradigm is based on a kind of autonomy, which is focused on the justice of allowing one’s free expression of individual rights to choose and have access to death as a solution to suffering. EPAS is thus characterised by individual control over one’s destiny. Relationship to others is mainly relevant where they are involved in decision-making towards, and implementation of, EPAS as a means to this end. These relationships are detached; not necessarily based on trust; and one needs safeguarding from abuse of EPAS by rules, technical expertise, professionalism and monitoring. Consequently there is little need for the development and application of private values involved in giving and receiving. An engagement with the whole life is not necessary. This paradigm is based on little personal experience and awareness of various relevant aspects, including the nature and operation of E and PAS and their safeguards, dying, and palliative care. It operates as a public policy but is seen as a private affair.
The characteristics that are *predominantly* expressed in either of these two paradigms are shown in Table 2.

**Table 2. Characteristics that differentiate the two paradigms**

<table>
<thead>
<tr>
<th>Individual autonomy</th>
<th>Interdependence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public policy</td>
<td>Private experience</td>
</tr>
<tr>
<td>Technical rules, law, monitoring</td>
<td>Relational process</td>
</tr>
<tr>
<td>Justice</td>
<td>Care, relationships</td>
</tr>
<tr>
<td>Outcome, ends</td>
<td>Process, transformation, outgrowing, means</td>
</tr>
<tr>
<td>Independence</td>
<td>Interdependence, equilibrium</td>
</tr>
<tr>
<td>Progress</td>
<td>Development, growth, phronesis</td>
</tr>
<tr>
<td>Rights</td>
<td>Relationships</td>
</tr>
<tr>
<td>Choice as right</td>
<td>Choice to accept</td>
</tr>
<tr>
<td>Fear of suffering</td>
<td>Trust, care, relationship</td>
</tr>
<tr>
<td>Distrust</td>
<td>Trust</td>
</tr>
<tr>
<td>Meaninglessness in dying</td>
<td>Meaning in life with disability</td>
</tr>
<tr>
<td>Personal detachment</td>
<td>Relationship</td>
</tr>
<tr>
<td>Control</td>
<td>Acceptance</td>
</tr>
<tr>
<td>Justification, professionalism</td>
<td>Virtues, practice</td>
</tr>
<tr>
<td>Rational agency</td>
<td>Independent practical reasoner</td>
</tr>
<tr>
<td>Conditional, contractual</td>
<td>Unconditional relationships</td>
</tr>
<tr>
<td>Individual</td>
<td>Individual in community</td>
</tr>
<tr>
<td>Bureaucracy</td>
<td>Informality</td>
</tr>
<tr>
<td>EPAS</td>
<td>Phronesis, growth, flourishing</td>
</tr>
</tbody>
</table>
The two paradigms then are not merely different. In effect they are opposing frameworks even though they contain opposing as well as complementary values. This is because the interdependence paradigm incorporates autonomy within its framework, such as deriving control or independence through acceptance of one’s situation as dependent. Conversely the individual autonomy framework does not, or is less able to, incorporate aspects of the interdependence framework, such as acknowledged dependence, acceptance, unconditional relationships and personal growth. Within an overly individualistic autonomy paradigm on the public issue of EPAS policy there is little room for expression of the informants’ private paradigm of unconditional relationships through which suffering is transformed into wellbeing. Informants sensed, if not knew, of the oppositional nature of the two paradigms as evidenced by their belief that the dominant individualistic paradigm was accompanied by significant problems, including social alienation. They also sensed it from the different qualities of the experience of their two lives, one with, one without disability. Yet they supported EPAS based on this same paradigm. Their individual autonomy framework focused on an individual right to choice as a route to EPAS. Circumstances warranting EPAS included subjectively defined unbearable suffering, not necessarily in the presence of a terminal condition. They said, in other words, that an individual has a right to decide when they had had enough of life and use EPAS at any time of their life, not necessarily only when close to death. The autonomy-rationale for EPAS is often accepted as valid because of a widely held assumption that EPAS is a dignified extension of good life, enabled by one’s freedom of expression of individual autonomy (Dworkin, 1993). Hence the publicly often-used phrase, as it was by my informants, of dying with dignity. But most informants knew that good life is not lived in this manner. They drew stark contrasts between their independent lives prior to acquiring quadriplegia and their good, relationally enabled, wellbeing post-disability. Yet they did apply the socially dominant individualistic framework to suffering when discussing EPAS. They did not call it individual autonomy but they applied an overly individualistic emphasis on one’s rights to choose EPAS. The dominant cultural paradigm influences kinds of suffering we encounter, such as over-treatment under medically futile conditions; how we perceive them; and the kinds of public responses we apply towards them. But apparently it did not exert such influence in the informants’ private lives. The two opposing paradigms appeared to exist simultaneously, within the one person,
though separated in private and public spheres. The informants’ position on EPAS therefore appears coherent with dominant social values but not with their private experience. The paradigms’ simultaneous co-existence within flourishing informants might be regarded as remarkable because they knew that the interdependence framework is a practical and viable way to overcome suffering and can lead to personal wellbeing. In stark contrast to this private view EPAS has death as an outcome in response to suffering.

In MacIntyre’s terms, flourishing informants could have been expected to extend their private experience of interdependence into their reasoning on EPAS. After all, independent practical reasoners’ are distinguished by three characteristics. The first is an ability to detach oneself from the “immediacy of their desires” (p. 96). Informants indeed showed that, in many respects, they had learned to have their own needs met within relationships with others and in consideration of their needs. The second characteristic is an ability to imagine alternative futures, referring to people in relatively independent states being able to think of themselves in more dependent states. My informants were well able to think of their futures in this way, having had direct experience of an independent life as well as of pronounced dependence. They had met this fact by choosing to accept their life as it was. In an illustration of the validity and value of such practical reasoning, imagining oneself in a more independent state, was associated with unhappiness and a preference for death in some informants. On the other hand some informants supported EPAS because they learned that “life can do them a funny turn”. There is unpredictability about that fact which, for them, was a reason to leave the door open on EPAS. This appears to contradict their practical knowledge of shifting forward the boundaries of what kind of life was still worth living. Informants therefore seemed to exhibit the third characteristic of an independent practical reasoner to a lesser degree than the first two characteristics. This characteristic is the ability to recognise and make “true practical judgements on a wide variety of kinds of good” (p. 96). In other words my informants’ flourishing indicated their status as independent practical reasoners. As such they could have been expected to apply their experience of interdependence to the good of overcoming suffering, in relation to EPAS. But they did not.

Flourishing informants could also have been expected to adopt a more coherent position with regard to their private and public values, according to
Habermas’ (1989) *emancipatory* or *critical knowledge* theory. The dominant individualistic paradigm underlies the issue of EPAS in various ways, as discussed. My informants’ paradigm of individual autonomy as they apply it to the issue of EPAS, exhibits many of Habermas’ characteristics of analytical/empirical knowledge. Informants’ views on EPAS involved technical control of the natural phenomenon of suffering and dying, under conditions of detached objectivity, involving causal relationships between people, that make it “obligatory [to filter] out the merely emotive from cognitive contents” (p. 303). The meaning of analytical/empirical knowledge is its predictive technical *employability*, “established only by the rules according to which we apply theories to reality” (p. 308). And of course, rules to predict safe outcomes of EPAS dominated my informants’ thinking also. Including ethical neutrality, enabled through the mechanism of individual choice, these characteristics are as much part of the dominant paradigm of analytical/empirical knowledge as they are of the informants’ individual autonomy paradigm as they apply it to EPAS. In Habermas’ (1989) terms, EPAS appears to insufficiently acknowledge a relationship between objective knowledge and human interest, as in MacIntyre’s terms such knowledge has been detached from conceptions of the human good, that is amelioration of suffering. Habermas calls this an illusory state, as analytical/empirical knowledge inevitably has its origin in the *life-world of human action*. This is where the second kind of knowledge, historical–hermeneutical knowledge, is located. In this study it is constituted by my informants’ history and experiences as people with disability. It is concerned with “securing human existence” through “reconsolidating the consciousness of the individual in relation to the norms of the group” (p. 313).

Habermas’ third kind of knowledge, critical, or emancipatory knowledge, is derived from reflection upon any differences between dominant ideologies and how people experience their lives. It involves a comparison between knowledge and human interest, which may dispel false consciousness of certain societal realities. Dispelling false consciousness in this way appears closely related to MacIntyre’s (1999) third characteristic of an independent, practical reasoner which enables one to recognise and make “true practical judgements on a wide variety of kinds of good” (p. 96). As informants seemed to lack this ability they also appear not to have arrived at Habermas’ emancipatory knowledge. Informants, evidencing privately held
emancipatory knowledge in their daily life, could be said, in Habermas’ words, to have aided “mankind’s evolution towards autonomy\textsuperscript{12} and responsibility”. However, they did not appear to have united their … “knowledge and interest … nor “reconstruct[ed] what has been suppressed” (p. 315). The dominant paradigm, analytical/empirical knowledge overrode their private, historical–hermeneutical knowledge. One illustrative example of this is their insistence that EPAS could be safeguarded with rules within the declining society that they described, ignoring obvious links between dominant social values and negative outcomes of its practices. Informants had opportunities to reflect on their knowledge and private experience. However a presence of their emancipatory knowledge or ability to make judgements on a wide variety of human goods, as part of an independent practical reasoner’s characteristics, is not apparent. Their apparent false consciousness about the realities of suffering and responses towards it, needs to be explained, in order to better understand their views on EPAS.

6.4.1 Explaining false consciousness

Festinger’s (1957) cognitive dissonance theory provides an explanatory framework for the informants’ application of opposing frameworks towards suffering, one in the private and the other in the public sphere. Festinger’s theory would predict that informants would experience an internal discomfort, or cognitive dissonance, in the face of this apparent inconsistency between their experience and beliefs. But they did not appear to feel any great dissonance. At most they felt some confusion and discomfort when discussing EPAS for those who might be suffering but did not possess the capacity to make a rational decision for themselves. Festinger theorised that where dissonance exists, it might be reduced through personal or cultural factors. There are a number of ways in which people try to reduce their dissonance. They might reduce their discomfort by changing the view or behaviour that causes their dissonance. They might add more cognitions of the type that support the view or they might decrease the importance of the elements in the views that cause the dissonance. Social support of others might be significant in helping to

\textsuperscript{12} Autonomy here is used in terms of the relational autonomy that informants expressed in their private, daily lives, where independence relied on assistance from others and they had taken on the responsibility of accepting this situation. It is that kind of autonomy, which, in Habermas’ terms unites knowledge with human interest.
personally reduce the dissonance. Cultural dissonance reducers include overt dominant beliefs of others and exposure to information emanating from a community or society. When many others all experience the same dissonance this can reduce one’s own dissonance through being seen as normative. In relation to my findings, personal and cultural dissonance reducers often overlap. In the following analysis I will try to identify such personal and cultural dissonance reducers as explanatory factors for the informants opposing beliefs. Whereas many of these points appear to strengthen informants’ views on EPAS they might not be sufficient to indicate why there is little dissonance between the informants’ interdependence and individual autonomy views. That will be discussed after presentation of these, nevertheless relevant, points.

Information, knowledge and social support: Festinger (1957) explains that the greater the number of people that one knows who already agree with one’s own opinion, the less will be the magnitude of dissonance created by someone’s disagreement. Informants showed a poor conceptual knowledge of EPAS and its practice, little knowledge of the suffering involved in dying, and of palliative care. Low levels of public knowledge have been identified about the nature and effectiveness of rules with regard to EPAS (Kennedy, 2002), about palliative care (Enklaar, 1999; MacNamara, 2001; Webster & Kristjanson, 2002) and awareness of death and dying (Aries, 1973; Becker, 1974; Gorer, 1955; Kastenbaum, 2000; MacNamara, 2001). Their lack of knowledge is a normal experience. So even if they were aware of their knowledge as lacking, little dissonance would probably arise through the mechanism of social support.

The mass media appeared to be an important source for their information on EPAS. There is little evidence of their use of wider sources of information on the subject. Some of their extreme examples of suffering in relation to EPAS were taken from television programs. In both Australia and the Netherlands, as in other Western countries, there has been a growing trend towards high public approval ratings for the practice and legality of EPAS, based on a principle of a right to individual choice, over some considerable time. Within such a dominant culture of support for EPAS I suggest that media coverage of EPAS issues has mostly been reflective of this level of public approval. I have not found any studies of the content and direction of media coverage of EPAS but my personal observation of the media coverage in Australia
would confirm an atmosphere of majority support for EPAS. In the Netherlands information from government, the main physicians’ professional body the “Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst” (KNMG) and the largest voluntary euthanasia society in the world, the Nederlandse Vereniging Voor Euthanasie (NVVE) is overwhelmingly supportive of EPAS. There is only some low profile, minority opposition to EPAS in the Netherlands, which is constituted mostly by organisations with religious affiliations. Besides, in an overwhelmingly secular society like the Netherlands opposition to EPAS from religious organisations lacks credibility. During my three-month stay in the Netherlands in 2000, I was only aware of, and viewed, a number of television programs that were broadly supportive of EPAS.

Two factors therefore strengthened the informants’ view of support for EPAS. Informants had poor and selective knowledge and information on EPAS and on directly relevant issues and lacked that knowledge which might counter this knowledge. The dominant culture of apparently overwhelming support for EPAS probably reduced the possibility of any dissonance arising from their privately held belief in interdependence and their use of the dominant social ideology of individual autonomy on EPAS. But the combination of poor knowledge of the relevant concepts and issues, combined with overt social acceptance of EPAS, based on a right to individual choice, strengthened their view on the public issue of EPAS. In this way, when discussing EPAS, they mostly used cognitions of the type that support EPAS and had the social support for that view, being dissonance reducers.

Distance from dying and death experience: This issue is related to being under-informed. Most informants had little direct exposure to dying. This is a normal experience as death is widely a suppressed reality in contemporary Western societies and people often die in clinical, medical environments away from the settings of daily life (Aries, 1973; Becker, 1974; Gorer, 1955; Kastenbaum, 2000; MacNamara, 2001). So, dying and death were remote from their daily personal experience and this remoteness is normal. They were also distant, as their own death was a future scenario, not of immediate impact for themselves, and they were mostly projecting EPAS for others. Thus their reflections on death through EPAS for others carried few personal implications for themselves. Dissonance between their private view of
interdependence in response to suffering and their view of the public issue of EPAS would be reduced by the remoteness of the issue in relation to them.

Relevant to these first two points, Festinger (1962) gives the example that if someone were standing in the rain but could see no evidence of getting wet dissonance would arise because past experience indicates that this is out of the ordinary. If the past experience of rain had never occurred such dissonance might not arise. For most of my informants there was no past experience or information that indicated to them that EPAS had not been properly functioning in their own country or elsewhere. Furthermore this gap in their knowledge is related to a normal experience of being under-informed about dying and death, palliative care, the nature and practice of EPAS and the nature and effectiveness of its safeguards.

**Internalisation of the dominant worldview:** Dissonance can arise from dominant cultural norms where that culture can define what is consonant and what is not (Festinger, 1957). If one’s own norms were at odds with the dominantly held cultural norms, dissonance would be experienced. My informants used the socially dominant framework of individual rights to choice in their views on EPAS, a view that is also associated with dominant social values of progressivism and rationalism. I suggest that their application of the socially dominant framework, rather than the interdependence framework, is related to the overwhelming expression of that dominant paradigm in the fabric of daily life. At many levels they would receive daily messages confirming the validity of that dominant view. As such internal values are often held unconsciously (Harman, 1998) it is not surprising that they applied these values in describing their views on EPAS, a concept itself shaped by these dominant social values. On the other hand, the interdependence worldview, valued in their lives, is not socially valued. Dependence and vulnerability in the dominant worldview are seen as obstacles towards the desired human status of being a rational free agent in a competitive world. The devaluation of people who have disabilities is in part related to this view of what it is to be human. Naturally people with disabilities would not like to draw attention to their vulnerable and dependent states in referring to it in the high-profile EPAS debate where the debate reflects an overwhelming support of socially dominant individualist values. Some Dutch leaders specifically remarked on the difficulty of calling attention to their vulnerability and dependence in a world that did not value these. Seeing EPAS as a public issue and
the interdependence view as private functions as a mechanism to reduce dissonance, something that I will discuss later.

Progressivism: If a specific view is, by definition, included in a more general view and the two are inconsistent, dissonance arises (Festinger, 1962). But the informants included euthanasia with other progressive developments, such as legalised abortion and, in the Netherlands, a tolerant approach to drug taking. Their support for euthanasia was thus consonant with other issues that are generally accepted as progressive and seen as evidence of tolerance. Tolerance and being progressive generally being seen as positive, this strengthened their public view of EPAS. Progress has since the nineteenth century been seen as modern with its themes of emancipation, analysis and secularism. It has a disregard for history in “dismis[sing] each yesterday with something like contempt” (Barzun, 2000, p. 521) as expressed perhaps in my informants’ faith in technological approaches to a better future for people with disabilities while expressing a world of increasing social alienation. Progressivism played a role in the historical Dutch euthanasia policy process. The necessity of changing the law in line with social change was a dominant idea in the Netherlands (Kennedy, 2002; ten Have, 1998). To illustrate the power of this idea Kennedy (2002, p. 96) quotes Josephus Jitta in 1986. Mr. Jitta was a Dutch President of the Supreme Court, who was involved in some prominent Dutch euthanasia cases, and acted as a committee member of the Dutch voluntary euthanasia society:

Some fifteen years ago nude recreation was completely unacceptable: presently it has been socially accepted. Society changes. The result is that laws have to be adapted. That also goes for euthanasia.

Therefore EPAS is perceived as good, partly because of its association with the valued, socially dominant ideology of progressivism. This is a factor in the informants’ support of EPAS as, at least superficially, consonant with their experience of interdependence, except that in the interdependence paradigm tolerance of others is indeed a virtue and is not indifference as it is in the dominant paradigm (ten Have, 1998). Therefore this association of tolerance with EPAS strengthened informants’ support for EPAS and might reduce any dissonance or stop it from arising when informants discuss EPAS as a public issue.
The importance of reason: EPAS is a rational approach to a good death as rational agency is an important part in its discussion even though informants gave only token support to a need to establish one’s capacity to choose EPAS. Rationality has long been seen as more important than experience (Cassell, 1991) or the emotional (Goleman, 1996). This is connected to the dominant scientific notion, within the analytical–empirical knowledge paradigm, that nothing is real unless it can be observed and measured. The interdependence paradigm balances reason and emotion in a dynamic process which leads to independent practical reasoning. But my informants did not appear to feel much of any dissonance that could be expected between this experience and their support for the rational approach in EPAS. Again, I suggest that the socially valued paradigm of rationalism reinforced informants’ support for EPAS as a public issue.

The professionalisation of care: Care necessarily has a dual nature and this is reflected in the word itself. On the one hand it refers to giving another:

[S]erious attention and thought; caution to avoid damage or loss, protection, supervision; taking charge of; [to] see to the safety and wellbeing of; interest, affection or liking.

On the other hand it also refers to “worry, anxiety, [to] feel concern” (The Australian Oxford Dictionary, 1990). This same duality is expressed for instance in the Dutch word zorg. So personal or public health care refers to both the action of caring for someone and worry and anxiety as part of it. One could worry or be anxious about the other’s suffering. It could also involve the worry, or the cares thrust upon carers who become exhausted. It could refer to anxieties that the cared-for person has, about “having to ask for everything” – their dependency on the other, or about feelings of being an undue burden. Any genuine and long-term care relationships would likely face these dual dynamics of loving attention and cares. It has to necessarily operate within the forcefield of these apparent polarities of care. In MacIntyre’s (1999) terms such tension can only be bridged by unconditional commitment to one another, involving inevitable trade-offs about one’s own immediate welfare. Such care requires the suffering person to be seen as a whole person, with unique social, cultural, spiritual and other dimensions (Cassell, 1991). Should the inevitability of worry, as a part of care, not be acknowledged we then end up with a detached (professional) relationship where the effects of meaningful care
are weakened. Commitment to others has become harder to generate, as indicated by the informants’ world of increasing alienation. Techno/professional approaches to human need have become part of the practices of the dominant value framework (Callahan, 1998). This appears reflected in the informants’ preference for detachment between a person requesting EPAS and the physician carrying it out as it is in the leaders’ perception of people with disabilities being treated as care objects, rather than as persons, in their welfare societies. Indeed, the power of the technocratic world has influenced our values and ethics away from the notion of a human being as a whole person (Kass, 1985). Western society values maximum individual independence (Ells, 2001; MacIntyre, 1999; Wendell, 1996). It has commodified much care into goods and services and prefers technocratic and managerialist approaches to human need (Barzun, 2000; Cocks, 1994, 1998). Conversely it exhibits a reduced tolerance for suffering, imperfection, dependence and fragility in a world in which everything is potentially makeable and controllable (Barzun, 2000). Hence our worry about suffering of others that we cannot solve, but only palliate or support, can be taken away, in the dominant paradigm, by reaching out to professional expertise and technology, in the form of medical killing. My informants’ support for EPAS in order to ameliorate the suffering of others that results from observing a loved one die, could be explained in this way. It is coherent with the socially dominant way of dealing with some problems of suffering. Dissonance between the informants’ two beliefs of interdependence and autonomy might have been expected, as they knew the value of engageing with others in both senses of care. But for them the application of dominant social values of professionalism and technology, when discussing EPAS as a public issue, reduced any dissonance, should it even have arisen.

The medical imprimatur: The medical profession is a very powerful one in Western culture. Physicians are not only central, trusted figures within the large Western public and commercial health care infrastructures but also function as gatekeepers to many state entitlements. This is a familiar phenomenon to many people with disabilities. It is therefore perhaps not surprising that my informants echoed the main public discourse on EPAS, when they allocated a central role to doctors in assessing capacity to make decisions for oneself to have EPAS. While expressing caution in trusting doctors in this process they also needed doctors for
access to killing drugs, their expertise in administering them and assessments of
capacity to choose EPAS. Doctors, by their professional “white coat” status lend
legitimacy to the process of EPAS. They can, by virtue of that status, make killing
part of the socially valued medical profession’s practice. By virtue of their social
status doctors can influence our behaviour and how we morally judge our own
actions, as Stanley Milgram (1974) has so famously shown. The legitimacy that
doctors can lend to medical killing may have bridged any discomfort informants may
have felt about supporting EPAS as a public issue while holding a private,
apparently opposing paradigm. Any dissonance between the informants’ knowledge
of the healing powers of reciprocal relationships and allowing a person to be killed
by their own choice in order to ameliorate their suffering might therefore not arise or
is lessened by it. Furthermore, the use of physicians in EPAS is a widely shared
social assumption allowing the cultural dominant norms to further support the
informants’ views on EPAS.

*Rules for trust:* Because of an unequal relationship between patient and
doctor, informants expressed a degree of distrust in physicians’ role in EPAS. They
suggested several safeguards to this situation. They wanted family and friends
involved in the EPAS decision-making process. Most of all they wanted *strict rules,*
within a legal framework, to safeguard EPAS from being abused. This framework
reflects the type of relationships which, in MacIntyre’s terms would be the socially
more influential conception of practical reasoning. Dissonance could be expected to
arise at this point as they also knew of the effects of bureaucracy in having their
disability-related support needs limited. In their private relationships, personal
commitment and trust in others, in meeting their sometimes-intimate needs, provided
the bridge between negative feelings about dependence on others and their
flourishing. Within the unequal doctor–patient power relationship, where the price of
professionalism is reduced personal commitment to the patient, rules must provide
the bridge. The use of rules as safeguards to abuse of EPAS is a part of *technical*
solution to the (social) problem of suffering. This normative social paradigm of
preference for technical solutions could thus reduce any dissonance about support for
*EPAS as a public issue* versus their experience of the validity of the interdependence
framework. Their ignorance about the precise nature and effectiveness of rules as
safeguards did not matter to them, especially as this too is part of the normal social
experience. It was enough to know they were there, or should be there, as a means of adding cognitions that supported their view on EPAS.

In conclusion I suggest that all of the above factors play a role in strengthening the informants’ views on EPAS, which they describe as a public issue. They mostly do not see EPAS as applicable to themselves, and certainly not for reason of their disability. Crucially these factors point to a division between the informants’ private world and their view on the public issue of EPAS. Combined, these dimensions of reinforcement of their view on EPAS and the private/public division explain why there is little dissonance between their opposing paradigmatic attitudes towards suffering in their private world and in their views about EPAS. They lack information and experience, which might contradict some of their views on EPAS. This gap in knowledge and experience contributes to a certain remoteness of their private world of interdependence in relation to the world of others. A number of socially dominant values are consonant with their views on EPAS. These values include respect for individual rights to choice, progressivism and rationalism, identifiable as belonging in Habermas’ (1989) dominant empirical–analytical knowledge paradigm. Associated with this knowledge are technological, detached approaches to care, the imprimatur of medical technical expertise and a faith in a technological approach to trust. These dominant values play an influential role in preventing any dissonance, which might arise if informants would reflect on the different types of knowledge within the private and public spheres. But the division between the private and public, which is facilitated by their gap in knowledge about EPAS, dying and palliative care, militates against such reflection.

However there are further influences that maintain the division between their private and public worlds, which provide further explanation for the lack of apparent dissonance. Within Reinders’ (2000) subjective view of their lives, most informants led a fulfilling, rewarding life. They had outgrown suffering by means of acknowledging dependence and vulnerability within meaningful relationships. In the objective view from the outside they might think to themselves that they might choose a life without this task, if they had a choice – by means of EPAS. Indeed, as indicated by some leader-informants and others (Pijnenburg, 1998; ten Have, 1998), some might think that some people like those with disabilities ought to be entitled to choose EPAS for reason of disability. It is difficult to integrate the objective view
into the subjective view grounded in one’s own experience without having the detached objective view undermine the commitment, which enables the care, and flourishing, in one’s lived, subjective experience to occur, as “simply a waste of energy” (Reinders, 2000, p. 81). Such alienation from their valuable private experience may thus have played a role in the few informants’ view of EPAS as something that could deliver them from their life with disability, a life which appeared as relatively poor in committed relationships. Furthermore, in a world that does not value dependence and vulnerability, informants appeared to have found it difficult to insert their private experience into the discussion of the public issue on EPAS. Indeed informants did not mention dependence on others as a reason to have EPAS, even though studies have found this to be a strong motivator underlying requests for it (van der Maas, van Delden & Pijnenborg, 1991; Oregon’s Death With Dignity Act, 2000). Confirming the presence of a social background which highly values individual independence and views the dependency of disability as humiliating (Wendell, 1996), a leader spoke of being seen as “wimps” if the Dutch disability movement would discuss disability in such terms. These are reasons why it was difficult to integrate one’s private experience into the public objective view, something believed to be true for anyone (Reinders, 2000). It may in part explain why my informants kept a division between the private and the public, with an effect of suppressing any dissonance between their private experiences and views on the public issue of EPAS.

Dividing our world into private and public spheres has further importance in relation to the underlying right to choice in the EPAS debate. According to Reinders (2000), a minimalist or narrow approach to publicly enforceable morals is derived from the widely divergent individual, private views in the pluralistic, liberal society. In that liberal view of the world public morality does not provide a single concept of what is good life and does not provide guidance in private lives. Inevitably social conflicts will arise but the dominant social values of individual freedom and equality will make a distinction between what level of morality is in the private or public spheres. Public morality confines itself to outlining the conditions by which persons can arrive at a moral conception for themselves and live by that. In other words, public morality accords people individual rights to choice and self-determination by which they make their own moral decisions. Public morality in liberal society does
not concern itself with the morality of individual choices as long as their consequences remain in that person’s private sphere. Public morality then can only operate at a level of narrow morality, at the consensus level of individual autonomy. Reinders (2000) points out that there are more demanding or wider moral values than those of choice and self-determination, such as benevolence and generosity. These values are found “in a civilised and flourishing society, but they are not necessary for the possibility of public justification” (p. 14). My informants used a wider morality in their daily, interdependent lives, by which they flourished. They drew values of empathy, patience, candour, persistence and acceptance from the practice of their relational lives.

On the issue of EPAS the informants reduced their dissonance between the interdependence framework and their beliefs about the role of individual autonomy by applying the narrow, public morality to individual decision-making about life and death. They might not agree with the person’s choice for EPAS. In fact they preferred that all were done to relieve suffering first, some evidence perhaps of their attempt to apply the interdependence view to EPAS. But if, in spite of everything, the person insisted on EPAS they could justify that by according them a right to self-determination. There was no need for them to use wider morality, such as represented by the virtues they had acquired. Dissonance need not arise by applying the tolerance of allowing others the right to choose, requiring no further worry about what led to the request for EPAS. They thereby avoided any need to attempt the difficult task of integrating their subjective and objective views, which would have provided tensions, which might, on reflection, have led to critical knowledge, or perhaps to alienation. Ten Have (1998) illustrates the different natures of the narrow and wide approaches to EPAS as follows:

In a policy of toleration, one asks different questions than in a normative policy, where one would ask questions of happiness and palliative efforts to accomplish agreed-upon goals at the end of life. Thus supplying euthanasia can easily be a substitute, a kind of indifference, for what people really want. (p. 220)

The influences of the dominant paradigm then overwhelmingly tend to suppress any dissonance that informants might have felt between their private experience and support for EPAS. Festinger (1957) believed that the more internal dissonance is reduced the more difficult it becomes to shift beliefs.
6.5 Research question 4.

**Do cross-national disability perspectives on the above issues lead to deeper understanding of and insight into the issues of euthanasia and physician-assisted suicide and their practical applications?**

There is no substantial difference in the responses or national contexts between the Dutch and Australian samples. But there was a difference between grassroots and leader samples. Leader informants showed a greater awareness of EPAS, palliative care; had more experience with issues of dying; and appealed to *relational autonomy* in relation to EPAS while noting an opposition to EPAS by most of the Australian leader sample. Juxtaposing the similar grassroots findings, one set arising from a Western country with some 30 years experience of allowing EPAS and another from one with less experience appears to validate the suggestion of significant influence of dominant social values in thinking about EPAS as a public issue. Australia and the Netherlands are both liberal democracies where the paradigm of individual choice to goods is strong, including in EPAS. There is agreement among EPAS proponents and opponents of two major trends that underlie the Dutch (Enklaar, 1999; Griffiths, Bood & Weyers, 1998; ten Have, 1998), Australian (Magnusson, 2002; Somerville, 2000) and other Western societies’ (Callahan & Hanson, 1998; Callahan, 1994; Griffiths, Bood & Weyers, 1998; Mann, 1998) debates about EPAS. These are the interrelated trends of the dominance of an individualist paradigm, which values individual autonomy and choice; and an overly techno-medical approach to health care. The similarity in findings also confirms the suggestion that this influence of the dominant paradigm helps to suppress the acknowledgement of private experience as one of value to questions of human suffering and end-of-life decision making.

6.6 Conclusion

The findings in response to my first research question are that both Dutch and Australian parts of this study’s sample support legal EPAS as a public policy. Their support seems close to the high levels and the substance of public support for EPAS. They based their views on relatively uninformed, and indirect, knowledge of relevant issues such as the concepts and practice of EPAS, dying and palliative care. Their
position in support of EPAS appears inherently problematic, primarily because the informants’ construct of EPAS would make safeguarding of an EPAS policy difficult. Any concerns about abuse were allayed by insistence on strict safeguards. These appeared unenforceable however within the open-ended parameters that informants applied to an individual’s right to choose for EPAS based on individually assessed subjective experience of unbearable suffering. The dominant social values of individual autonomy, including individualism, materialism, progressivism and rationalism are involved in the informants’ construct of EPAS.

Findings in relation to the second research question are that informants successfully applied an interdependence paradigm, found in their private experience, to threats to their physical, psychological and social integrity, or intactness as a whole person. These threats were in essence the same as those they identified as valid reasons for others to have EPAS. In the interdependence paradigm, which is little valued in society, these threats were transformed by embracing and outgrowing them, resulting in a personal level of wellbeing, or flourishing. Applying the societally valued dominant paradigm of individual autonomy to such threats led to avoidance of suffering through death assisted by EPAS. The findings in relation to the third research question are that the stark contrasts in the natures and outcomes of the two paradigms did not apparently lead to any significant cognitive dissonance within informants. It appeared then that they might hold their view on EPAS as Habermas’ (1989) “false consciousness”, having failed to recognise the opposing natures of the two paradigms applied to the single issue of suffering. Consequently they did not reflect on any such tensions and did not develop critical knowledge on the realities associated with the nature of suffering and its amelioration.

There appear to be four interrelated reasons for the informants’ apparent non-development of critical knowledge. Firstly, much of their knowledge of issues that were relevant to the EPAS issue was not well informed. Secondly, they divided their experience and views into two spheres: their experience of interdependence into a private sphere and their views on EPAS into a public sphere. They did this based on some remoteness of the issue of EPAS to their own experience and to protect themselves from any devaluation of their private experience. Thirdly, the dominant social, paradigm of individual autonomy exerted overwhelming influence on their views on EPAS. This was so because EPAS as a public issue was consonant with the
dominant paradigm, which makes up much of the public sphere. Fourthly, an ideology of individual choice, which is embedded within this dominant paradigm, allowed informants to avoid using their private experience of interdependence in informing the issue of EPAS. The first two reasons facilitated a feeling of remoteness from the issue of EPAS as one concerning others. The third reinforced their views on EPAS as socially valid. The fourth allowed them to defer the EPAS question of wide morality to a mechanism of value-free individual choice, therefore not requiring engagement with values embedded in their private experience. These are powerful reasons for not feeling much dissonance between their private experience and public views and for not developing critical knowledge. However, these conclusions should be treated cautiously in view of the framework of relational autonomy that leaders applied to EPAS, in contrast to the grassroots sample. It can only be suggested that the greater awareness that leaders displayed of dying and palliative care meant that they had greater opportunities to develop critical knowledge. No conclusions can be drawn from this contrast between grassroots and leader samples in view of the small, unsaturated leader sample.

The finding in response to the fourth research question is that there is little difference between the findings in both countries. A similar value culture appears to exist in both the Netherlands and Australia in relation to values applied to end-of-life decision-making such as EPAS. These results appear to confirm the conclusion of the strong influence of the dominant values of individual autonomy in responding to public policy such as EPAS.

The informants’ experience and practice within the interdependence paradigm appears to offer much of value in relation to amelioration of suffering. The paradigm seems not only relevant to people with quadriplegia but there is evidence of its wider presence and utility, among ageing and dying persons. As such it appears as a practical response to the human condition. The interdependence approach appears as part of human nature, with the dual benefits of outgrowing of suffering and achievement of individual and communal wellbeing, or flourishing. Indeed, these and others’ findings appear to confirm MacIntyre’s (1999) argument of the universality of his interdependence theory. That is, his theory is applicable to all human beings viewed over their lifetime. However, other parts in our human nature such as prejudice towards devalued others, such as people with intellectual disability
or other cognitive impairments, also existed in some flourishing informants who had acknowledged vulnerability and dependence in their own lives. This finding does not counter the validity of MacIntyre’s concept of practical independent reasoners however. It probably demonstrates different levels of personal growth, or phronesis, among individual informants within the interdependence paradigm and within the complexity of multi-faceted human nature and condition. As MacIntyre, Reinders (2000), Luke (1987) and many other studies, besides mine, have demonstrated, the personal growth process involving value change, in relationship with others, is itself an important source of wellbeing. In such a view of respect for differential rates of individual growth, equal intrinsic worth is presumed to be possessed by every human being under an assumption that all human beings have potential for inner growth, which is immeasurable. In the interdependence view committed relationships constitute effective safeguards against suffering and in maintaining wellbeing. By contrast the dominant paradigm, which holds that respect for individual autonomy in itself enables a good and dignified life and death, appears to be less reflective of human nature, at least in its approach to a goal of non-suffering. Individual flourishing or outgrowing of suffering is not part of it. In the dominant paradigm’s view the lives of those who do not possess sufficient rational agency are valued differently from those who do and therefore become more vulnerable to abuse of EPAS. This paradigm must rely on regulation as safeguards against suffering within its context of more detached relationships. Based on my informants’ views, regulation has been shown to be problematic as it has in (Dutch) practice.

The potential contribution of the privately experienced interdependence paradigm by means of its transfer to the public policy issue of EPAS appears thwarted by a range of factors, which are mostly related to an overwhelming influence of dominant social values associated with individualism, including its mechanism of individual choice. This dominant paradigm also contains seeds of the heightened vulnerability of many people with disabilities. Disability, if understood as primarily characterised by a high level of vulnerability and dependence, is part of the human condition, as MacIntyre argues. The contemporary context of widespread social and environmental turbulence and decline, within which current and future EPAS policy, with its inherently problematic nature, is administered, may pose further challenges to our social ethics. Because of widespread unacknowledged
vulnerability and dependency, these challenges would not just be pertinent to people with disabilities, but to anyone.

Given the wide relevance of the interdependence paradigm it is more likely than not that many of its virtues are expressed in many citizens’ daily lives. Despite the overwhelming nature of the presence of the dominant value system my informants have suggested that the interdependence paradigm can be chosen at any time. However, the interdependence paradigm seems to especially emerge out of necessity, at times when people face grave threats to their wellbeing. My findings can be seen as a dual contribution from subjugated knowledge arising from disability experience. This contribution is firstly that the private interdependence paradigm is of practical value in response to suffering and may lead to human flourishing. Secondly, one cannot assume that the experience of interdependence and practice of its virtues, will necessarily be transferred to public policy as a source of wider social values by people who have privately adopted the interdependence paradigm.

My findings suggest that the interdependence paradigm is a practical and rewarding approach to suffering, including at end of life, and superior to the individual autonomy paradigm. However any consideration of adoption of the interdependence paradigm in public policy towards suffering, including at the end of life, ought to not only acknowledge the utility of the interdependence paradigm. It is not enough to acknowledge human dependency and vulnerability. The influences of the dominant social values of an individualistic concept of autonomy and complex human nature, which involves prejudice, must also be acknowledged if the interdependence framework is to emerge in public policy in the area of end-of-life care and decision-making.

6.7 Further research

In order to further test the validity of this study I suggest that it be replicated using samples of people with different types of disability and with non-disabled populations. This study suggests that grassroots people with disabilities may hold different views on EPAS than do leaders in disability movements. Comparative studies between these two groups may contribute to a greater understanding of various disability perspectives in this area. Furthermore studies of the applicability of the interdependence paradigm to other bio-ethical issues and to public social policy
of various kinds may or may not demonstrate its wider utility. Studies of the extent to which non-disabled persons might experience a private–public divide on bio-ethical questions, including EPAS, may shed further light on my findings. Finally, this study found suggestions of EPAS performed on non-terminally ill people with disabilities and one case of apparent coercion to have EPAS. There appear to be few studies of the incidence and nature of such phenomena in this area. Such research, both in countries where euthanasia and physician-assisted practices are legal and illegal, may introduce valuable empirical data into social and ethical debates on EPAS.
REFERENCE LIST


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Dear

Project title: “Attitudes towards euthanasia and assisted suicide by people with disabilities in the Netherlands and Australia: Cross-national perspectives”.

Researcher: Erik Leipoldt, phone and fax (h/w)__________________________

Email: ealeipol@student.cowan.edu.au

I am doing this research for a Doctor of Philosophy degree in Human Services at Edith Cowan University. I also have a personal interest both through having experience of disability myself (I have quadriplegia and use a wheelchair) since 1978 as well as being involved in disability services, advocacy, advocacy development and policy advice for some 15 years.

The purpose of this study is to identify how the perspectives of people with quadriplegia and those of some leaders in disability movements may contribute to learning more about euthanasia and assisted suicide and why it may or may not be a good idea to practice it.

This seems an important question as it is known that people with disabilities are seldom heard in public debates on these issues. Through interviews, I aim to collect the feelings, stories and thoughts about this directly from people with quadriplegia and disability movement leaders. I hope that what I find out by doing this research will help people, with or without disabilities, and those in positions to make decisions about euthanasia to more fully understand this situation, so that their views and circumstances can be taken into account.

Interviews will last from one to two hours and it may be necessary to meet with you twice if you have more to say or I need to check something with you. In any case I will need to check with you, sometime after the interview, whether my descriptions of the experiences you’ve told me about are correct.

All interviews will be done in your preferred location, provided I can get there with my wheelchair. Interviews will be done in private and will be audio taped. You will be able to stop the tape at any time, and ask that anything is removed from the tape. Nobody’s name will be on the tape. Each tape will have a code number only. What is on the tapes will be typed up and these papers will also have numbers only. Any others who may have access to the data, such as transcribers, will have signed an assurance of confidentiality. When the research has been finished, anticipated by March, 2002, the tapes will be wiped. Participants may
have their interview tape(s) sent to them instead if they wish. Meanwhile
the tapes will be kept in a safe location, where only the researcher can get
access. No names will be used in the final report and any quotations of
what anybody said will remain anonymous. The master list matching
names to codes on tapes and transcripts will be kept in locked storage.

During the course of the study you have the right to withdraw at any time
and request the return of your data.

ELIGIBILITY
There are some eligibility requirements for participants. Please consider them
carefully and ask me questions if they seem unclear in any way:

- Participants must have had a cervical spinal injury for no less than five years,
- Quadriplegia is acquired as a result of trauma and not through disease,
- Persons who are suffering from clinical depression are not eligible to participate
given the sensitive nature of the research.
  It is thus important that you withdraw from participation should you be
  experiencing depression.

I can be contacted on the above numbers and e-mail should you have
questions at any time. Alternatively you may contact my Principal
Supervisor Dr. Alan Tapper on 08 94005555 or via e-mail:
a.tapper@cowan.edu.au.

Whereas your confidentiality is protected you should note that this does
not extend to issues of abuse and neglect, should the researcher come
across any in the course of this study, as the researcher may be legally
obliged to report these.

Thank you for participation.

Sincerely,

Erik Leipoldt
Edith Cowan University
Joondalup 6017
Faculty of Community Services, Education & Social Science.

Due to the sensitive nature of this study, counselling is available,
should you need this, during, or after your participation in this study.

You may contact X on tel. … or pager …. She is aware of this study.
THIS IS TO CERTIFY THAT I,

hereby agree to participate as a volunteer in the above named project.

I hereby give permission to be interviewed and for these interviews to be tape recorded. I understand that only the researcher, transcribers, coder and myself will have access to the data obtained, and that there will be no identifying evidence on any disks, cassettes and transcripts. I also understand that the information may be published, but my name will not be associated with the research.

I understand that I am free to not answer any questions. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I have been given the opportunity to ask whatever question I desire, and all such questions have been answered to my satisfaction.

I am, to the best of my knowledge not clinically depressed and have had my spinal injury for more than five years.

Would you please tick to clearly indicate your agreement with the following two statements and sign below. Thank you.

Yes I agree to participate by being interviewed  __

I agree to the interview being tape recorded   __

Signed:

Participant__________________________
Date_____/_____/______

Witness_____________________________
Date_____/_____/______

Researcher__________________________
Date_____/_____/______

Witness_____________________________
Date_____/_____/______
Geachte


Onderzoeker: Erik Leipoldt. Tel. en fax (Kunt u mij misschien helpen? Ik heb een klein aantal mensen nodig die geïnterviewd zouden willen worden door mij over bovengenoemd onderwerp. Ik zoek naar een aantal mensen met cervicale dwarslaesie en wat toonaangevende sleutelfiguren in de brede Nederlandse gehandicaptenbeweging. Tussen mei en juni 2000 zal ik in Nederland zijn voor interviews.


Het doel van mijn onderzoek is uit te vinden hoe de perspectieven van mensen met dwarslaesies en ook van leiders in de gehandicapten beweging bij zouden kunnen dragen aan een verder begrip over euthanasie.

Dit lijkt een belangrijk vraagstuk want het schijnt dat de opinies van mensen met handicaps weinig of niet aan bod komen in het publieke euthanasie debat. Terwijl ik hoop dat mensen met handicaps verse perspectieven hierover kunnen bijdragen tot nut van mensen met en zonder een handicap. Door middel van interviews hoop ik de gevoelens, opinies, verhalen en gedachten hierover direct van mensen met handicaps te vernemen. Zulk een onderzoek is, zover ik weet, nog nooit uitgevoerd..

Ik heb een voorkeur voor deelnemers met een dwarslaesie in Noord- of Zuid-Holland daar ik zelf in Purmerend of Amsterdam gebaseerd zal zijn. Ik zoek naar mensen die op zijn minst vijf jaar
een dwarslaesie hebben, veroorzaakt door een ongeluk, operatie e.d., en niet dus door een ziekte van de een of andere aard. Ik zoek tot een aantal van zo’n 15 mensen in deze categorie.

U kunt ook vragen stellen aan mijn mentor, Dr. Alan Tapper op 61 8 94005555 of via e-mail: a.tapper@cowan.edu.au.

Ik hoop van u te horen. Als u denkt anderen te weten die aan deze studie mee zouden willen werken in een interview (mensen met cervicale dwarslaesie in Noord en Zuid-Holland of/en leiders in de Nederlandse gehandicaptenbeweging) zou ik dat graag van u vernemen.

Met vriendelijke groeten,

Erik Leipoldt
Dear

Your name has been suggested to me as one of a person who fulfils a leadership role in the disability movement in Australia. In that capacity I am asking you whether you might be interested to participate, by means of 1 or 2 telephone interviews, in my Ph.D. study entitled “Attitudes towards euthanasia and physician-assisted suicide held by people with disabilities in the Netherlands and Australia: Cross-national perspectives”.

The purpose of my study is to identify how people with disabilities and leaders in the disability movements in both countries may contribute fresh perspectives to the general euthanasia debate. I have interviewed a number of persons in the Netherlands and am now commencing interviews in Australia.

I have some personal interest as I have had quadriplegia myself (C 5/6) since 1978. I have also had involvement in disability services, advocacy- advocacy development and policy advice.

My study seems important as it is known that perspectives of people with disabilities are seldom publicly heard on this issue. Their unique experiences and perspectives may well benefit the general euthanasia debate. Through interviews I aim to collect the stories and thoughts about my topic directly from people with disabilities and leaders in disability movements.

I hope that my findings will assist people, with or without a disability, to gain further understanding on this sensitive and complex issue.

Interviews, done by phone or e-mail where necessary, take between 1 and 2 hours and there may be a need for a follow-up interview. If you are interested in being interviewed by me I would appreciate hearing from you. I can then answer any questions you may have and send you full information on confidentiality, consent giving, and other matters. Depending on numbers needed and participant criteria being met I may not interview all interested persons. I will of course let you know about that as soon as possible.

HOW TO MAKE CONTACT:
You can ring me on [redacted] On the first number you can leave a message for me to return your call if necessary or send a fax. You may also contact me by e-mail on: ealeipol@student.cowan.edu.au. Additionally you may also contact my Supervisors Dr. Alan Tapper or Dr. Bob Jackson, at Edith Cowan University on (08) 94005555 or by e-mail a.tapper@cowan.edu.au or r.jackson@cowan.edu.au.
Thank you for taking the time to read my letter. I hope you will consider participating and I look forward to hearing from you. I will be pleased to answer any questions you may have.

Sincerely,

Erik Leipoldt
B.Soc.Sci. Human Services (Hons, 1st Class), Assoc.Dip. Arts (Human Service Administration)
APPENDIX C

**Project title:** “Attitudes towards euthanasia and assisted suicide by people with disabilities in the Netherlands and Australia: Cross-national perspectives”.

**Researcher:** Erik Leipoldt, phone and fax [Redacted]

Email: ealeipol@student.cowan.edu.au

I am doing this research for a Doctor of Philosophy degree in Human Services at Edith Cowan University. I also have a personal interest both through having experience of disability myself (I have quadriplegia and use a wheelchair) since 1978 as well as being involved in disability services, advocacy, advocacy development and policy advice for some 15 years.

The purpose of this study is to identify how the perspectives of people with quadriplegia and those of some leaders in disability movements may contribute to learning more about euthanasia and assisted suicide and why it may or may not be a good idea to practice it.

This seems an important question as it is known that people with disabilities are seldom heard in public debates on these issues. Through interviews, I aim to collect the feelings, stories and thoughts about this directly from people with quadriplegia as well as from disability movement leaders. I hope that what I find in this research will help people, with or without disabilities, and those in positions to make decisions about euthanasia to more fully understand this situation, so that their views and circumstances can be taken into account.

Interviews will last from one to two hours and it may be necessary to meet with you twice if you have more to say or I need to check something with you. In any case I will need to check with you, sometime after the interview, whether my descriptions of the experiences you’ve told me about are correct.

Interstate interviews will be done per telephone or by e-mail. If by phone, they will be taped. You will be able to stop the tape at any time, and ask that anything is removed from the tape. Nobody’s name will be on the tape. Each tape will have a code number only. What is on the tapes will be typed up and these papers will also have numbers only. Any others who may have access to the data, such as transcribers, will have signed an assurance of confidentiality. When the research has been finished, anticipated by March, 2002, the tapes will be wiped. Participants may have their interview tape(s) sent to them instead if they wish. Meanwhile the tapes will be kept in a safe location, where only the researcher can get access. No names will be used in the final report and any quotations of
what anybody said will remain anonymous. The master list matching names to codes on tapes and transcripts will be kept in locked storage.

During the course of the study you have the right to withdraw at any time and request the return of your data.

There may be a need to disguise your identity in the final presentation of data in consideration of the fact that the disability field is small and descriptive data could lead to your identification. This will be discussed with you.

Whereas your confidentiality is protected you should note that this does not extend to issues of abuse and neglect, should the researcher come across any in the course of this study, as the researcher may be legally obliged to report these.

I can be contacted on the above numbers and e-mail should you have questions at any time. Alternatively you may contact my Principal Supervisor Dr. Alan Tapper on 61 8 94005555 or via e-mail: a.tapper@cowan.edu.au.
THIS IS TO CERTIFY THAT I,

_________________________________________,

hereby agree to participate as a volunteer in the above named project.

I hereby give permission to be interviewed and for these interviews to be tape recorded. I understand that only the researcher, transcribers, co-coder and myself will have access to the data obtained, and that there will be no identifying evidence on any disks, cassettes and transcripts. I also understand that the information may be published, but my name will not be associated with the research.

I understand that I am free to not answer any questions. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I have been given the opportunity to ask whatever question I desire, and all such questions have been answered to my satisfaction.

Yes I agree to participate by being interviewed   __ (tick)

I agree to the interview being tape recorded   __ (tick)

Signed:

Participant__________________________
Date______/______/______

Witness_____________________________
Date______/______/______

Researcher__________________________
Date______/______/______

Witness_____________________________
Date______/______/______
Dear

“Attitudes of people with disabilities towards euthanasia and physician-assisted suicide in the Netherlands and Australia: Cross-national perspectives”

Following our earlier conversation this month, about distribution of my letter to a number of people with spinal injury in connection with my Ph.D. research I write to you again.

Please see enclosed 30 copies of my letter, on Edith Cowan University letterhead. The University’s Ethics Committee has approved it and a copy of their letter to me advising thus is also enclosed. My research proposal was approved by them in January 2000. Please feel free to contact Dr. Crothers (Ethics Committee Executive Officer) or one of my supervisors (Dr. Alan Tapper on 94005555 or Dr. Bob Jackson on 94005659).

I would greatly appreciate it if you would distribute these letters, with your cover note if you wish, to potential participants in my research.

I can also advise you that ‘X’ has agreed to be available to speak with any participants who, given the research topic, may have personal difficulties in the course of participation. Thus far, after some pilot interviews in Perth and 14 interviews in the Netherlands, any counselling has, to my knowledge, fortunately not been necessary. Participants are individually informed before commencement of the interview that this counselling is available and are given Ms. Beer’s contact details. They are also asked whether they suffer from depression or have done so in the past.

I would appreciate it if you would select 30 people with cervical spinal injury, i.e. quadriplegia. I would ask you to select no fewer than 8 female persons in this sample. I will of course inform all responding persons whether or not I require their participation. This will depend on the response rate and content of interviews.

Further criteria for potential participants are:
- Resident of Perth/Fremantle metropolitan area.
- Having had cervical spinal injury (quadriplegia) for no less than 5 years,
- Not being treated for clinical depression or suspected to be depressed,
- Injury as a result of trauma, not disease,
- A range of shorter-term to longer-term experience and different levels of quadriplegia is desirable in the targeted sample.

Would you please advise me of the date of distribution of the letters and of the cost associated with this mail-out? Thank you.

Please do not hesitate to contact me for any further details you may require.
Thank you again for agreeing to offer your assistance in this matter. I greatly appreciate it.

Sincerely,
APPENDIX D(NL)

**Studie titel:** “De houdingen tegenover euthanasie door mensen met handicaps in Nederland en Australië: Internationale perspectieven.

Onderzoeker: Erik Leipoldt. Tel. en fax (spatie)

Geachte mevrouw, heer,

Kunt u mij misschien helpen? Ik heb een klein aantal mensen nodig, die geïnterviewd zouden willen worden door mij over bovengenoemd onderwerp. Ik zoek naar een aantal mensen met een cervicale dwarslaesie en enkele toonaangevende sleutelfiguren in de brede Nederlandse gehandicaptenbeweging. Tussen mei en juni 2000 zal ik in Nederland zijn voor interviews.


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Ik zoek naar mensen die op zijn minst vijf jaar een dwarslaesie hebben, veroorzaakt door een ongeluk, operatie e.d., en dus niet
door een ziekte van de een of andere aard. Ik zoek tot een aantal van zo’n 15 mensen in deze categorie.

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Ik hoop van u te horen. Als u denkt anderen te weten die aan deze studie mee zouden willen werken in een interview (mensen met een cervicale dwarslaesie in Noord – en Zuid-Holland of/en leiders in de Nederlandse gehandicaptenbeweging) zou ik dat graag van u vernemen.

Met dank en vriendelijke groeten,

Erik Leipoldt
APPENDIX E

Interview guide

These are not literal questions, only a framework for the researcher’s reference. Some may be used, some not, depending on informant responses. There are adaptations for leaders’ interviews.

Introduction, purpose of interview and study and consent giving.

Describing the individual experience of disability and impact on their lives.

- To start of with, you may like to tell me anything that would get me to understand a bit of what kind of person you are – e.g. what is most important to you, your interests, anything…
- How long have you had the disability, what caused it?
- What did you do before it and what do you do now?
  - (education, employment, recreation)
- What supports do you have and how do they work for you?
  - (health care-doctors, community support service, financial costs, community access, significant relationships)
- How would you describe in your own words what life with a disability is like for you?
- Can you tell me how your disability may have made a difference to your life?
- What may be some of the best and some of the worst things about it for you – examples?
- How independent or dependent do you feel you are?
- How may this situation play a role in your life?
- If you would be able to change three things you see as reasonable to ask for or achieve what would they be?

Describing their understanding of and opinions on euthanasia and physician-assisted suicide.

- In your own words, how would you describe what euthanasia and physician-assisted suicide is?
• What are your thoughts about these issues?

• What about people with disabilities, including mental illness, intellectual, physical?

• Have you ever experienced issues around death and dying for others or yourself?

• Do you think euthanasia should be legal or not?

• Do you think it happens now?

• How safe can euthanasia practices be? For whom?

• How might rights and choices of people come into this, if at all?

• What roles do compassion and suffering play in this, if at all?

• Can you say whether you think terminal illness is an important consideration or not in addressing suffering?

• How do you see the roles of doctors in this, if any?

• Do you see any alternative or complementary approaches to euthanasia?

• What do you know about palliative care?

• What possible approaches to these questions do you think our society will adopt within the next 5 to 15 years?

• How would you describe the main characteristics of those societies?

• What influence, if any, does your own disability have on your views?

• Do you wish to comment on anything else?

• Demographic questions, that is age, level of quadriplegia/ type of disability, organisational affiliation, gender, disability, income, religion, town/suburb of residence.

• Why did you choose to contribute to this study?

• Are you able to suggest any other potential interviewees?