From:
Sent: Thursday, 10 April 2008 12:41 PM
To: Legal and Constitutional, Committee (SEN)
Subject: Inquiry into the Rights of the Terminally ill Bill 2008

Wednesday April 9, 2008

Dear Sir,

I had the opportunity as the Professor and Director of Palliative Medicine at the University of Melbourne in 2007 to visit Dr Nitschke at his home in Darwin and examine his medical records of his series of patients involved with the ROTI legislation in the Northern Territory. I also studied the coroner's files on these patients. We wrote these medical cases up in the Lancet (see reference below). I came to the conclusion that the practice of medicine and palliative care at that time in Darwin was poor, with the absence of radiation therapy for pain resulting from metastatic bone cancer, substandard treatment of or non-recognition of depression, and other instances of a poor standard of palliative medicine. I became convinced that the euthanasia legislation jeopardized the practice of quality medical care. I urge your committee to study the attached publications in peer-reviewed journals and the medical literature.

It is my conviction that the practice of medicine will deteriorate as a result of re-introduction of euthanasia and that such legislation ought to be resisted for the greater good of potentially vulnerable patients who might otherwise become the victims of poor medical care.

I have just learnt of this inquiry into the Rights of the Terminally ill (Euthanasia Laws Repeal) Bill 2008 and wish to draw to the Senate Standing Committee's attention a series of studies and publications conducted into the Northern Territory ROTI legislation. The first chapter is attached as a file and this volume can be found in the Parliamentary Library, Canberra. I apologize for the submission of this material at the eleventh hour. I would be willing to answer questions if I could be of benefit to the committee.

Yours sincerely
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DEADLY DAYS IN DARWIN

David W Kissane, MD

Seven patients entered Australian medical folklore during 1996-7, when for a period of nine months, euthanasia was a legal medical treatment within the Northern Territory, a large, sparsely populated and mostly desert region of the north-central part of the country. Two men and two women died making use of this legislation, while three others attempted to, but in fact died from other causes. All seven people attended the euthanasia advocate Philip Nitschke, who subsequently permitted the author to go over each of their stories with him to prepare them for publication, so that these historic medical facts could be placed on the public record $_1$. This chapter reviews this unique Australian social experiment, looking especially at the clinical histories and decision-making processes involved for these seven patients, the role and effect of the relevant legislation and the socio-political climate in which this remarkable tale evolved.

THE NORTHERN TERRITORY, AUSTRALIA

Representing one sixth of the country's landmass, the Northern Territory has a population of nearly 180,000 people, one quarter of whom are indigenous people. Like the Australian Capital Territory centered on Canberra, the Northern Territory does not have the full legislative powers of Australian States, and its laws are subject to review by the Commonwealth when it can be shown that its Acts are in conflict with the views of the nation. However it does have a parliament of 25 elected members who sit in its capital, the modern city of Darwin – a city rebuilt after its 1974 destruction by tropical cyclone Tracey.

Many of the residents of the Territory are transient and young, moving to the tropics to gain work for a few years before returning south again. Almost half of the deaths in the Northern Territory are of indigenous people, whose health status is often very poor. Thus the infant mortality rate is nearly twice that of the rest of the country and the median age at death for men (53.9) and women (64.0years) is almost 20 and 16 years below the national Australian figure, respectively [2]. Aboriginal Australians die more commonly from diabetes, circulatory, respiratory, infectious and parasitic diseases as well as external trauma. Their language does not have words for suicide or euthanasia, and there is a lack of interpreters to have their health needs addressed [3].

The Anti-Cancer Foundation gave evidence to the Territory's Select Committee Inquiry on Euthanasia about the lack of palliative care in the Northern Territory [4]. There was no dedicated oncology unit, no radiotherapy, and no dedicated palliative care unit or hospice before the legislation was introduced. A palliative care home nursing service was subsequently commenced in October 1995. There was the perspective that the elderly, the poor, and socially disadvantaged persons lacked access to good medical care, yet the barriers preventing such access were not investigated by this Select Committee on Euthanasia [4]. Key politicians moved headstrongly to create an Act they termed The Rights of the Terminally Ill (ROTI) Act 1995, Northern territory of Australia [5]. It was passed by 13 votes to 12 on the 25th May 1995, and enacted through passage of its Regulations [6] on July 1, 1996. Australia became the first country in modern times to practice legalised rather than just sanctioned euthanasia.

THE ROTI ACT

Under this legislation, a terminally ill patient, who was experiencing pain, suffering and/or distress to an extent deemed unacceptable, could request their medical practitioner to assist them to end their life. The provision of an opinion on the existence and terminal status of the illness was required by a second medical practitioner, a resident of the Territory, who needed special expertise in the illness and qualifications in a medical specialty recognised by fellowship of a specialist college in Australia.

If the first medical practitioner did not have special qualifications in palliative care, defined by the Regulations as either 2 years' full-time practice in palliative medicine, or not less than 5 years in general practice, then a third doctor with such qualifications was required to give information to the patient on the availability of palliative care.

Finally a psychiatrist was required to examine the patient and certify that he or she was not suffering from a treatable clinical depression. The Act required a period of 7 days to pass between the initial request to end life made to the first doctor and the patient's signing of an informed consent form, witnessed by two medical practitioners. A further 48 hours later, assistance to end life could be provided.

A death as the result of assistance under the Act was not taken to be unnatural, but a copy of the death certificate and relevant section of the medical record relating to the illness and death in each case had to be forwarded to the coroner. The coroner was subsequently required to report to Parliament the number of patients using the Act.

THE EUTHANASIA ACTIVIST, NITSCHKE

The intention of the law was that the person's usual doctor would occupy the role of the first medical practitioner, but instead it became filled by one doctor only, Philip Nitschke, a public advocate for euthanasia who volunteered to assist these patients. I first met Nitschke at educational meetings, where as a psychiatrist and professor of palliative medicine, I was asked to debate issues involved in physician-assisted suicide and euthanasia. I expressed interest in learning more about the clinical details of his patients so that these could be written up as an historical record. He eventually agreed to me visiting him at his home in the outer suburbs of Darwin. I was accompanied by a fellow academic, Annette Street, a medical sociologist with experience in ethnographic research, and having obtained formal consent from Nitschke, as prescribed by the university's ethics committee, we audiotaped 18 hours of interview with him. As he reviewed his medical records, we explored the medical decision-making processes and reviewed the specialist opinions he had obtained. Analysis was also undertaken of documents from the coroner's court, public texts created by patients in the form of letters and televised documentaries, and other comments made by the media, rights groups and politicians. Nitschke reviewed transcripts of the taped interviews for validation, and carefully reviewed the clinical material that was jointly published in the first instance [1].

Nitschke had not previously been involved with the care of the terminally ill, having been a mature medical graduate from the University of Sydney in 1989. In earlier life, he had completed a Doctorate of Philosophy in physics from Flinders University in South Australia and then worked as a political activist for the Aborigines in the Wave Hill uprising against the pastoral company Vesties. He spent a period as a ranger with the Northern Territory's Parks and Lands, living off the land whenever he went bush. Once he had graduated as a medical practitioner, he did his internship at the Royal Darwin Hospital. There he led a protest by the junior medical staff of the hospital opposing nuclear disaster drills during the visit of an US nuclear-powered ship into the Darwin harbour. In the following year, he was not reappointed to the junior medical staff and initiated discrimination tribunal action against the

Darwin Hospital, which he won eighteen months later. In the interim, he'd worked as a locum general practitioner and became a member of the Northern Territory Voluntary Euthanasia Society. When the Australian Medical Association, Northern Territory branch, declared its opposition to the ROTI Act, he publicly declared his willingness to assist patients with euthanasia. From that day, he became a constant media personality campaigning for the introduction of the Regulations and availability of the Act. Patients began to seek him out for assistance in accessing the ROTI Act, and he developed what he called his 'deliverance machine', a computer that asked patients to confirm their intention to die and wish to proceed by further pressing the computer's spacebar. His publicised technique involved the insertion of an intravenous line, and preparation of a barbiturate to induce sleep, which was then followed by a muscle relaxant medication to induce paralysis and respiratory arrest, leading to death. Via simple machinery, the computer regulated the introduction of these agents into the intravenous fluid, once the patient had again confirmed their desire to die.

Nitschke's role during this time involved constant travel with his political activities and he was not able to provide continuity of care as the regular care attendant to patients who sought him out. Rather he solicited opinions from specialists to meet the Regulations of the Act and thus co-ordinated the preparation of the patients for euthanasia. Before the Act officially became law on July 1, 1996, two patients made dramatic public appeals to hasten the passage of the regulations, each supported by Nitschke as an advocate for their right to access euthanasia. The first of these, a woman named Marta Bowes, appeared on the Sixty Minutes Television show [7], while the second, Max Bell, made a dramatic 3,000 kilometre journey from Broken

Hill to Darwin, documented by the Australian Broadcasting Commission as ‘The Road to Nowhere’ [8.]

CRIES FOR EUTHANASIA

The stories of these two patients are indicative of people who seek euthanasia.

Marta was a divorced 68-year-old teacher and member of the Hemlock Society, who flew into Australia from New Mexico declaring that she had terminal cancer. Her subsequent post mortem revealed that this was not true. Early stage bowel cancer had been newly diagnosed in the USA, but Marta declined surgery, fearing altered body image should a colostomy prove necessary. She made a serious suicide attempt in Albuquerque following her diagnosis of cancer, taking an overdose of insulin that necessitated admission to intensive care. There appeared to be deep-seated reasons for her unhappiness, including the death of her daughter in earlier years and estrangement from her son in recent years. Alienated and with few friends, her campaign on national television and through letters to the press argued passionately for access to managed death. Her eventual suicide from barbiturate overdose concluded a life latterly marred by an untreated depressive disorder, masked by her dramatic campaign for euthanasia.

Wanting to comply with the requirements of the ROTI legislation, Nitschke arranged for Marta to be examined by a psychiatric registrar, who returned the observation that she denied feeling depressed. His records showed no elaboration of details about her rift with her son, but Marta later broke down with a television reporter when pressed for details about this relationship. That evening she became further distressed and called Nitschke threatening immediate suicide. He dissuaded her from impetuous action, but she maintained her desire to die and did suicide three weeks later.

The autopsy confirmed an early stage bowel cancer and death from barbiturate overdose, supplemented by asphyxia. The coroner determined that Marta suicided on September 24, 1995, in a hotel room in Darwin. In the coroner’s file was a copy of a letter, dated August 25, 1995, to a member of the Voluntary Euthanasia Society of NSW, describing that Marta now had a kit with enough barbiturate to kill, and adding, ‘Now I have advice that I have the correct amount and I will have a relative and a doctor with me until I am gone. I plan my final exit at the end of September.’ Photographs of her death scene held in this coroner’s file revealed a book of her poetry from earlier years on a coffee table beside her. Among these poems were some describing her nostalgic and loving feelings for her son.

The second person involved in the public campaign in the lead up to the ROTI Act was the man Max Bell, who drove his taxi 3000 kilometres from his outback home to Darwin, also seeking euthanasia. Single, isolated, and somewhat cantankerous, this 64-year-old man described on national television the meaningless of his life [9]. He said, “I’m just existing. I can’t see the point anymore. I’ve seen my time. I’m ready for the sweet long sleep.” [9] A gastric cancer had been diagnosed one year earlier. Bell believed he could access the ROTI legislation if he travelled to Darwin, but as appeals were proceeding through the Supreme Court and doubt existed at that time that the legislation would become law, this man returned to Broken Hill. He subsequently died a natural death.

The sad plight of these individuals as they told their stories showed the force of tragic human narrative in influencing public opinion. The euthanasia societies maximised their campaign using every opportunity to capitalise on sensational press over this period. Alas, such reporting promoted adversarial and entrenched positions, which may have actively prevented these individuals accessing the medical care that might have appropriately assisted them. For example, the medical reports provided by Nitschke to the coroner in his investigation into the death of Marta Bowes cited 12 consultations between July 4 and September 23. His prescriptions included analgesics for pain relief and Temazepam and Pentobarbital for sleep. His record on September 16 noted, ‘Increasingly talking of ending her life, tried repeatedly to dissuade her to no avail, became angry when I persisted.’ On September 23, his record concluded, ‘No sign of depression. Repeated her intention to carry out her wish, unable to convince her otherwise.’ She died twenty-four hours later. Nitschke did not invoke the Mental Health Act to protect Marta from being a danger to herself in wanting to suicide, which one could argue was his duty of care. Rather he believed in her right to suicide and lamented the availability of legislation that would assist her to achieve her wish. For others that followed, however, that legislation became law.

THE ROTI ACT BECOMES LAW – BOB DENT’S DEATH

The first patient to make use of the ROTI Act was Robert Dent, who suffered from metastatic prostate cancer and died in his Darwin home from euthanasia on September 22, 1996. A prominent Sydney psychiatrist, John Ellard, subsequently told the media of his willingness to fly to Darwin to examine Dent and certify, as required by the ROTI Act, that he was not suffering from a treatable depressive disorder. Dent himself published a posthumous letter to the nation $_9$, in which he said,

> For months I have been on a roller coaster of pain made worse by the unwanted side effects of the drugs. Morphine causes constipation – laxatives work erratically, often resulting in loss of bowel control in the middle of the night. I have to have a rubber sheet on my bed, like a child who is not yet toilet-trained. Other drugs given to enhance the pain-relieving effects of the

> morphine have caused me to feel suicidal to the point that I would have blown my head off if I had had a gun.
>
> I can do little for myself. My red cells are decreased in number and deformed because of the cancer in the bone marrow. This anaemia causes shortness of breath and fainting.
>
> My own pain is made worse by watching my wife suffering as she cares for me; cleaning up after my “accidents” in the middle of the night, and watching my body fade away. If I were to keep a pet animal in the same condition I am in, I would be prosecuted. I have always been an active, outgoing person, and being unable to live a normal life causes much mental and psychological pain, which can never be relieved by medication.
>
> [Extract from Dent RB, 1996]

During his middle years as a carpenter, a building venture in Adelaide led to financial difficulties and a period of depression, treated with medication and counselling for some time. During his latter years in Darwin, Dent watched colleagues die ‘bloody horribly’, and feared a similar fate. Visiting nurses noted that he wept frequently; Nitschke observed angry exchanges in Dent’s household. The full complexity of his circumstances was not, in my opinion, well understood through a single assessment by a visiting psychiatrist philosophically supportive of the euthanasia legislation.

Dent’s prostate cancer was metastatic on diagnosis in 1991 and managed with anti-androgen approaches. In 1995, he first needed transurethral resection of the prostate for blockage of urinary flow. While he travelled to Perth for unproven therapies utilising microwaves, he did not travel to Adelaide for radiotherapy for bone pain. However, Nitschke did not consider his pain to be excessively troublesome, but rather recalled him weeping, saying he felt it pointless to continue suffering. Dent’s regular care providers were not told that he was being assessed for euthanasia, and were shocked to learn of his death. While Dent’s wife was present, his sons who resided in another state were unaware. Cremation was excluded under the ROTI Act, but was sought in the Buddhist tradition. The coroner was therefore required to hold an inquiry to determine cause of death before permission was granted for cremation.

JANET MILLS – THE SECOND EUTHANASIA DEATH

The second person to receive euthanasia had also become a public figure. Janet Mills was a small 52-year-old married woman, who wore a beanie on her head during national media presentations. Although ill for 12 years with mycosis fungoides, it had become systemic since 1994 and was treated with chemotherapy without resolution of her skin itch. Her general practitioner had treated her depression with an average dose of the antidepressant, doxepin. Record of her psychiatric examination revealed loss of interest and pleasure, lowered mood, poor concentration, insomnia, reduced reactivity to her surroundings, hopelessness, helplessness, worthlessness and a strong desire to die. Clearly she suffered from a severe major depression with poor response to initial antidepressant treatment. Alas, a forensic psychiatrist, who lacked experience in working with the medically ill, reviewed her. He judged her depression to be ‘consistent with her medical condition’ and added that side effects may limit further increase in dose of her antidepressant medication. This judgement blocked her access to a range of potentially effective treatments that may have altered her subsequent choices.

When Mills first travelled from another state to Darwin, Nitschke looked for a specialist who would provide the second medical opinion. Two surgeons agreed to see her and then withdrew; one physician assessed her and declined to certify that she was terminally ill. There was no attention to her depression over this time as the focus was on bureaucratic processes. After Mills made a public appeal on national television for a specialist to come forward and confirm that she was terminally ill, an orthopaedic surgeon was driven to compassion and agreed to see her, subsequently certifying that the ROTI Act had been complied with. Having obtained the necessary signatures, she returned home to farewell her family before returning to Darwin to receive euthanasia on January 2, 1997. The coroner of the day ignored the breaches of the Regulations.

THE NEXT TWO DEATHS

The identity of the next two people to make use of the ROTI Act has remained confidential. The third, a man, appeared totally isolated, while Nitschke obtained permission from the son of the fourth patient, a woman, to tell her story in an anonymous manner.

The first was an isolated English migrant, who lacked family in Australia. He had suffered from gastric cancer and developed jaundice from compression of his common bile duct by tumour. Usual management options involving stenting of his common bile duct did not appear to be pursued. This man was indecisive over a two-month period, commenting on the pointlessness of his life, but not able to take the final decision. His exploration of access to the ROTI Act appeared based on hopelessness and meaninglessness, a demoralized mental state, but without development of a formal depressive disorder. A superficial examination by a psychiatrist, which did not occur until the day of his death, and which Nitschke noticed to last only twenty minutes, provided indirect confirmation of his sense of pointlessness to his life. From the psychiatrist’s office, he was taken home to a musty house that had been shut up for several weeks. Nitschke had to hunt for sheets to cover the bare mattress. It rained heavily in Darwin that summer afternoon and

Nitschke later spoke of his sadness over the man's loneliness and isolation as he administered euthanasia.

The fourth euthanasia patient was flown in from another state. Suffering from breast cancer, this 70-year-old divorced mother of five had recently watched her sister's death from the same cancer and been horrified by what she perceived to be the indignity of double incontinence. She feared she would die in a similar manner. She was also concerned about being a burden to her children, although all three daughters were trained nurses. She had stayed with one daughter over six months of chemotherapy treatment for retroperitoneal lymphatic spread of her tumour that caused lymphoedema of her legs. There appeared to be little response to her chemotherapy and so her son arranged her transport to Darwin. All five children travelled with her and were present to say farewell in the hotel apartment before she died.

ESTHER WILD – A FINAL CASE AT THE CLOSURE OF THE ACT

The seventh case in this series was a woman, Esther Wild, who met the requirements of the Act, but deferred her death until she was ready and, in the interim, the Act was repealed. She was a 56-year-old woman with advanced carcinoid syndrome. Following initial diagnosis in 1977 and a prolonged period of remission until 1991, she then needed extensive abdominal surgery to resect tumour, but was left with bilateral leg lymphoedema. She retired from her nursing job at this stage. Further recurrence in 1996 necessitated bowel bypass surgery to overcome an obstruction, but she was left with a colostomy. She developed an antibiotic-resistant infection of her wound drain tube, leaving her with a smelly persisting discharge through a permanent fistula. She was troubled with its odour, but fortunately the medication octreotide lessened the discharge.

Over subsequent months, she gradually became more and more unhappy. She stopped reading, ceased letter writing, and withdrew from friends. Having thought increasingly about euthanasia, she completed the necessary documentation, but did not yet want to die. A team of nursing friends supported her in her home with the help of her general practitioner. In the interim, the Commonwealth Government on March 25, 1997 repealed the ROTI Act. One month later, her general practitioner's medical record described her as mentally and physically exhausted, more distressed than ever before, and now actively suicidal. As she sat with a fixed gaze, she displayed psychomotor retardation indicative of a serious depression. Alas, no one seemed to consider treatment of her depression.

Instead, as a protest at the repeal of the legislation, a television documentary was made about her death from prolonged sedation. Film clips were shot every few hours interspersed with a commentary by Nitschke about progress in getting her to die. Nitschke administered massive doses of morphine and midazolam, starting with 1440mg morphine and 15mg midazolam over the first twenty-four hours, eventually reaching 4800mg morphine, 200mg midazolam, and 400mg ketamine per twenty-four hours by the fourth day, plus further doses of chlorpromazine and phenobarbitone when she was restless. She awoke three times across this saga! Autopsy showed death from bronchopneumonia with mixed drug overdose, but the coroner decided in the difficult political climate to take no further action. Such massive doses of medication being used to bring about a death from pneumonia developing during deep prolonged sleep has become known in Australia as "pharmacological oblivion" [10].

The protagonists of euthanasia have suggested that this is what they must now do without legislation such as the ROTI Act to assist those wanting to die. Such management of a patient clearly involved a poor standard of medical care and the classic mistake of failing to obtain a second opinion when the management appeared hard going. Esther Wild died prematurely, and although she consented to the treatment she received, she was not in my opinion fully informed of other potential options of care. Her depression, the cause of much of her suffering, went untreated.

While not a large series, these seven deaths are important for their completeness as a sample of patients who actively sought euthanasia during the period of controversial legislation in Australia. Moreover, because their clinical histories have been able to be examined, the effectiveness of the legislation can now be assessed from a much more informed position.

SAFETY AND EFFECTIVENESS OF THE ROTI LEGISLATION

The legislation did not precisely define what was meant by ‘the terminal status’ of a patient, leaving this up to the judgement of the two key medical practitioners involved. This cast them in a gatekeeping role. The second medical practitioner was to be a specialist with expertise in the disease. One might have expected this to be a medical or radiation oncologist for patients with cancer, but instead we found that surgeons filled this role. Clearly they are involved in the diagnosis and initial management of cancer, but in our society, ongoing care is usually then transferred to a cancer specialist. There was one oncologist working in Darwin by the time the Act became law, but Nitschke found that only surgeons were willing within this community to certify that the patient was terminally ill, a curious state of affairs!

The purpose of the Regulations was to protect the broader community and in particular vulnerable patients, while permitting a healthy and rational individual to choose euthanasia for him or herself. A key intent of the legislation was however that the patient did suffer from a terminal illness. The above cases illustrated how problems developed with this assessment of prognosis, best exemplified when different specialists gave varied estimates of Janet Mills' potential length of life. There was no capacity within the Regulations to deal with such a difference of opinion. Moreover, when an orthopaedic surgeon came forward following Mill's public appeal for a certifying specialist, and he did not have expert knowledge of mycosis fungoides, a rare tumour involving both the skin and lymphatic systems but not the bones, this was ignored by relevant authorities. Such breaches of the Regulations were permitted by a legal system wanting to facilitate the legislation, thus removing the very safety features that had been designed to protect the vulnerable.

The other gatekeeping role was that of the psychiatrist, required to protect a patient whose rational choice might be marred by a depressive disorder. This was the part of the certification schedule most feared by patients and Nitschke reported that all seven described patients saw this step as a hurdle to be overcome [1]. Fear of the power of the psychiatrist militated against the development of a therapeutic alliance, a trusting relationship through which one's story can be openly and honestly discussed, as is necessary for a thorough assessment. The protective intent of the legislation was not accomplished because of this barrier. Indeed, four of the 'Seven deaths in Darwin' revealed prominent features of depression, highlighting its strong role in decision-making by those seeking euthanasia. Alarmingly, these patients went untreated by a system preoccupied with meeting the requirements of the Act's schedules rather than delivering competent medical care to depressed patients.

DEMORALIZATION –AN UNRECOGNISED YET HIGHLY PERTINENT FACTOR

Review of these patients' stories highlighted for me the importance of demoralization as a significant mental state influencing the choices these patients made [11]. They described the pointlessness of their lives, a loss of any worthwhile hope and meaning. Their thoughts followed a typical pattern of thinking that appeared to be based on pessimism, sometimes exaggeration of their circumstances, all-or-nothing thinking in which only extremes could be thought about, negative self-labelling and they perceived themselves to be trapped in this predicament. Often socially isolated, their hopelessness led to a desire to die, sometimes as a harbinger of depression, but not always with development of a clinical depressive disorder. It is likely that the mental state of demoralization influenced their judgement, narrowing their perspective of available options and choices. Furthermore, demoralized patients may not make a truly informed decision in giving medical consent. The third person to receive euthanasia in Darwin (name withheld) was an example of a demoralized patient, as also was Max Bell.

Demoralization syndrome has been considered, albeit briefly, in the consultation-liaison psychiatry literature and is an important diagnosis to be made and actively treated during advanced cancer [12]. It is recognised by the core phenomenology of hopelessness or meaninglessness about life. The prognostic language within oncology that designates ‘there is no cure’ is one potential cause of demoralization in these patients, a cause that can be avoided by more sensitive medical communication with the seriously ill. While truth telling is needed, hope must also be sustained so that life may be lived out as fully as possible. Patients with advanced cancer can be guided to focus on ‘being’ rather than ‘doing’, savouring the experiential moment of the present, so that purpose and meaning are preserved through inherent regard for the dignity of the person. Active treatment of a demoralized state by hospice services would involve counselling and a range of complementary therapies, use of community volunteers and family supports, all designed to counter isolation and restore meaning.

FEAR OF LOSS OF DIGNITY, BURDEN AND DEPENDENCE

Just as the Dutch express fear of unworthy dying as a prime reason for euthanasia, [13,14] so too in this Australian cohort, concern about loss of dignity, becoming dependent on others and potentially being a burden were prominent reasons for the request for euthanasia [15].

A considerable challenge exists in cancer care to protect patients from perceptions, based on life's earlier experience as onlookers, that their own journey and death will be similar to others. Research has repeatedly shown how quality of life is appraised differently by patient, carer and clinician [16-18]. A patient with cancer can adjust to the experience of gradual frailty over time, so long as adequate reassurance is given about the thoroughness of care along the way. Family onlookers can have a more difficult task, never more so than with medical families, whose members carry a variety of memories of decay, bodily disintegration and disability, often times with revulsion and disgust.

One of the unspoken discourses within the medical community is the story of disgust at what is witnessed during everyday care. Bedsores, gangrenous limbs, smelly fistulas and stomas - medicine is replete with horror tales of rotting bodily decay. Little research has evaluated how staff copes and adjusts to these experiences by repressing the ugly in favour of the value of the whole person that they have come to know. Undoubtedly for some, this experience is not easy. Families also need help to adapt to such predicaments, helping them remember the complete person rather than focussing on the failing bodily part. Open communication about such reactions is a vital means of debriefing, normalising human response and affirming the courage involved. Family meetings occur all too infrequently, denying thus the opportunity for members to share feelings and transcend their initial human responses to adversity.

Acceptance of euthanasia by a family, as exemplified by case four, where five children travelled to Darwin with their mother, might subtly confirm to the patient that he or she would indeed be a burden, interfering with busy lives, and that any remaining length of life was unimportant. These unspoken messages have further profound effects on morale. Many elderly patients fear being a burden, but seek reassurance and expression of gratitude for efforts in years gone by. Families are challenged to take care that they do not misunderstand a tentative suggestion by a family member that they might be a burden. As a clinician, I believe that any patient who is convinced they are a burden has lost perception of their own worth, sacrificing their life heroically to advantage their family. Exploration of such stories invariably reveals a demoralized perspective.

REPEAL OF THE ROTI ACT

Rather than a bill being prepared by a political party, it was a private member's bill, the Euthanasia Laws Bill 1996, which was introduced into the Commonwealth Parliament of Australia on September 9, 1996, that sought to repeal the ROTI Act. It was introduced by Kevin Andrews, a member from Victoria, and parliamentarians were permitted a conscience vote rather than having to follow party line. While Territorians attempted to argue that it was an issue of States' rights, most commentators focused on the appropriateness of the legislation itself. In Australia, the Federal Parliament can overrule the laws of its Territories, although it cannot overrule State laws. Before this bill came into effect on March 25, 1997, the issue was thoroughly explored by a Senate Legal and Constitutional Legislation Committee [19].

This body received 12,577 submissions, a record for our country, 93.3% of which were opposed to euthanasia [19]. Noteworthy were those from the indigenous community, which comprises nearly one quarter of the Northern Territory's population. Concepts of euthanasia were unfamiliar to Aborigines, many dialects having no words for it in their language. Providing assistance to make a person die was considered likely to be an instrument of sorcery or payback within their culture and traditionally regarded as morally wrong. Evidence was received that hospitals had become feared as places in which Aborigines could be killed without their consent. A submission from Djiniyini Gondarra stated, ‘Our ancient Law/Madayin does not empower our Traditional Narra/Parliaments to create Law/Wayuk, that give an individual the right to take the life of another’ (p 47) [19]. The Senate committee concluded that the ROTI Act had an unacceptable impact on the attitudes of the Aboriginal community to health services.

Many other submissions gave testimony to the importance of improving palliative care services and aiming at the delivery of quality medical care rather than empowering doctors to kill. Concern was expressed at the change that euthanasia would bring to this delivery of medical care, alluding to the complex decision-making that goes on within a doctor’s mind when he or she determines that a patient’s life is no longer worthwhile. It was pointed out that the boundary transgression involved when a doctor has sex with his patient is similar to that involved when a doctor kills his patient [20]. The Commonwealth Parliament strongly upheld the bill that rescinded the ROTI Act.

THE EUTHANASIA DEBATE IN AUSTRALIA

As it other countries, euthanasia societies were more active in Australia during the second half of the twentieth century, sponsoring a range of medical treatment bills similar to ROTI in State parliaments across the country [21]. Public opinion polls emphasised fear of pain and suffering in generating a rising tide of support for euthanasia [22]. Bioethicists Kuhse and Singer, amid others, surveyed doctors’ and nurses' attitudes regarding voluntary euthanasia, utilising questions that blurred the boundary between respect for a natural dying process and killing the patient [23-26]. Community support for voluntary euthanasia was rising, while palliative care remained in its infancy in many sectors of the country [27-28]. Since ROTI, some of this has changed, with greater funding being made available for palliative care. The Northern Territory has developed a dedicated palliative care service in Darwin and across other aspects of the region, but nationally there is still much to be done.

Our society's unspoken attitude toward dying merits some understanding. There is a reduced role for religion in promoting acceptance of dying for many in the community, and the belief that death is a transition to a heaven or another life has been replaced with the simple notion that life for that person ends. For such individuals, however, there is a wish, and indeed, a community expectation that they will die a heroic death [29]. With awareness of death approaching, such a patient, accompanied by family or carers, is encouraged to display acceptance calmly and courageously. However for others, when their death is feared to lie outside this script of insightful courage, a death with too much suffering, loss of dignity or following the development of meaninglessness in their life, medically managed deliverance is perceived to bring welcome relief from a feared predicament. Euthanasia or physician-assisted suicide thus returns this person to an experience of heroism in their choice of a managed death, holding considerable public appeal to those otherwise contemplating some undignified manner of dying. Such attitudes continue to prevail in our Australian culture, where medicine is perceived to omnipotently provide the technological solution to all suffering [30].

Within this climate, Kuhse and Singer sought to further expose end of life decision making in Australia through a comparison of our medical practice with that reported by the Remmelink Commission appointed by the Dutch Government in 1990 and restudied in 1995. The Netherlands and Australia have fairly similar populations and annual death rates. In conducting their study, Kuhse and her colleagues administered an English version of the retrospective questionnaire used by the Dutch, but without interviews to verify understanding [31]. Furthermore, they varied the wording of key questions to combine both actions or omissions that did not seek to prolong life with those aimed at hastening death. In the process they combined normal care that is respectful of natural dying with actions that hasten death. This conflation of the arguments about allowing to die and killing led to their grossly flawed conclusion that in 36.5% of all Australian deaths, a medical end of life decision was made with the explicit intention of ending the patient's life. The incorporation of actions or omissions aimed at not prolonging life would include a doctor who appropriately decided not to initiate futile intensive care or ventilatory support for a patient dying from terminal cancer. The wide range of ordinary treatment decisions that have nothing to do with intention to kill, but which were included in their questions, rendered any comparison with the Dutch meaningless.

Moreover, their utilitarian thinking equated the decision not to treat and the cessation of futile treatment with killing. Such thinking is flawed. For an action involving the omission of a treatment to carry culpability for death causation, the treatment must be proven to be clinically effective in the circumstances and the underlying condition potentially reversible. As the dying process unfolds in a terminal patient, the condition becomes irreversible, and interventions could cause harm through prolonging the dying, if they were inappropriately applied. "Moral-equivalence" arguments based on outcome cannot ignore the assessment of clinical proportionality and appropriateness.

A sad consequence of their survey was the evidence it provided for widespread misunderstanding among Australian doctors about the contribution of morphine to death. Kuhse and colleagues claimed that 30.9% of deaths resulted from a probable life-shortening effect of opioids [31]. There is no determinative fatal dose of morphine; rather, it is the increment in dose relative to a prior dose that is relevant [32]. In pain management, gradual dose escalation by 50-100% of the previous dose is usual practice, although patients who are not new to the drug can usually tolerate substantially higher increases. Despite a sustained international campaign by the World Health Organisation, appropriate opioid usage is surrounded by myths and fears among the general public and health care professionals, appearing to be largely attributable to the non-medical utilisation of this class of drug [33]. The survey work and public comment by Kuhse and Singer has sustained this mythology about opioids in a misinformed and damaging manner.

Palliative care is inevitably drawn into debates about euthanasia and physician-assisted suicide, creating an unfortunate comparison that proffers hospice as *the* solution, perpetuating the myth of an available solution to all suffering. Palliative care as an emerging new specialty has much to offer in providing excellence of care at the end of life, for indeed, there is much that can still be done. A major task remains to ensure broad coverage of palliative care on medical and nursing school curricula and to advance the distribution of hospice services so that they become equitably available to all. While we remain unable to guarantee the quality of medical care within our societies, there can be no place for euthanasia, but a vital need does exist for good palliative care.

CONCLUSION

The brief period of legalised euthanasia in Australia provided a useful window of opportunity to view the experience of such a social experiment. Despite considerable legislative effort to draft safe regulations that would protect the vulnerable, review of the clinical accounts of patients that sought access to this legislation revealed blatant failure of the Act to achieve its purpose. Given the level of error rate that does occur in medical practice, this experience suggests it would be impossible to safely legislate for doctors to kill. Certainly the gatekeeping roles designed by this Act failed to protect depressed, isolated and demoralized patients. Cast in a legislative and bureaucratic stance, these gatekeepers ceased to practice the craft of medicine, to the neglect of the patients they sought to serve.

Important lessons can be learnt from this social experiment. They point to the need to develop palliative care, something that was a major failure of the Perron government in the Northern Territory. They also highlight the distress that exists in society, the challenge that this brings to medicine and the comprehensive responses, fiscally, socially, politically and medically that are needed to respond to suffering within our world.

We are challenged to better understand the dignity of the person, their fear of dependence, loss of control and bodily decay, together with systemic responses that include family-centered care and adequate means of staff support. Disorders of hope and meaning warrant greater study, alongside depression in the medically ill. But if there was a key lesson from the Act permitting euthanasia in the Northern Territory, Australia, it was that it does not appear possible to safely legislate to grant autonomy for the few, without creating danger to many other vulnerable individuals in society. We should continue to work to prevent suicide, including physician-assisted suicide in the medically ill.

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