Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia

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Summary

Background During the 9 months between July, 1996, and March, 1997, the provision of euthanasia for the terminally ill was legal in the Northern Territory of Australia. Seven patients made formal use of the Rights of the Terminally Ill (ROTI) Act; four died under the Act. We report their clinical details and the decision-making process required by the Act.

Methods We taped in-depth interviews with the general practitioner who provided euthanasia. Further information was available from public texts created by patients, the media, and the coroner.

Findings All seven patients had cancer, most at advanced stages. Three were socially isolated. Symptoms of depression were common. Having met criteria of the Act, some patients deferred their decision for a time before proceeding with euthanasia. Medical opinions about the terminal nature of illness differed.

Interpretation Provision of opinions about the terminal nature of illness and the mental health of the patient, as required by the ROTI Act, created problematic gatekeeping roles for the doctors involved.

Introduction On May 25, 1995, the Northern Territory Parliament in Australia passed the Rights of the Terminally Ill Act 1995 (ROTI). The Act became law on July 1, 1996, making the Northern Territory the first place in the world to have legalised euthanasia. By contrast, in the Netherlands euthanasia is sanctioned and has been openly practised since 1991, but remains technically illegal. In Oregon, USA, physician-assisted suicide was first enacted on Dec 8, 1994, but was deferred through appeals, until it was confirmed by a second referendum on Nov 22, 1997.

The Northern Territory ROTI Act was appealed against in the Supreme Court, but on July 24, 1996, it was ruled valid. On Sept 9, 1996, a Member of Parliament from Victoria introduced into the Commonwealth Parliament of Australia the Euthanasia Laws Bill 1996, designed to repeal the ROTI Act. This bill came into effect on March 25, 1997. In Australia the Federal Parliament can over-rule the laws of its Territories, although it cannot over-rule State laws.

The Northern Territory has a population of roughly 180 000 spread over one sixth of mainland Australia, and one third of this population is indigenous. During the period when the ROTI Act was law, four people died under the Act, on Sept 22, 1996, and Jan 2, Jan 20, and March 1, 1997. We studied the clinical decision-making process during this period of legal euthanasia. PN was the only Darwin medical practitioner who reported euthanasia deaths. He agreed to be interviewed by DWK, a consultant psychiatrist and professor of palliative medicine, and AS, a medical sociologist. We describe seven case histories of patients who sought to use the Act. Our aim was to make overt the decision-making processes involved in their care. The report is necessarily limited by the scope of medical records and the memory of PN, but we judge that it provides a useful profile. Since we have differing views about euthanasia we have not attempted a critique of the management of these patients nor a debate about euthanasia, but we simply place the case material on the public record.

The ROTI Act, 1995, stated that a terminally ill patient, experiencing pain, suffering, and distress to an extent deemed unacceptable, could request a medical practitioner for assistance to end his or her life. The doctor had to be satisfied on reasonable grounds that the illness was terminal and would result in the patient’s death in the normal course and without application of extraordinary measures. A further requirement was that there were no medical measures acceptable to the patient which could reasonably be undertaken to effect a cure, and that any further treatment was only palliative in nature. The doctor needed to certify that the patient was of sound mind and making the decision freely, voluntarily, and after due consideration.

A second medical practitioner, a resident of the Northern Territory, was required to examine the patient...
to confirm the existence and terminal nature of the illness, and to give an opinion on prognosis to be recorded on the schedule used for certifications under the Act. The regulations required that this practitioner hold a qualification in a medical specialty related to the terminal illness, 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’ general practice, a third doctor with such qualifications was required to give information to the patient on the availability of palliative care. A psychiatrist was also required to examine the patient and confirm that he or she was not suffering from a treatable clinical depression in respect of the illness. 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 h later, assistance to end life would be provided. A death as the result of assistance given 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.

Methods
In this study, we used 18 h of in-depth audiotaped interviews with PN in Darwin. The interviews drew on his medical records and invited him to talk about decision-making processes for identified patients under his care during the period of legalised euthanasia. We also analysed documents and public texts created by patients in the form of letters and televised documentaries, documents from the coroner’s court, the media, rights groups, and politicians, and the research on euthanasia and physician-assisted suicide.

The university’s ethics committee approved the study, and PN gave informed consent as the key informant. Although some patients and doctors went on the public record, we have kept their identities confidential in these cases. PN reviewed transcripts of the taped interviews for validation, and carefully reviewed the clinical material.

Results
Seven deaths were identified through PN and the coroner’s records. Two patients sought euthanasia but died before the Act became law. Three patients were socially isolated, and four had the support of spouse, children, or friends. Several treatment options remained available to patients, but their focus with PN was on euthanasia. Consensus over the terminal nature of illness proved difficult to reach in two cases.

Case 1
A divorced teacher aged 68 travelled to the Northern Territory to seek euthanasia some months before the ROTI Act was passed. She committed suicide in Darwin in September, 1995. Beside her was a letter, which said: “I have decided to end my life because I am terminally ill from cancer. I have maybe a few months to live”. Her medical history included bilateral breast-reduction surgery, diabetes, moderate alcohol consumption, a suicide attempt when aged 67, and carcinoma of the caecum. She had declined surgery for the carcinoma when it was first diagnosed 6 months before her death.

In Darwin, a computed tomography scan confirmed a thickened caecum, but the patient’s liver appeared normal and there was no para-aortic or pelvic lymphadenopathy. Her surgeon confirmed that biopsy at colonoscopy had diagnosed adenocarcinoma. Although the patient labelled herself as “terminally ill” when speaking to the media, PN understood her to know there was potential for surgery to be curative and that her prognosis was good.

During formal psychiatric assessment for suitability for euthanasia, the patient explained that she refused surgery for fear that it would leave her physically disabled. She was a member of the Hemlock Society. She had few friends in Darwin. She acknowledged estrangement from her son, but there was no elaboration of this, nor of her attitudes and feelings at the time of her suicide attempt 4 months previously. She did not mention her daughter, who had died quite young. She denied feeling actively suicidal, and was judged euthymic with satisfactory cognitive function.

The patient maintained her interest in dying, giving an interview on national television in which she stated she would commit suicide if the regulations necessary for the operation of the ROTI Act 1995 were not soon made law. During the evening after the interview was recorded, she became agitated and distressed, and threatened to kill herself. PN remembered this as the only occasion on which he saw her upset as she spoke about her losses and bitterness towards her son. She committed suicide 3 weeks later.

Necropsy revealed a 6·5 cm tumour at the ileocolic valve (on histology, an adenocarcinoma), with involvement of ileocolic lymph nodes but no distant spread. The patient’s liver showed cirrhosis but no tumour. Blood pentobarbital concentration was 8·2 mg/L. The coroner determined the cause of death as barbiturate overdose and asphyxia.

Table 1: Sociodemographic and clinical details of patients

<table>
<thead>
<tr>
<th>Case</th>
<th>Age (years)</th>
<th>Sex</th>
<th>Marital status</th>
<th>Cancer diagnosis</th>
<th>Prominent pain</th>
<th>Depressive symptoms</th>
<th>Other clinical issues</th>
<th>Mode of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>68</td>
<td>F</td>
<td>Divorced</td>
<td>Caecum</td>
<td>No</td>
<td>Suicidal</td>
<td>Diabetes, arthritis</td>
<td>Suicide</td>
</tr>
<tr>
<td>2</td>
<td>64</td>
<td>M</td>
<td>Single</td>
<td>Stomach</td>
<td>No</td>
<td>No</td>
<td>Nausea</td>
<td>Natural</td>
</tr>
<tr>
<td>3</td>
<td>66</td>
<td>M</td>
<td>Married</td>
<td>Prostate</td>
<td>Controlled</td>
<td>Past history, suicidal thoughts</td>
<td>Anaemia, constipation</td>
<td>Euthanasia</td>
</tr>
<tr>
<td>4</td>
<td>52</td>
<td>F</td>
<td>Married</td>
<td>Mycosis fungoides</td>
<td>No</td>
<td>Yes, on antidepressants</td>
<td>Pneumonia</td>
<td>Euthanasia</td>
</tr>
<tr>
<td>5</td>
<td>69</td>
<td>M</td>
<td>Single</td>
<td>Stomach</td>
<td>Controlled</td>
<td>No</td>
<td>Jaundice</td>
<td>Euthanasia</td>
</tr>
<tr>
<td>6</td>
<td>70</td>
<td>F</td>
<td>Divorced</td>
<td>Breast</td>
<td>Controlled</td>
<td>Yes</td>
<td>Frailty</td>
<td>Euthanasia</td>
</tr>
<tr>
<td>7</td>
<td>56</td>
<td>F</td>
<td>Single</td>
<td>Carcinoid</td>
<td>Controlled</td>
<td>Yes</td>
<td>Fistula with odour, lymphenodema</td>
<td>Sedation</td>
</tr>
</tbody>
</table>

ARTICLES
became a further difficulty—on one occasion ribs broke during a hug. Neither radiotherapy nor strontium was available in the Northern Territory. The patient took morphine for generalised bone pain, but was distressed by intermittent nausea, constipation, and diarrhoea, and he required catheterisation.

The memory of friends whom the patient saw die "bloody horribly" led him to fear a similar fate. He spoke of feeling sometimes so suicidal that if he had a gun, he would have used it.9 PN was embarrassed to witness sharp exchanges with others in which the patient would "yell and scream, intolerant as hell; you'd realise it's a last pathetic attempt at asserting himself".

The patient was cared for at home by a community palliative-care team. The patient wept frequently, and told PN that he felt it pointless to continue suffering. The patient thought his oncologist and palliative-care team minimised the severity of his predicament. In the end, they were not told he was being assessed for euthanasia, and the news of it came as a shock to those involved. A psychiatrist from another state certified that no treatable clinical depression was present.

The patient’s wife was present and gave support while he received euthanasia; his sons were unaware of events until afterwards. Cremation was excluded under the ROTI Act, but was sought in the Buddhist tradition. A coroner’s inquiry had to determine cause of death before permission was granted for cremation.

Case 4
This patient developed an indolent rash, mycosis fungoides, 12 years before the request for euthanasia. The rash was initially treated with psoralen and ultraviolet A, topical nitrogen mustard, and total body electron beam, with good effect. The patient had a remission for 6 months during 1994. On recurrence, she developed lymphadenopathy and nodular skin lesions, which showed that the illness had become systemic. She was treated with oral chlorambucil without improvement, then with four cycles of intensive chemotherapy. There was evidence of reduction in mass disease, but the patient complained of fatigue and her pruritus persisted, which made her reluctant to continue further chemotherapy.9 Her oncologist advised that the median survival of a patient with mycosis fungoides in this systemic phase was 9 months, and he said that he had no further active management to offer.

Pain was well controlled. The dominant problem was pruritus, which resulted in skin trauma, infection, eyelid oedema with closure, and persistent aural discharge. The patient’s dermatologist suggested various medications including haloperidol, pimozide, fluoxetine, and nalozone. An ear, nose, and throat specialist offered guidance about ear discharge.
Case 5
This elderly man lived alone in the Northern Territory, had never married, had migrated from England, and had no relatives living in Australia. He had had a partial gastric resection for carcinoma of the stomach. He sought euthanasia because he saw no point in going on with pain and suffering when he was advised that he would not recover.

Computed tomography 4 months before euthanasia revealed diffuse smooth thickening of the peritoneum throughout the abdomen, associated with a moderate amount of free ascites. The liver was of normal size and uniform density and the gallbladder was absent. There was mild dilatation of intrahepatic and extrahepatic biliary ducts without evidence of a discrete obstructing mass. The residual gastric remnant was distended. There was no evidence of abnormal abdominal or pelvic lymphadenopathy. There was partial obstruction of the right kidney, with its ureter dilated as far as the common iliac vessels. There was no discrete obstruction mass, but there was evidence of adjacent peritoneal disease. The left kidney was normal.

About 2 months after the scan, the patient was staying in hospital, and telephoned PN to discuss euthanasia. The patient's surgeon confirmed the prognosis as hopeless and agreed to certify this. However, the patient sought time to think about euthanasia, and invited PN back twice over the next 2 months. The patient queried the time to think about euthanasia, and invited PN back twice over the next 2 months. The patient queried this decision, and PN encouraged him to wait. Finally, the patient signed the consent and selected a date for euthanasia.

The patient was assessed by a psychiatrist on the day on which euthanasia was planned—this timing was not excluded by the Act. The patient was emaciated, clinically jaundiced, and so weak that he needed a wheelchair for transport. Nevertheless, he was alert and able to converse, giving a clear account of his illness and wishes. He denied being depressed. He complained of mild background pain incompletely relieved by medication. He was constantly nauseated, vomited intermittently, and kept down only liquids. PN recalled that on this occasion the psychiatrist phoned within 20 min, saying that this case was straightforward. The patient was taken back to his own home, which had been shut up for some weeks. PN recalls his sadness over the man's loneliness and isolation as he administered euthanasia.

Case 6
This divorced woman flew to Darwin from another part of Australia, accompanied by her children. She had advanced metastatic carcinoma of the breast and had had primary surgery in 1994. The patient's sister had died recently from breast cancer, and she was distressed at having witnessed this death, particularly the indignity of double incontinence. The patient feared she would die in a similar manner. She was also concerned about being a burden to her children, although her daughters were trained nurses.

PN was first contacted by one of the patient's sons, who gave a coherent account of his mother's disease. She had been well until mid-1996, when her legs began to swell and retroperitoneal lymphatic involvement was diagnosed. Despite chemotherapy, the disease progressed, and regular analgesia was needed for abdominal pain. The patient moved to live with a daughter, but became more frail and lost strength over 6 months of active treatment, and eventually became bedridden. Although receiving palliative care, she said, "I don't like being like this; I want to die". She discussed euthanasia with her children, who agreed and organised her flight to Darwin.

In Darwin, the patient was judged by a general surgeon to have extensive metastatic disease, for which there was "no further conventional treatment that would alter her prognosis, which was that of death in the near future". A psychiatrist certified that she was not clinically depressed and that she had full comprehension of her situation. A week after the patient arrived in Darwin, she was moved from hospital to a hotel apartment, where she said goodbye to her children, speaking to each in turn. She underwent euthanasia surrounded by her family.

Case 7
This 56-year-old woman lived alone. She first developed a carcinoid tumour of her small bowel in 1977, presenting with intussusception. The mesenteric lymph nodes were involved at that time. She remained well until abdominal discomfort developed in 1991, when recurrent carcinoid was found at laparotomy. She underwent wedge excision of hepatic metastases, debulking of pelvic tumour, and bilateral oophorectomy. Inguinal lymph nodes were involved, leading to lymphoedema. The patient retired from her nursing job at that stage.

In 1996, the patient developed a subacute bowel obstruction, and needed ileocolic bypass and loop sigmoid colostomy. There was evidence of diffuse pelvic tumour and malignant ascites. She made a slow recovery, complicated by meticillin-resistant *Staphylococcus aureus* infection of a wound-drain site that eventually became a infection.
permanent fistula. She was troubled by odour from the fistula, and thereafter limited her social activities. Discharge from her fistula was lessened with octreotide.

Over subsequent months, the patient’s bilateral lymphoedema worsened, her sleep was disturbed, and she started to lose weight. She had intractable pain in her right groin, extending around to her back. The pain was treated with subcutaneous morphine, but the patient became more and more unhappy. She had been an avid reader, but stopped owing to poor concentration. She withdrew further, and stopped letter-writing. No longer able to leave the house, the patient needed a friend to sleep at her house in case she needed assistance overnight. By February, 1997, having thought increasingly about euthanasia, the patient completed the necessary documentation, but did not yet want to die. She continued with palliative care and support from a team of nursing friends beyond the repeal of the ROTI legislation in March, 1997.

However, by mid-April, 1997, the patient’s general practitioner described her as mentally and physically exhausted, more distressed than ever before, and now actively suicidal. The patient sat with fixed gaze and drooping eyelids. Given that the ROTI Act was no longer available, the patient agreed to an intravenous infusion of morphine and midazolam as terminal sedation. At first, the infusion contained morphine 1440 mg plus midazolam 15 mg over 24 h, and the doses increased to morphine 4800 mg plus midazolam 200 mg plus ketamine 400 mg per 24 h over the next 3 days, supplemented by boluses of phenobarbitol and chlorpromazine when the patient was restless. The patient’s management generated much discussion, since it was documented on national television. At necropsy, cause of death was given as bronchopneumonia, carcinomatosis, and mixed drug overdose; the coroner decided to take no further action.

Discussion

In their review of euthanasia in the Netherlands in 1995, van der Maas and colleagues estimated that some 2-3% of deaths resulted from euthanasia, 0-7% without the patient’s explicit consent. Moreover, van der Wal and colleagues concluded that only 41% of all cases of euthanasia or physician-assisted suicide were reported. Euthanasia is broadly accepted within Dutch society. By contrast, a survey in the USA that explored attitudes towards euthanasia or physician-assisted suicide showed that only 1% of nurses, 13% of medical students, and 44% of the general public believed that euthanasia was acceptable. Euthanasia is seen as a controversial issue, with many people expressing concern about the potential for abuse or neglect. Some argue that euthanasia is a necessary means of relieving suffering, while others believe that it is a violation of human rights and a threat to the sanctity of life.

In their study, van der Maas and colleagues found that the most common reasons for euthanasia were: (1) terminal illness; (2) severe pain; (3) suffering; (4) depression; and (5) a sense of hopelessness.

However, in cases of euthanasia, the decision to allow the patient to die is complex and involves a number of factors. The decision-making process involves the patient, their family, and healthcare professionals. In some cases, the decision may be made by a team of doctors, while in others it may be made by a single doctor. The decision-making process is often difficult, as it involves balancing the patient’s desire to die with the potential for suffering and pain. It is important to involve the patient in the decision-making process, as they are the ones who are most affected by the outcome.

In cases of euthanasia, it is important to consider the patient’s decision and their ability to give informed consent. It is also important to consider the patient’s suffering and the potential for relief. In some cases, it may be possible to provide palliative care to relieve suffering, while in others it may be necessary to consider active treatment. It is important to involve the patient in the decision-making process, as they are the ones who are most affected by the outcome.

In conclusion, the decision to allow a patient to die is a complex and difficult one. It is important to consider the patient’s decision and their ability to give informed consent. It is also important to consider the patient’s suffering and the potential for relief. In some cases, it may be possible to provide palliative care to relieve suffering, while in others it may be necessary to consider active treatment. It is important to involve the patient in the decision-making process, as they are the ones who are most affected by the outcome.

Medical practitioners working with the ROTI Act had to exercise clinical judgment about the nature and process of an illness, its previous and current management, and any further potentially worthwhile treatment. The decision-making process involved review of the accuracy of diagnosis and the suitability of treatment, with exclusion of confounding factors. This could be described as a gatekeeping function, in which the vulnerable are protected through the wise application of the law. The potential length of future life of a patient with cancer can be very difficult to judge accurately, and differences of expert opinion were evident in two of these cases.

The ROTI Act specifically required a psychiatrist to confirm that patients were not suffering from a treatable clinical depression. Confirmation was not easy since patients perceived such a mandatory assessment as a hurdle to be overcome. PN understood that every patient held that view. To what extent was the psychiatrist trusted with important data and able to build an appropriate alliance that permitted a genuine understanding of a patient’s plight? In case 1, there was important background detail about the death of one child and alienation from another, which was withheld during the psychiatric assessment. These experiences may have placed the patient in a lonely, grieving, demoralised position: an unrecognised depression may have led to suicide. Four of the seven cases had symptoms of depression, including reduced reactivity, lowered mood, hopelessness, and suicidal thoughts. Case 4 was receiving treatment for depression, but no consideration was given to the efficacy of dose, change of medication, or psychotherapeutic management. PN judged this patient as unlikely to respond to further treatment. Nonetheless, continued psychiatric care appeared warranted—a psychiatrist can have an active therapeutic role in ameliorating suffering rather than being used only as a gatekeeper to euthanasia. Ganzini and colleagues showed that only 6% of psychiatrists in Oregon, USA, thought that they could be a competent gatekeeper after a single assessment of a patient. This finding illustrates the difficulty of legislation of this sort—there is an important role for psychiatry in oncology and palliative care to ensure that depression is actively treated, but a gatekeeping role may be flawed if seen as adversarial by patients and viewed as blocking successful treatment, rather than being one part of proper multidisciplinary care.

The ROTI Act was designed to encourage patients to make active and early use of palliative care, and to be
fully informed about care options. However, the political debate surrounding the Act tended to cast practitioners of palliative care as opponents of the euthanasia campaigners, potentially to the detriment of patients’ care. Furthermore, palliative-care facilities were underdeveloped in the Northern Territory, and the patients in our study needed palliative care. Burt suggests that the US Supreme Court identifies a constitutional right to palliative care, especially for the alleviation of pain and other physical symptoms, for people facing death.

Pain was not a prominent clinical issue in our study. Fatigue, frailty, depression, and other symptoms contributed more to the suffering of patients. There is a need to respond creatively to social isolation, and to treat actively all symptoms with early and skilled palliative care. Education in providing palliative care is a priority for many communities, including the Northern Territory.

Our case material shows that the assessment of depression is difficult in the terminally ill, and accurate prediction of prognosis is subject to disagreement. There are clear limitations of the gatekeeping roles of the medical specialist and psychiatrist in the ROTI legislation. However, we have deliberately avoided being drawn into the debate about euthanasia and physician-assisted suicide.

References