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;[1] 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.

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Introduction

On May 25, 1995, the Northern Territory Parliament in Australia passed the Rights of the Terminally Ill Act 1995 (ROTI).[1] The Act became law on July 1, 1996, making the Northern Territory the first place in the world to have legalised euthanasia.[2] By contrast, in the Netherlands euthanasia is sanctioned and has been openly practised since 1991, but remains technically illegal.[3,4] In Oregon, USA, physician-assisted suicide was first enacted on Dec 8, 1994,[5] 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 Supereme 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,[1,2] 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

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

Table 1: **Sociodemographic and clinical details of patients**

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 case reports. 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, four died under the Act, and one died after its repeal. Sociodemographic and clinical characteristics of the patients are given in table 1. Four had some symptoms of depression. Cancer was the only form of illness, and most patients presented at advanced stages, but some deferred euthanasia once satisfied that they met the requirements of the Act.

The safeguards usually considered in legislation for euthanasia are summarised in table 2. A palliative-care nursing service was set up after the legislation 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,[6] 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[6] 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.

Patient	Palliative care		Treatment options remaining	Family aware	Social isolation	Length of contact with PN (weeks)	Specialist giving second opinion	Consensus on terminal status
	Nursing	Medical						
1	No	No	Several	None (estranged)	Yes	12	None	Not terminal
2	Yes	Yes	Symptomatic	None	Yes	16	None	No
3	Yes	Yes	Radiotherapy, strontium	Spouse (children unaware)	No	25	General surgeon	Yes
4	Yes	No	Depression, symptomatic	Spouse, children	No	12	Orthopaedic surgeon	No
5	No	No	Treatment of obstruction	None (alone)	Yes	8	General surgeon	Yes
6	Yes	No	Symptomatic	Children	No	1	General surgeon	Yes
7	Yes	Yes	Depression, symptomatic	Friends	No	8	General surgeon	Yes

Table 2: **Overview of protective safeguards for patients who considered euthanasia**

Case 2

This patient was a single man who lived in a simple cottage in outback Australia. He had no identified relatives, but several friends were supportive to him. He had been a professional golfer, then a taxi-driver, but had ceased work owing to illness. He had surgery for gastric carcinoma 1 year before he contacted PN. The patient believed that the law on euthanasia was close to being processed, and he sought euthanasia because he just could not enjoy life: "I'm just existing, I can't see the point anymore. I've seen my time. I'm ready for the sweet long sleep".[7] He was living on milk and yoghurt, unable to enjoy other food, and was feeling progressively weaker. His pain was well controlled.

The patient decided to drive 3000 km from his outback home to Darwin. He put his affairs in order and set off. After he arrived in Darwin, news broke of intended appeals against the legislation, and the Northern Territory's Chief Medical Officer cautioned practitioners against use of the Act until these uncertainties were settled. The general practitioner and psychiatrist who had previously arranged to examine this patient were unwilling to proceed. Regulations were then released that required the opinion of a specialist as the second certifying medical practitioner.

The patient had two hospital admissions for stabilisation of symptoms due to metastatic disease. When it became clear that he would not obtain the professional opinions necessary for euthanasia, the patient drove home again. PN had forged a friendship with this man and felt considerable responsibility for the journey the patient had made. PN travelled to the patient's home to help during the final weeks. The patient died peacefully whilst receiving good medical and nursing care at his local hospital.

Case 3

The first patient to die via legal euthanasia suffered from metastatic carcinoma of the prostate. He had worked as a carpenter, pilot, lay minister with a missionary society, and massage therapist. During middle age, he had counselling and antidepressant medication for several years. He had had two sons from his first marriage, which ended in divorce. He remarried and moved to the Northern Territory. Late in life, he became a Buddhist.

The patient had carcinoma of the prostate, which was diagnosed on inguinal-node biopsy in 1991 and managed with orchiectomy. He later underwent hernia repairs. In 1995, urinary retention was managed by transurethral resection, and this procedure was repeated 1 year later. The patient was treated with cyproterone acetate, but declined chemotherapy. During the patient's last year, anaemia aggravated breathlessness, and was only temporarily eased by blood transfusion. There was partial collapse of one lung, and pathological fractures 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.[8] 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 naloxone. An ear, nose, and throat specialist offered guidance about ear discharge.

Psychiatric assessment was sought after the request for euthanasia. The patient said, "it's bad news, because I scratch day and night. My hands and feet blister. Yes, I want to go. I know it's the right time. I can't take any more. It's so hopeless. You want to get something to help, but you can't." She described insomnia, poor concentration, and loss of interest in her usual hobbies, tending just to lie in bed. Her latest medication included doxepin 50 mg three times daily, lorazepam 1 mg three times daily, and flunitrazepam 2 mg at night. The psychiatrist noted that the patient showed reduced reactivity to her surroundings, lowered mood, hopelessness, resignation about her future, and a desire to die. He judged her depression consistent with her medical condition, adding that side-effects of her antidepressant medication, doxepin, may limit further increase in dose.

When the patient first travelled to Darwin, PN looked for a specialist who would give a 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. At this politically controversial time, the patient made a public appeal for help, which was broadcast on national television. After this programme, an orthopaedic surgeon agreed to see her and certified that the ROTI Act had been complied with. Having obtained the necessary signatures, the patient went home to spend Christmas with her family, before returning to Darwin, accompanied by her husband and one child. She underwent euthanasia on Jan 2, 1997.

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 what would occur, and given his indecisiveness, 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 daugher, 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 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 midzolam 200 mg plus ketamine 400 mg per 24 h over the next 3 days, supplemented by boluses of phenobarbital 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[3] estimated that some 2·3% of deaths resulted from euthanasia, 0·7% without the patient's explicit consent. Moreover, van der Wal and colleagues[4] 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[10] that explored attitudes and experiences of oncology patients found that those with depression were more likely that those without depression to request assistance in committing suicide. These findings matched those of other studies in Australia,[11-13] Canada,[14,15] and the USA,[16] which have all found an association between depressive disorder and the desire to die. The citizens of Oregon reconfirmed by referendum their desire to be able to undergo physician-assisted suicide if terminally ill.

The limitations of our study include the small sample, from which it is difficult to make generalisations, and uncertainties about clinical details in some cases. Thus, when questioned about options like stenting for obstructive jaundice or the management of bowel obstruction, PN acknowledged limited experience, not having been involved in care for the dying before becoming involved with the ROTI Act. Despite these limitations, the narrative that emerged is rich in describing those patients who sought euthanasia, and it provides helpful insight into the utility of regulations on euthanasia.

The ROTI Act[1] defined a terminal state as one leading to death in the "normal course" of illness progression. The first patient would not have met these requirements of the Act, because her cancer had not yet reached the stage at which it would have resulted in death; she was the type of patient who seeks euthanasia without a terminal or hopeless situation. The fourth case showed the Act's lack of ability to deal with differences of opinion: one oncologist gave the patient's prognosis as 9 months, but a dermatologist and a local oncologist judged that she was not terminally ill. Other practitioners declined to give opinions. In the end, an orthopaedic surgeon certified that the ROTI provisions for terminal illness had been complied with.

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[17] 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.[18]

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[19] 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.

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Effect of witnessed resuscitation on bereaved relatives

Sir—Sue Robinson and colleagues' (Aug 22, p 614)[1] results cannot be said to be meaningful enough to support Robinson's view, available on the internet from the day that the paper was published (http://news.bbc.co.uk/hi/english/health/newsid_154000/154852.stm), that it should become common practice for relatives to be allowed to witness resuscitation.

The main reason that relatives are excluded from watching resuscitation is to protect patient confidentiality, rather than to spare the next of kin psychological distress. Doctors have a duty of confidentiality to patients and are obliged to treat them with due regard to privacy and dignity.[2] This duty extends to the critically ill and those who subsequently die. To allow relatives to be present during resuscitation breaches this confidentiality, and if patients survive they could theoretically take legal action. That Robinson and colleagues did not encounter problems with their three survivors is hardly reassuring.

The methodology of Robinson's study seems to have been weakened because, over 15 months, only 25 patients were recruited. There is no indication what proportion of total resuscitation attempts this number represents, and without this information it is difficult to be convinced that the study group was representative. The investigators administered a battery of psychological tests to eight relatives who had witnessed resuscitation. We doubt the validity of this approach given the small numbers of patients in the study and the uncertain nature of their selection. They state that the tests found lower psychological morbidity in the group who witnessed resuscitation, but do not mention that this did not reach significance for any test. This finding is hardly surprising since their own calculation had predicted that they would need 64 patients in each group to detect a moderate effect.

14 references are cited, the most recent published in 1995, but we are surprised that no reference is made to the Resuscitation Council's 1996 report on this subject.[3] Surely its content is highly relevant to this study.

The trial was terminated because the "clinical team became convinced of the benefits to relatives of allowing them to witness resuscitation". This is a value judgment that calls into question the objectivity of the study.

Robinson and colleagues have undertaken a difficult task, but, in this era of evidence-based medicine, it is surely not acceptable to advocate widespread changes to medical practice based on interviews with eight people, no matter how well the study may be publicised in the lay media.

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Authors' reply

Sir—We regret that the BBC news health page on the internet has been misquoted. We did not offer data directly to any internet site. The statement on the internet referred to by Stewart and colleagues was made by an emergency physician unconnected with our study. We did not say that witnessed resuscitation should become common practice. We proposed that the routine exclusion of relatives was no longer appropriate and that relatives should be offered the option to remain in the resuscitation room.

Stewart and colleagues' main objection to witnessed resuscitation seems to be that it represents an infringement of confidentiality. This argument is disingenuous. Critically ill patients are rarely in a position to give consent for discussion of their illness, injuries, treatment, or prognosis with attending family. Such information is given in good faith to family members who are present. A refusal to give information about a spouse's cardiac arrest on the grounds that consent had not been obtained would be met with incredulity. Viewing a patient's body after death is not conditional on receiving consent from the deceased. In our view, witnessed resuscitation does not compromise confidentiality above and beyond standard medical practice in the UK.

The reasons for the number of patients in our study are clearly stated in the report. It does not follow that a study with a small number of patients is an unrepresentative sample. With respect to the potential for treatment effect bias, however, the absence of randomisation is generally worse than departure from a representative sample. Our study did use randomisation. We stated the reason for early termination in the summary. This decision was a precautionary sacrifice of the number of patients to keep to a minimum any potential bias in a randomised trial without blinding. The early termination of a study does not render the achieved sample unrepresentative.

The study was a pilot study intended to discover whether the relatives of our patients wished to be present during a resuscitation and whether witnessing resuscitation had any adverse effects on relatives. There were limited published data on which power calculation could be based. The analysis calculated to show 80% power in the identification of a moderate effect among bereaved individuals was based on Horowitz's examination of a single test, the impact of events scale.[1] We clearly stated in the discussion that the pilot study could detect large differences and that a proposed larger study would be able to detect the presence of more subtle differences.

Our results were based on detailed interviews with not eight, but 18 bereaved relatives and have provided baseline data for future work. Finally, the 1996 Resuscitation Councils Report[2] provides guidance on how to facilitate witnessed resuscitation; it is a consensus statement based on the experience of medical and nursing practitioners and relatives. Although the report is relevant to the practice of witnessed resuscitation, it is not pertinent to a discussion of the results of this study.

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1 Horowitz M, Wilner N, Alvarez W. Impact of events scale: a measure of subjective stress. *Psychomatic Med* 1979; **41:** 209–18.
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Euthanasia legislation

Sir—The report by David Kissane and colleagues (Oct 3, p 1097)[1] exemplifies the dangers of euthanasia legislation from a clinical perspective. Difficulties in the assessment of depression and suicidal symptoms in terminally ill patients, particularly on a single clinical assessment, are well documented. Having take the decision to kill themselves some individuals may seem less depressed than previously,[2] and the focus on pursuing assisted suicide may distract both the patient and the doctor from the underlying despair, fear, and helplessness.

The request for assisted suicide needs to be viewed as a form of communication between the patient and the doctor with respect to their fears of dying, loss of control, and hopelessness.[2,3] Studies of suicide among patients with cancer have highlighted the need for better attention to the psychological needs of such patients, and for the involvement of a doctor who has a long-term responsibility for their care.[4] Such patients commonly seek reassurance that the doctor will not abandon them but will continue to ensure their care at all stages of the disease. The case histories described by Kissane and colleagues highlight the difficulties that can arise from addressing these needs when the goal of euthanasia dominates clinical care.

When caring for a dying patient, the doctor can be overwhelmed by the patient's suffering, along with their own sense of impotence and helplessness. The wish for relief from suffering for all involved may even include a wish for the patient to die. Professional esteem tends to be centered on the ability to treat or to cure,[3] which is challenged by the suffering of dying patients and their families. The prohibition against assisted suicide provides a much needed landmark amidst the complex emotions that can arise for doctors in these situations.[5] These emotional issues that affect doctors are missing from the report by Kissane and colleagues.

The relationship between doctor and patient exists within a therapeutic framework, which allows the doctor to understand the patient and the needs that may lie behind requests for assisted suicide. The role of the psychiatrist in an assessment of the competency of such patients is a gate-keeper function that cuts across this framework and the task of establishing a therapeutic alliance. Legislated psychiatric assessment presumes that the role of the psychiatrist is solely that of making a psychiatric diagnosis or assessing so-called rationality; this ignores the role for assessment of the complex issues that contribute to the patient's suffering so as to formulate appropriate therapeutic interventions in the context of developing a trusting relationship. This is rarely achievable within one interview and the process involved does not lend itself to legislative intervention.

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1 Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *Lancet* 1998; **352:** 1097–102.
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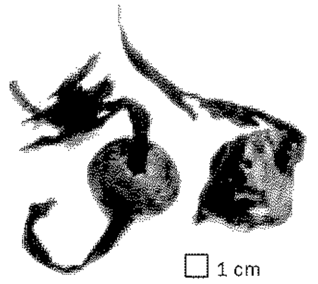
5300 years ago, the Ice Man used natural laxatives and antibiotics

Sir—In September, 1991, the snout of the Val Senales glacier (south Tyrol, north Italy) receded because of global warming. In doing so it revealed the mummified body of a man who lived about 5300 years ago: the Ice Man. His body was extraordinarily well preserved, because after death it was dried quickly by the alpine winds and then froze, encased in the perennial ice. He was found with his personal effects, which included straw-lined leather shoes, leather clothing, an impermeable cloak made of woven grass, a bear skin cap, a pack that still had some food in it (dried deer meat and a prune), a finely worked birch-bark pouch, a wooden bow, a leather quiver with a number of arrows (some unfinished), a flint-bladed knife, and a wood-handled copper-bladed axe. The discovery of his clothing and equipment is all the more important because they were not the customary funerary offerings, well known from the archaeological excavation of thousands of tombs, but rather the objects the man used in his daily life. The study of the mummy has resulted in several important and in part unexpected archaeological and medical discoveries.

For example, the Ice Man had a number of specialised tattoos that were produced by making multiple parallel or intersecting linear incisions with a scalpel, filling the incisions with a mixture of herbs, and lighting the herbs, which also had the effect of cauterising the incisions. Most of these tattoos were made on the skin over joints that were affected by arthrosis (lumbar spine, knee, and ankle) and the Ice Man might have used these tattoos as a form of localised therapy for muscle and joint pain.[1] Among the objects found with the mummy were two cork-like lumps about the size of walnuts, each of which was pierced and tied to a leather thong (figure). Paleobotanical study revealed that they are the woody fruit of *Piptoporus betulinus*, a bracket fungus.[2]



Two spheroid masses obtained from the woody fruit of the *Piptoporus betulinus* fungus

Piptoporus betulinus contains toxic resins and an active compound, agaric acid, which are powerful purgatives and result in strong though short-lived bouts of diarrhoea. *Piptoporus betulinus* also contains oils that are toxic to metazoans and have antiobiotic properties, acting against mycobacteria.

An analysis of the content of the Ice Man's rectum revealed *Trichuris trichiura* eggs,[2] which cause a condition that might have progressed without symptoms, but more likely resulted in abdominal pain and cyclic anaemia; this cyclic anaemia would explain the low iron content of the mummy's striated muscles and the repeated ungual hypoplasia, which in turn shows that the man had recurrent generalised stress at roughly 30-day intervals during the last phase of his life.[3]

The discovery of the fungus suggests that the Ice Man was aware of his intestinal parasites and fought them with measured doses of *Piptoporus betulinus*. The toxic oils in the fungus were probably the only remedy available in Europe before introduction of the considerably more toxic chenopod oil from the Americas. The efficacy of chenoprod oil was increased by adding a strong laxative that caused expulsion of the dead and dying worms and their eggs.

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Viewpoint

Euthanasia and the potential adverse effects for Northern Territory Aborigines

John J Collins, Frank T Brennan

Subsequent to previous reviews,[1,2] the national Australian Parliament voted to over-ride The Rights of the Terminally Ill Act.[1-3] Before this vote, the Act had been amended by the Northern Territory Parliament and challenged by a repeal bill in the Supreme Court of the Northern Territory. The High Court of Australia adjourned a challenge to the Northern Territory law until the national Australian parliament debated and voted on the bill to over-ride Northern Territory law. An analysis of the experience of the Northern Territory is pertinent because it shows the type of problems and concerns encountered as one multicultural region attempts to resolve this conflict.

The Rights of the Terminally Ill Act allowed a medical practitioner to terminate a patient's life, subject to certain guidelines. The controversies about the Act related to the process by which it was formulated, the imprecision of the legislation despite multiple amendments and its failure to protect vulnerable groups from potential abuse, the problems related to the ethics of euthanasia, the conflict between an individual's choice and the public interest, and medical and sociopolitical considerations.

The traditional Aboriginal viewpoint, which prohibits euthanasia, was rejected by the Northern Territory Parliament as an argument against the Act at a time when there was heightened concern in Australia about Aboriginal self-determination and health. The ethics of allocation of resources to euthanasia in a community that has challenging health-status indicators, and the risk of further alienation of this community from the health-care system by this legislation are also concerns.

The estimated population of the Northern Territory (172 100) is the smallest population of all the Australian states or territories.[4] It has the highest proportional Aboriginal population (27%).[4] Almost half of all deaths in the Northern Territory are of indigenous people.[5] The median age at death for men (53·9 years) and women (64·0 years) is almost 20 and 16 years below the national Australian figure, respectively.[4] The infant mortality rate in the Northern Territory is 11·3 deaths per 1000 livebirths, nearly twice the national rate.[4] Although diseases of the circulatory system, respiratory disease, and external causes were the leading causes of death in the indigenous population, diabetes, and infectious and parasitic diseases also account for more deaths than in the non-indigenous population.[5] Although the epidemiology of patients who requested euthanasia under the Northern Territory law is not known, one report suggested that most of these patients were elderly women with cancer, were not from the Northern Territory, were from poor socioeconomic backgrounds, and a "disproportionate minority" were from rural areas.[6]

The health-care systems for indigenous patients are part of a "unique complex, which includes descriptions of well-being, explanations of illness causation, healing practices, and prerequisite social behaviors for the person experiencing the illness and her or his kin".[7]

The Northern Territory Select Committee on Euthanasia obtained written and oral submissions on the proposed euthanasia legislation from the Aboriginal community. The Committee was asked by Aboriginal representatives for more time to make a considered response to the proposed bill.[8] The North Australia Aboriginal Legal Aid Service submitted that euthanasia and suicide were not well known and understood in the Aboriginal culture.[8] There is a lack of interpreters to serve some rural Aborigines for whom English is a fourth or fifth language.[8] One linguist said ". . . most non-English-speaking Aborigines in the Northern Territory are being denied the opportunity to make an informed response to this proposed legislation".[8]

Maydjarri expressed concern in oral evidence about the compounding effect of euthanasia legislation on an already existing Aboriginal fear of modern medicine.[8] The Aboriginal Resource and Development Services submitted that dying in Aboriginal communities is seen as something that occurs naturally. Intervention by an outside agent would be viewed as murder or sorcery and, therefore, illegal under Aboriginal law. Intervention by euthanasia, even if the individual consents, may result in retribution in the form of payback for Aborigines.[8] A further concern was the ability of a third party to sign the certificate of request on behalf of the patient, which could potentially expose that third party to payback from the patient's family.[8]

The Anti-Cancer Foundation noted shortcomings in palliative-care services in the Northern Territory.[8] These included no dedicated oncology unit or specialists in the top end of the territory, no radiotherapy unit, and no dedicated palliative-care unit or hospice. The Northern Territory Palliative Care Service, which consists of a group of interdisciplinary health-care professionals, was started in October, 1995. By October, 1996, 180 referrals had been made to the service for advice, support, education, and provision of resources (Bronwyn Russell, Manager, Northern Territory Palliative Care Service; personal communication).

The New York State Task Force on Life and the Law[9] gave a warning of the potential ill-effects of euthanasia legislation on marginalised groups and ". . . unanimously concluded that the dangers of such a dramatic change in public policy would far outweigh any possible benefits . . . the risks would be most severe for those who are elderly,

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Lancet 1997; **349:** 1907–08

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poor, socially disadvantaged, or without access to good medical care."

Although euthanasia was voluntary under the Rights of the Terminally Ill Act, Aboriginal fears were not quelled by the education programme implemented by the Territory Health Services.[10] The reports of the education consultants indicated widespread Aboriginal opposition to the legislation. The educators faced hostility, with some communities asking health workers to sign statements that euthanasia would not be carried out.[10] Follow-up audio tapes for Aboriginal communities had voices electronically distorted to avoid identification, such was the concern of people about being seen as connected with this issue.[10]

Recent data confirm that Aborigines have a significantly poorer health status than the non-Aboriginal community of the Northern Territory.[11–14] For example, the incidence of acute rheumatic fever among Aboriginal people of rural northern Australia is the highest in the world.[11] Although community-controlled Aboriginal medical services and Aboriginal health workers have helped to bridge the gap between Aboriginal communities and the practitioners and institutions of western medicine,[15] many Aborigines still feel alienated by the culturally inappropriate approaches.[15] Aboriginal parents have many fears about taking their children to hospital, which is perceived as a hostile, aggressive, and frightening environment.[16] The risk of implementation of the Rights of the Terminally Ill Act was the further alienation of the Aboriginal community.

Euthanasia was raised to the status of a medical treatment because "assistance" was taken to be medical treatment for the purposes of the law. Conventional medical practice, which has prohibited killing, had been altered. To comply with the law, medical practitioners were to be guided by "appropriate medical standards". However, there are no appropriate standards for doctors killing their patients. The implications for harm to the doctor-patient relationship by this change, especially for the Aboriginal patient, was acknowledged by the Select Committee on Euthanasia.[8]

The Act required a psychiatric consultation to exclude only "treatable depression in relation to the illness". Other potentially treatable psychiatric disorders, for example adjustment disorders, anxiety, or delirium, did not have to be excluded. The Act did not require a medical practitioner to address the multiple aetiologies of psychological and existential distress of the dying patient that may result in a request for euthanasia.[17] Psychosocial assessment and intervention were not required. Although depression may influence an HIV-infected patient's interest in physician-assisted suicide, other features of the disorder may also influence their decision.[18] Data suggest that the care of HIV patients must include not only interventions for pain and depression, but also interventions for psychological distress and social isolation.[18]

No inquiry was made when the Act was being drafted about how euthanasia legislation would affect the role of psychiatrists and palliative-care physicians when they were treating terminally ill patients. For example, a question asked by psychiatrists to exclude depression and tendencies towards suicide is: "Have you ever thought of killing yourself?" which becomes a loaded question in relation to euthanasia.[8] In addition, euthanasia contravenes the philosophy of palliative medicine, which affirms life and neither hastens nor postpones death.[19]

Palliative care is still new to the Northern Territory and its provision is hampered by the small, geographically dispersed, and isolated population. The barriers that prevent Northern Territory health-care professionals from adequately treating pain and other symptoms in terminally ill patients, and from dealing effectively with end-of-life issues, were not investigated by the Select Committee on Euthanasia. Data from the USA indicate that educational, attitudinal, and legislative barriers often prevent patients from receiving acceptable pain and symptom management during their illness.[20] Data also suggest that the willingness of physicians and nurses to endorse assisted suicide is influenced by factors such as their perception of their own competence and actual experience in the management of cancer-related symptoms, and at least one element of the "burn-out" syndrome.[21] The possibility that these factors could influence the assessment of patients who request assisted suicide was not considered in the Northern Territory debate.

We thank Kathleen M Foley and Russell K Portenoy, from the Memorial Sloan Kettering Cancer Center, New York, USA, and Charles B Berde, from the Children's Hospital, Boston, USA for their review of this paper.

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patient who had had a myocardial infarction, a non-infarct patient with one cardiovascular risk factor (hypertension or non-insulin-dependent diabetes mellitus [NIDDM]), or a patient with both risk factors. They were also asked about a man who was otherwise healthy and symptom free, but had a raised plasma cholesterol concentration. Replies were analysed from 117 GPs and 164 physicians, of whom 128 said they managed serum lipid concentrations.

For the post-infarct patient, 13 (11·1%) GPs said they would not initiate lipid-lowering drugs unless the serum cholesterol concentration was at least 6·5 mmol/L, although three said they would refer the patient to a lipid clinic. Only 36 (30%) GPs regarded 5·5 mmol/L or less as a suitable threshold for treatment. 24 (35%) physicians said they would treat at a threshold of at least 6·5 mmol/L, and 37 (31%) would treat at 5·5 mmol/L or less.

In the non-infarct patient with NIDDM alone, 33 (28%) GPs but only four (3%) physicians said they would initiate lipid-lowering drugs if cholesterol were greater than 8·0 mmol/L; three GPs said they would not treat at all. For a patient with hypertension alone, 34 (29%) GPs and nine (7%) physicians would treat at 8·0 mmol/L, with a further eight GPs withholding treatment. In the patient with both hypertension and NIDDM, five (4%) GPs and one (1%) physician would use 8·0 mmol/L as their threshold. In the otherwise healthy 60-year-old man, 32 (27%) GPs and 16 (12%) physicians said they would initiate lipid-lowering drugs if serum cholesterol were 10·0 mmol/L or more, or would not treat at all.

This postal survey has shown alarmingly differing criteria for starting lipid-lowering drugs, with quite a few GPs and physicians withholding therapy in contravention to the various guidelines outlined in Durrington's paper.[1] Clearly, the message is not getting through.

We can only speculate on the reasons why UK doctors are withholding this treatment. Opinions may be influenced by the financial cost or by lack of awareness of the evidence-based advice from experts. Alternatively, these findings may indicate a general attitude of therapeutic lethargy. The multiplicity of guidelines and risk tables to which we have been subjected may have been unhelpful in their complexity or their failure to differentiate between the notions of risks from a given concentration of cholesterol in relation to the benefits of treatment. We hope that the new joint guidelines by the British Cardiac Society, the British Hyperlipidaemia Association, the British Hypertension Society, and the British Diabetic Association help to resolve the current state of affairs.[2] However, we doubt it will.

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Seven deaths in Darwin

Sir—David Kissane and colleagues' report (Oct 3, p 1097)[1] contains some puzzling features. The first patient did no more than make a request for euthanasia but she did not qualify under the Act, mainly because she did not have severe pain and had not been terminally ill. I know this to be true because Philip Nitschke sought my opinion about her request. Why she is included in the paper is a mystery, unless it is in an attempt to damn the Northern Territory Act.

The second patient died through a process of extreme cachexia and asthenia. In addition, his psychological distress, based partly on the rejection of his wish to die earlier and with dignity, was obvious. Anyone who saw the television footage of this tragic man, by then little more than a living skeleton, being bodily transported in and out of bed because of his inability to do anything himself could only be astonished to see his death described as peaceful. Obviously some physicians believe a death in coma is peaceful, no matter how drawn out it might be, whether it is medically induced and irrespective of the extreme anguish and loss of dignity before and during coma.

Kissane implies a diagnosis of depression in four of the cases on the basis of some symptoms, without ever having known the patients in question personally, and despite the fact that patients 3–7 all had expert psychiatric diagnosis (from three different psychiatrists), which indicated that there was no treatable clinical depression. One would expect to find some symptoms of depression in a person dying with unrelievable pain. The key question addressed by the Act was whether any symptoms of depression were out of proportion to the physical situation, and thus whether treatment by psychological means would have any influence on the patient's request. In any event, as Philip Nitschke has said, these patients would have refused psychiatric treatment which was their right.

Finally, it is surprising that Kissane and Annette Street did not reveal their antagonism to voluntary euthanasia in the text, which would have allowed readers to place their interpretation in the context of Philip Nitschke's contribution.

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[1] Kissane D, Street A, Nitschke P. Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act. Northern Territory, Australia. *Lancet* 1998; **352:** 1097–102.

Author's reply

Sir—We indicated in our paper that we held different views on euthanasia. We were not seeking to debate the issue, but rather to report the clinical details of these patients. Philip Nitschke was the initial source of clinical data, which was confirmed in specialists' letters and the coroner's records.

The presence of worthlessness, hopelessness, and helplessness leading to suicidal ideation is diagnostic of severe depression. Active treatment of such a clinical state can do much to relieve distress and improve quality of life. I disagree with the approach favoured by Rodney Syme that attempts to gauge the proportionality of depressive symptoms to physical state. This attitude can lead the clinician to miss the diagnosis of comorbid depressive disorders that need to be assessed in their own right.

Studies indicate that the presence of a depressive disorder leads patients to choose a reduced number of potential life-sustaining interventions, such as oxygen, blood transfusion, or antibiotics. Treatment of depression restores interest in these interventions.[1] Clearly, a patient's judgment about the value and meaning of their life will be affected by the presence of depressive disorder. The development of a therapeutic alliance, rather than a single assessment session, is critical to the management of depression and cannot be achieved by a gatekeeping role for the psychiatrist, as occurred under the Northern Territory's euthanasia legislation.

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