An exchange visit to examine issues relating to technologies used to relieve suffering at the end of life

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Jane Seymour
Rien Janssens

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Introduction

This report is based on an exchange visit between Jane Seymour, The University of Sheffield and Rien Janssens, The University of Nijmegen, Holland. The aim of the exchange was to compare and contrast issues relating to the social, ethical and clinical implications of new technologies for managing suffering at the end of life in the UK, Holland and Belgium. In these three countries the regulatory contexts are significantly different, and these contexts were examined with particular reference to the organisation and delivery of palliative care. The practice of sedation at the end of life (known as terminal or palliative sedation) was explored as a critical case study. During the exchange attention was focused upon the following evaluative questions:

- What are the social, ethical and clinical implications of new technologies to manage suffering at the end of life?
- What new risks and uncertainties do these technologies raise in relation to the practitioner-lay relationship? (For example, do medics risk becoming ‘technologists of the body’ rather than ‘healers’ (Webster 2002: 451)
- How can these risks be addressed?
- What are the implications of such technologies for perspectives on what constitutes a ‘good’ or ‘natural’ death?
- To what extent, and how, should the public, patients and their informal carers be involved in the control and deployment of these technologies?
- What areas for further research be identified?

Relevant projects within the IHT programme.

1. ‘Technology and Natural Death: A study of Older People’ 2001-2003 (Seymour, JE, Gott M, Clark D, Ahmedzai S and Bellamy G). *See extract from the End of Award Report to the ESRC in Appendix 1.*

2. Innovations in Cancer Pain Relief: Technologies, Ethics and Practices’ 2002-2003 (Clark D, Seymour JE, Winslow M and Noble B). *See information leaflet in Appendix 2.*

Host Organisations

The Palliative and End of Life Care Research Group, School of Nursing and Midwifery, University of Sheffield

Jane Seymour is a Senior Lecturer within the Palliative and End of Life Care Research Group, at the School of Nursing and Midwifery, University of Sheffield. The group explores preparation and planning for death; the needs and experiences of those with chronic and life threatening illness; patterns of care and communication; and educational issues for older people, professionals and family carers. It also identifies and evaluates bereavement support services, and examines experiences of loss and bereavement. Through long and close association with the Trent Palliative Care Centre and regular collaboration with other academic and clinical institutions, the researchers make a major contribution in this area of care to many different communities at local, national and international levels. Professor Sheila Payne, a health psychologist with a background in nursing, leads the research group.

Department of Ethics, Philosophy and History of Medicine, University of Nijmegen.

The ethics of palliative care is, together with ethics of genetics, the main research area of the department. The European *Pallium* project on palliative care ethics (that was conducted between 1998 and 2001 and coordinated by then head of the department Professor Henk ten Have) was an important instigator in this respect. This project intended to compare different conceptual understandings of palliative care in seven European countries and to assess differences in the ethical debates on end of life decision-making in the countries. Intense cooperation was established between the universities of Nijmegen and Sheffield. Now, several projects on palliative care ethics are conducted within the department. Research is undertaken in moral attitudes of palliative caregivers, moral debates in palliative care journals, multidisciplinary moral deliberation on end of life decision-making, and in the issue of palliative or terminal sedation.
It is the latter project (coordinated by anaesthesiologist Professor Ben Crul) that gave occasion to the research exchange. The project intends to ethically evaluate the option of palliative sedation based on qualitative and quantitative research methodologies. A large scale questionnaire study is currently being carried out, together with an interview study among those caregivers involved in end of life decision-making. Thus, the project intends to describe, not only the prevalence of terminal sedation, but also the medications used, the proper indications, and the decision-making process leading towards terminal sedation. One of the ethical questions given specific attention is to what extent terminal sedation can be considered as an alternative to euthanasia.

Centre for Religious Studies, Faculty of Theology, Catholic University of Leuven (Belgium).

A visit to the The Katholieke Universiteit Leuven (KUL), one of the oldest European universities, was kindly arranged by Professor Bert Broeckaert, who has been centrally involved in the deliberations at a policy level about palliative care and euthanasia in Belgium over the last few years, particularly in the period leading up the euthanasia legislation passed on 28 May 2002, which entered into force on 23 September 2002. Professor Broeckaert is now leading a detailed study of the practice of palliative sedation using ethnographic methods. The field work for this project had just started at the time of the exchange fellowship visit. Another relevant area of Professor Broeckaert's research is a study of older Somalian people's understandings of death and dying, which was starting at the time of the exchange. The Faculty of Medicine at the University of Leuven hosted, in collaboration Caritas Catholica Flanders, an international conference on October 18th and 19th 2002 'Between technology and humanity'[1], at which both Bert Broeckaert and Jane Seymour were invited speakers.

Sedation at the end of life: a background

Some dying people experience 'refractory symptoms' unresponsive to conventional therapies. In such circumstances, sedation may be used to engender deep sleep until death occurs (this practice is variously known as 'terminal' or 'palliative' sedation, and is called palliative sedation in this report). Clinical studies available indicate that delirium and agitation in terminally ill people with cancer, and extreme breathlessness are viewed by clinicians as indicators requiring palliative sedation. Pain is less commonly cited as a reason for the practice (Sykes and Thorns 2003). It is therefore remarkable that figures from a large scale study into end of life care in Holland published in May 2003 reveal that pain is the most often cited reason for deep sedation. Preliminary, unpublished results from the Nijmegen project mentioned above coroborate this. This study indicated that what is termed 'deep sedation' occurs in 6-12.2% of all deaths in Holland, with artificial hydration being withheld in the majority of these cases (van der Wal et al 2003: 77). Internationally, the percentage of patients reported as requiring palliative sedation varies from 5% -52% (Cowan and Palmer 2002; Radbruch 2002), and in a survey of clinicians in 8 countries, 77% reported carrying out the practice within the last year although in very few cases (Chater et al 1998). The wide variation in the figures seems due in part to differences in the

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[1] In a subsequent newsletter reporting the conference it was noted that: 'The issue was to comment ethically upon the expansion of technological innovations in diagnostic as well as therapeutic practice. The applications of these new technologies in the field of prenatal diagnosis, genetics, psychiatry, geriatrics and palliative care are indeed so many challenges for ethics to react adequately. In some instances technological innovations may well support and even further the care for patients as well as their humaneness. In some others however technology would seem rather a hindrance to care and humaneness' .

definitions[2] applied to what we term here ‘palliative sedation’ (Sykes and Thorns 2003). There is still a lack of clarity among caregivers about what constitutes palliative sedation. Other reasons for variation appear to relate to the type and location of units in which studies were conducted and cultural differences (Sykes and Thorns 2003: 316). Supposedly, quality of palliative care and creativity in managing difficult symptoms may also play a role.

With rare exceptions (Morita et al 2002)[3], there has been no investigation of the public, patient or carer views of this practice. With this in mind, older people’s understandings of palliative sedation (among other technologies, see Appendix 1) were explored in project 1. A paper based around the data from focus group discussions held during the first phase of the project has been published (Seymour et al 2002). Preliminary analysis of data from interviews with 45 older people during the second phase[4] of the project suggests they associated the following risks and benefits with palliative sedation (these are broadly in line with the issues raised by the focus groups):

Risks	**Benefits**
• I want to be awake when I die • I want to ‘fight for my life’, • I want to know what is going on around me	• This could enable someone to die peacefully and with dignity. • This could relieve suffering and fear of dying • This is what palliative care is
• This should not be done unless the patient and the family have agreed to it. • Everyone involved should be consulted • There is a risk of ageist treatment	• It is something that could be done in the patients and family’s best interests. • Maybe this should not be discussed with them.
• You will not be able to talk to your family or them to you. • I have things that I would want to say to my family and my children when I am dying. • The family will have to stand by and watch the patient ‘drift’ away	• The patient’s family will benefit by not seeing him in pain and suffering • This treatment may be more important for the family than the patient
• This may be a form of euthanasia • I don’t know enough about this and	• I think this may involve ‘helping someone on their way’ and this should

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[2] An enduring problem in definition is that sedation comprises various types and levels of treatment applied according to the degree of distress and the clinical condition of the person (see Morita et al 2002: 375).

[3] Morita et al’s study was a cross sectional survey of the 457 members of the Japanese general population who attended health related lectures for non professionals. Intermittent deep sedation for refractory physical and psychological distress was preferred over continuous deep sedation, and this preference was more likely to be expressed by younger and better educated respondents who also placed emphasis on death with dignity and preparation for death. 85% of respondents wished to have clear information about the reduction in consciousness that would result and 92% expressed positive attitudes to the idea of receiving information in advance of the need for the treatment.

[4] The interviews used third party story lines to examine attitudes to technologies used in end of life care, of which sedation was one.

need to know more	be liberalised • This may ‘put someone out of their misery
• This might render a person ‘the living dead’ • This takes you into the unknown • The mind and the body would be weakened by this	• Once you are asleep, you are restored as a whole person • This can ease the mind • It removes the ‘pressure of pain’ • If this could be controlled then the person could be awake sometimes

The themes raised by participants about the status of palliative sedation as medical treatment to ensure the relief of suffering; the distinction between this and euthanasia; the problems of consent, decision-making and the role of the family; and what constitutes a ‘good death’, parallel concerns evident in the published clinical, ethical and political literatures both in the UK and in mainland Europe. For example, as reported recently in the BMJ (Sheldon 2003: 465), Dutch ministers of health have just rejected a call from the attorney general for ‘terminal sedation’ to be covered by the same legal controls governing euthanasia, accepting medical arguments that the practice is part of normal medical care and is already covered by medical guidelines. It should be noted however that a widely supported guideline on use of sedatives at the end of life is yet to emerge. There are opposing positions in these literatures regarding the practice, definition and social meaning of palliative sedation. The variety of stances on euthanasia, on ethical issues such as the validity of the doctrine of ‘double effect’, and views about the need for adjunct interventions such as artificial hydration form a complicated international backdrop. Three aspects critical to its evaluation as an IHT can be identified:

First, clinicians are unsure about the social meaning and moral status of the care that they give to dying patients. Of most critical concern to clinicians is the distinction between the practice of palliative sedation and euthanasia[5] and how, if at all, the two relate. Large scale surveys (van der Maas et al 1996; Kuhse et al 1997; Deliens at al 2000) suggest that between 18 -30% of doctors *believe* they have hastened death using pain relieving and sedative drugs, in spite of evidence that such drugs rarely have this effect if administered in proportionate dosages (Bercovitch et al 1999; Sykes and Thorns 2003) which negates logically any need to appeal to the doctrine of double effect[6] to justify the practice (Sykes and Thorns 2003). Recent findings in the Netherlands

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[5] A taskforce set up by the European Association for Palliative Care in 2002 set out a narrow definition of euthanasia thus: ‘Euthanasia is killing on request and is defined as: a doctor intentionally killing a person by the administration of drugs at that person’s voluntary and competent request’ (Materstvedt et al 2003: 98). If this definition in accepted then it follows that any actions taken to end life without the express consent of the patient must be understood as non voluntary euthanasia or killing. Some of our respondents in Belgium and Holland criticised this definition for making no reference to the physician’s intention to give ‘good care’ to suffering persons.

[6] The principle of double effect relies on the clinician’s intention: where this is to primarily relieve suffering, then a secondary or unintended effect (such as foreshortening of life through the application of analgesics or sedatives) is understood to be justified if the positive, intended effect is in proportion

indicate that in no less than 51 % of all cases of palliative sedation, shortening of life was either perceived as the *only* aim by physicians (5 %) or was perceived to be an aim *next to* other aims (46%) (Van der Wal et al. 2003). One famous, although now discredited, position is to characterise the practice of sedation as 'slow euthanasia' (Billings and Block 1996), while more recently the practice has been posited as '...the final barrier against euthanasia' (Radbruch 2002: 238). Such divergent published interpretations of the meaning of the practice are likely to fuel clinicians' confusion and anxieties as they attempt to relieve suffering within current ethical and legal ethical frameworks. Thus in a report of seven years experience of palliative sedation in a palliative care unit, Muller-Busch et al (2003) suggest that many ethical concerns are raised by patients' requests and needs on the one hand and physicians' self understanding on the other hand.

Second, (and linked to the first) dying people are at risk of practices which either deny them symptom control (Lynn et al 1997) *or* are applied in a haphazard and inconsistent manner without regard for their preferences (Ashby 1998; Radbruch 2002). Hunt (2002: 225) captures the dilemmas from the clinician's perspective thus:

> 'Palliative clinicians should continue to feel challenged by questions in each case where palliative sedation is used. If it is used too early, the opportunity to resolve important issues is lost. If administered too late, the suffering of the patient is unnecessarily prolonged. Should sedation be intermittent or continuous, light or deep? Could other palliative treatments help? What do loved ones think? Most importantly what does the patient want? Such questions should be addressed with the aim of achieving a consensus among the stakeholders (the patient, family, and professional carers) about the appropriate place of palliative sedation'.

Thus, palliative sedation is a means of last resort, only justified when conventional options are no longer successful. And as such, it is also surrounded by the possibilities and risks of misuse and misinterpretation.

Thirdly, public understandings, as revealed by Morita et al (2002) and Seymour et al (2003), appear to raise some moral concerns that fall outside of those focused upon by bio ethicists and clinicians; these need to be better understood if the consensus referred to above is to be achieved. The role of the family in acting as the protector or representative of the dying person is

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to the negative, unintened effect. There is an ongoing international debate about the validity of the principle, and the extent to which other values and principles are of more relevance in conceptualising actions taken during end of life care (Hunt 2002). Thus, while in the UK, the report of the House of Lords Select Committee on Medical Ethics (1994) stated that the doctrine of double effect holds validity in problems in end of life care decision making (see paragraphs 22; 242-243), this stance is not shared across Europe.

one such issue. Other issues are the relationship between pain and personhood, and the meaning of suffering during dying. The significance of these findings is that, while it is acknowledged that they are not those of persons immediately facing their own death or that of a person close to them, they highlight some of the difficulties that may surround any attempt to develop a consensus position on the issue: whether this is sought in any immediate clinical situation or in clinician-public debate more generally.

The exchange provided an opportunity to discuss some of these issues and to develop questions that could be addressed within further research relating to the multi-dimensional appraisal and evaluation of technologies used to relieve suffering at the end of life

Summary of activities undertaken by Jane Seymour

At Nijmegen:

- Meeting with Professor Stans Verhagen, an oncologist, at the University Hospital of Nijmegen.
- Departmental meeting at which Jane Seymour presented a paper: Seymour, J.E., Gott M., Bellamy, G., Clark, D. and Ahmedzai, S. (in press) Planning for the end of life: the views of older people about advance statements. Social Science and Medicine
- Visit to the newly opened Bethlehem Hospice in Nijmegen, led by Paul Vogelaar. Attended a seminar with staff. .
- Meeting with Dr. Jaap Schuurmans, a GP who has published in the media about palliative sedation
- Visit to the Hospice Rozenheuvel and meeting with Dr Ben Zylich.
- Meeting with Maartje Schermer to discuss her PhD study of ‘The Different Faces of Autonomy: a study on patient autonomy in ethical theory and hospital practice’.
- Visit to The Department of Primary Care at the University of Amsterdam, hosted by Professor Dick Willems. A staff seminar was attended, at which ongoing research was presented.
- Meeting with Professor Ben Crul and Dr Rob Reuzel to discuss the project: *‘Moral Dilemmas in Terminal Sedation: An empirical and ethical study into the use of terminal sedation and its implications for patients, practitioners and palliative care practice’* (Crul et al 2001)

At Leuven:

- Visit to a palliative care hospital support team led by Nancy Cannaerts to discuss tensions that have developed since the introduction of the euthanasia law.
- Meeting with Professor Bernadette Dierckx De Casterle, professor of nursing.
- Meeting with Professor Chris Gastmans at the Centre for Bioemedical Ethics and Law.

- Visit to an in patient palliative care unit, and meeting with Patricia Claessens, researcher on the palliative sedation project led by Professor Broeckaert; Rita Van Nuffelen, the head nurse, and Dr Johan Menten, medical director.

Summary of activities undertaken by Rien Janssens

At Sheffield:

- Meeting with Dr. Bill Noble, medical director of the Sheffield Macmillan palliative care unit. Visit to the unit.
- Seminar meeting with team members of the Sheffield Macmillan palliative care unit.
- Informal meeting with Prof. David Clark in Sheffield, professor of medical sociology at the Institute for Health Research, University of Lancaster
- Meeting with Pete Saunders, Palliative care clinical team leader of the Macmillan palliative care unit.
- Meeting with Dr. Mike Bennett, medical director of St Gemma's hospice, Leeds.
- Meeting with Dr. Marie Fallon, head of the palliative care unit at the Western General Hospital, Edinburgh.
- Meeting with Deborah Gordon and Lorna McGoldrick, team members of the palliative care unit at the Western General Hospital, Edinburgh.
- Meeting with Prof. Sheila Payne, lead of the Palliative and end of life care research group of the School of Nursing and Midwifery, University of Sheffield.
- Meeting with Dr. Simon Woods, senior researcher at the University of Newcastle.
- Meeting with Dr. Katherine Froggatt, senior researcher at the Palliative and end of life care research group of the School of Nursing and Midwifery, University of Sheffield.
- Telephone conversation with Dr Nigel Sykes, medical director of St Christopher's Hospice, London.
- Meeting with Rev. Mark Cobb, chaplain, ethicist and services director at the Royal Hallamshire Hospital, Sheffield.

Findings

Perceived social, ethical and clinical implications

The UK respondents felt that as palliative care specialists they had to deal with the consequences of the paradoxical and potentially contradictory cultural meanings associated with technologies to relieve suffering. It was perceived that these create a barrier to the development of any deeper understanding of the ethical or legal frameworks surrounding end of life care, and that this is the case not only for patients and their family carers, but also for other clinical staff. One aspect of this was related to the recognition that the criteria for the practice of palliative sedation are disputed. Some categories of widely accepted indications (terminal restlessness, confusion or delirium) were not recognised as medical categories but as socially constructed definitions: thus one respondent talked about a ‘happy delirium’ which may be perceived by the clinician as not indicative of a need for sedation, while others ‘deliriums’ are seen as evidence of suffering. Future research questions could focus on how clinicians manage the requirement placed on them to interpret what are arguably fundamentally socially bounded expressions of suffering and to act according to predominant culturally acceptable mores and within legal/ethical frameworks.

From the perspective of our UK respondents, the skill of palliative care was identified as being able to interpret suffering correctly and to manage complex symptom problems against a backdrop of generalised distress *without* resorting to palliative sedation where this was possible. Those few patients who required palliative sedation were seen as being both memorable and disturbing. However, respondents in the UK clearly perceived that the use and incidence of palliative sedation was related to environmental constraints, with a clear implication that the definition of ‘refractory symptoms’ has much to do with the environment and the context of care as the particular clinical condition of the person in need. They perceived, on the whole, that the practice had been used more extensively in the past in the UK and had been associated with: i) the use of ‘heavy’ sedatives- such as phenol-barbitone and chlorpromazine- no longer commonly used in contemporary palliative care practice; and ii) cultural constructions of ‘good’ dying’ perceived to be associated with the traditional hospice model[7], and associated with the acceptance of sedation as a *necessary and inevitable* consequence of the attempt to control pain and other symptoms.

Of several contemporary clinical examples reported by UK respondents where palliative sedation risked being been used inappropriately, one involved a patient who appeared extremely agitated and who was referred from a general ward to the palliative care team. It was quickly established that the patient was suffering from were the consequences of reversible opioid toxicity,

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[7] It was argued by some that earlier models of hospice care may have accepted the sedative side effects of particular adjuvant therapies as useful in aiding comfort during death (example of chlorpromazine as an adjuvant), and had little concern with precise titration of drugs for individuals. It was perceived that that this is a ‘one size fits all’ approach which is in sharp contrast to the current emphasis on titration for individuals. The latter is, arguably, a more medicalised approach to palliative care problems, but one in which palliative sedation is used only for precise indications and never accepted as a side effect. A contrasting stance put forward was that modern palliative medicine is adopting a ‘factory’ approach to care by its reliance on clinical protocols and procedures which denies lateral and creative thinking adopted by earlier generations. Those voicing this critique saw this as ‘medicine by numbers’ approach as leaving less room for the traditional caring skills of being with and talking to patients. Alternatively, it might be argued that modern therapeutics allows more patients to be awake for longer, such that they can address emotional, spiritual and existential issues more ably.

something not recognised by the referring staff. A perceived contributory issue was the precarious skill mix of NHS clinical care: one respondent said that they perceived that the nursing skill mix on the wards has become gradually poorer and that therefore junior doctors, who rely extensively on advice from their nursing colleagues in order to manage patients with palliative care needs, are less able to make appropriate judgements. To this extent, palliative sedation (especially where suddenly applied) was seen as a measure of crisis intervention, which could potentially be largely avoided through continuous support and monitoring of the patient and through education and support of staff.

Significant linked problems were perceived to be related to discontinuities in care imposed by the current arrangements: most notably in developing the relationship with patients perceived as necessary for gaining informed consent and entering into collaborative decision making about care. One respondent drew the distinction between ‘sudden sedation’ and ‘proportionate sedation’. Sudden sedation intends to take away the patient’s consciousness whereas proportionate sedation is aimed at relief of suffering. The former was regarded as problematic since it implies a lack of anticipation and prevention, and thus a failure to act to protect patients from suffering. The latter stresses the crucial importance of good titration and constant awareness of the degree of suffering of the individual patient. Particular groups of patients were seen as at special risk: for example, those with heart failure, terminal dyspnoea, and those with whom no discussion had been held regarding prognosis. All of these fall outside of the current arrangements for specialist palliative care provision. To address their needs (of which discussions about the need or otherwise for palliative sedation is one tiny aspect) has huge implications for the resourcing and structuring of palliative and end of life care nationally and internationally.

In Holland and Belgium, most emphasis of the discussions surrounded the distinctions and boundaries between euthanasia and palliative sedation and the relative merits of these. In both countries euthanasia is now, under specific circumstances, a legal act. It appears that in the Netherlands, paradoxically, it is only after legalisation of euthanasia that palliative sedation has become of topical interest, and attention has begun to focus on the social, clinical and moral considerations of physicians that underpin what is seen to be a choice between the two practices.

In Holland, respondents indicated that the debate about the ‘right’ response to problems of end of life care must be set in the context of a Calvinist philosophy which tends to ‘privatise’ suffering and makes it culturally taboo to enquire too deeply[8] into the reasons an individual may request euthanasia. Some respondents perceived that any alternative discourse within which to

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[8] In contrast in the UK, any such request would most likely be dealt with by a detailed enquiry into what lies behind the request. It was perceived that this is now becoming possible in Holland, in a way which it has not been.

express suffering has, as a result, been unavailable. However, legalisation and clarification of the possibility of euthanasia are perceived to have created the conditions within which a more nuanced debate has flourished[9]. This involves the general public and patients to a much greater extent than can be perceived in the UK. It also involves the developments of alliances between ethicists and physicians in interpreting and representing end of life care issues for the mass media, politicians and the courts (see also Kater at al 2003): a situation that, in our opinion, applies equally to Belgium. The role of ethicists in the UK debate is apparently far less marked.

In Holland, some respondents perceive, as a result, the development of an alternative discourse of palliative care within which palliative sedation is promoted as a 'third way'[10]. One source of evidence about this that was discussed was a newspaper article entitled ' *Regret*' (Oostveen, 2001) in which some doctors spoke about cases of euthanasia they had committed and reflected on other possibilities, such as palliative sedation, which had become known. A need was perceived among respondents in Holland and Belgium to establish the precise differences between euthanasia and palliative sedation so that they can posited as realistic and rational[11] options and choices for those facing suffering during dying. While the state regulates euthanasia, it was strongly perceived that palliative sedation could be adequately regulated through the available professional channels. This involves making it clear that any attempt to commit 'slow euthanasia' is unacceptable[12], and moving towards a climate in which patients are, ideally, consulted in advance about their preferences for particular types of action to relieve suffering. Conceptually, ideas of the professional care giver being 'bound to the patient' and entering their suffering cannot be divorced from any consideration of the values that surround end of life decision making: to this extent, some respondents in Holland referred to the need to be honest about the possibility of 'double intention' (as opposed to 'double effect') in clinical work: where you act to relive suffering short of euthanasia but hope that death will not take too long to occur.

In Belgium, palliative sedation has been used for some time and the recent legalisation of euthanasia has focused attention on identifying the boundaries between the two practices. However, some respondents felt that palliative sedation is used as a precursor to a form of euthanasia that is not reported, regulated or conducted according to legal criteria. The legalisation

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[9] Although one respondent felt strongly that the euthanasia debate in Holland had dealt with many taboos, but had promoted the myth that all suffering could be controlled.

[10] Where the first and second are the polarised pro and anti-euthanasia stances of the past.

[11] Physician's choices were often seen as indicators of a particular coping style or emotional stance to death.

[12] There has been concerns about unreported involuntary termination of life being committed in the Netherlands. Annually, there are 900 such cases. Most cases concern use of high doses of medication with a supposed life shortening effect. In cases where communication with the patient was possible there had been negotiation even though a clear, well-considered request was not present. Other cases concerned newborns and patients with far advanced Alzheimer 's disease. Almost none of these cases are reported. Public control is largely absent.

of euthanasia was perceived by one respondent to whom we spoke as part of a evolutionary development in cancer and palliative care that was historically contingent (*kill the cancer; kill the pain; kill the patient*), and which would not endure as an appropriate response to suffering. Significant problems were now seen to attend clinical work, based partly on the way in which patients and the public have perceived that the law to enshrines an individual 'right' to demand euthanasia; and partly on the confusing position that clinicians now find themselves in at the bedside. Ideological and cultural stances in Belgium about the value of consciousness feature in this debate: thus some proponents of euthanasia argue that to be artificially rendered asleep, implies a 'living death' that is quite contrary to deeply held views about the value of free thinking and autonomy. This position is discernible in many critiques of modern medical approaches to end of life in international journals, where the lingering death (even if consciousness is absent) is seen as particularly inhumane. The media were also perceived to be a powerful influence.

Among ethicists, there has been much debate around the question of artificial hydration in deeply sedated patients; the idea being that if sedatives do not have a life shortening effect, withholding artificial hydration does. In some countries therefore, artificial hydration is started after the patient is no longer able to take fluids as a result of the sedatives. Withholding this form of medical treatment would be considered a medical decision intended to shorten the patient's life. Respondents we interviewed in Nijmegen were of the opinion that hydration is basically a futile treatment. However, if the patient or his loved ones ask for artificial hydration after sedation (a request would need to be made in advance for this by a patient), it can, under certain circumstances, be given. Recent data published by Sykes and Thorns indicate that in the terminal phase of a patient's disease process, hydration does not prolong life, and that moreover there are serious side effects such as oedema and aggravation of dyspnoea. For most of our respondents, although not all, withholding of hydration in a deeply sedated patient is not even a separate decision. Rather, patients and/or their loved ones may be informed of the medical reasons why hydration will not be started after sedation.

Risks and uncertainties in relation to the practitioner-lay relationship

In the UK, one respondent spoke about how palliative sedation was used as a last resort (albeit ideally planned) to avoid a scenario of '*dying horribly*': the risk was perceived that without recourse to such an option the fundamental trust between clinicians and patients may be threatened. The dying person may perceive that staff are helpless to aid him, and thus lose all faith in their ability to help and comfort him. However, some UK respondents perceived that some patients and their family carers believe that palliative care practices such as palliative sedation are used to hasten death 'by the back door'. Reports of carers saying: '*We know what you are doing*' or regarding sedation as a 'rite of passage' to death were reported. This gave rise to anxieties and concerns about how patients and families, and indeed other non-specialist professionals, perceive palliative care staff during end of life care. One respondent reported that some families see it as deceitful to give heavy sedation but to express intentions *not* to hasten death; another respondent perceived that the new climate of risk following the Shipman murders means that doctors are reluctant to write up appropriate medications. The nurses to whom we spoke reported that some patients and their families will request (albeit indirectly or obliquely) for treatment to *'finish it'* and that in so doing they sometimes draw parallels with the Holland and Belgium euthanasia laws. Reports were also of 'ritualised' requests from ward staff for the common combination of midazalom/ diamorphine for patients known to be near death.

One of our UK respondents gave a detailed account of the need to develop the clinical skill of understanding the dynamics and relationships in particular families in order to help inform decisions about the use sedation in the dying phase. Some families will be able to witness a degree of agitation or awareness, while others will ask for their relative to be sedated. Moreover, this individual described the difficult process of working with patients at an earlier stage of illness to find out what they want to know and how to help them to decide of particular courses of treatment.

In Holland, the legalisation of euthanasia was perceived to provide a 'way in' to potentially difficult discussions about end of life care between clinicians and patients and their families, and to create the circumstances where it was potentially possible to provide advance information about the 'option' of palliative sedation, and to reassure patients that their suffering would be relieved in a manner fitting with their wishes. This has also created a climate in which it is more acceptable to enquire into the reasons behind a request for euthanasia and to offer another means of managing distress. Equally however, respondents reported the need to be prepared to act in a patient's best interest by using palliative sedation to avoid unbearable suffering[13] in those cases where physical deterioration was not expected or where it had not been possible to hold such a discussion.

In Belgium, as reported above, the recent legalisation of euthanasia was perceived to have introduced various complexities and paradoxes in the physician –patient relationship. In the units that we visited, new procedures were being introduced in an attempt to contain these risks and to ensure that the clinical decision making process following requests for euthanasia or palliative sedation involved the explicit scrutiny and discussions of the multi-disciplinary team. Proforma

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[13] Such as that associated with breathlessness, haemorrhage etc..

had been developed to allow the recording of information about the nature of the request, actions taken and planned, and the outcomes. As part of the process to understand the decision making process in these circumstances and to compare and contrast approaches to decision making in different palliative care in patient units in Belgium, Professor Bert Broeckaert at the University of Leuven is leading a study which uses ethnographic methods. Researcher Patricia Claessens will study prospectively the decision-making processes relating to 100 patients admitted to three palliative care units in the region. Thus, decisions around palliative sedation (intermittent sedation, and light as well as deep sedation) can be situated within a larger context.

Implications for perspectives on what constitutes a ‘good’ or ‘natural’ death

A number of far reaching implications for concepts of the good or natural death can be identified from this opportunity to study clinicians’ views about palliative sedation:

- How is lack of consciousness perceived cross culturally? What are its links to ideas of ‘social death’, dignity and personal and bodily integrity?
- Time between onset of sedation and death was regarded as a critical determinant of the ‘good death’. It was perceived that if the time until death of a sedated patient takes too long families are at risk of ‘burning out’ (anecdotally it was reported that the critical time is 3 days); conversely death that occurs too quickly may be surrounded with doubt. Ethically, it was perceived that once a patient is sedated, caregivers and families usually hope the dying process will not take too long. This may mean that clinicians have a ‘double intention’ although, arguably, hope should be separated conceptually from intention.
- Good deaths of patients and caregivers may collide and cause problems of conflict. We were given the critical example of the man with a massive haematemesis who did not want the sedation that the staff desperately tried to offer to him; he bled to death while fully aware. While, from an ethical point of view, the patient’s refusal should be respected, such an experience may fundamentally challenge the deeply held assumptions of clinical caregivers about the right way to manage death and to give good care to those for whom they are responsible.

Public, patient and carer involvement

Several observations may be made in relation to the potential for public, patient and carer involvement in this field.

First, whereas the issue of end of life decision-making is only subject to public debate episodically in the UK, it is a more sustained subject in the Netherlands and Belgium. However, public debates in all three countries strongly focus on euthanasia and leave other important aspects aside. There is some evidence of public debate on palliative sedation in Holland and Belgium, but again this tends to relate to its alleged moral differences from euthanasia, although in clinical practice opportunities are perceived to address this issue in a more nuanced way.

Second, even though the professional autonomy of physicians is well-established within the medical domain, the degree with which it is defended in the three countries is different. Political, social and clinical movements that have given rise to euthanasia in Holland and Belgium have altered perceptions of the balance between physician and patient autonomy, and the degree to which each of these are moderated by influences emanating from the law and bioethics. In the UK a predominantly beneficence-based approach persists, whereas in Holland and Belgium the emphasis is placed more on the patients' autonomy. During our conversations with analysts in Holland, a helpful framework of understanding was offered: between the desire for complete control and the desire to entrust one's care to professionals (Schermer 2002). Here, even though control over oneself may be regarded as a legitimate value, if it is not counterbalanced by trust that others will care appropriately for you, it is not much more than an illusion. New understandings of autonomy, based on an ethic of care, are now coming more under attention, also in Belgium and the Netherlands. One of our conclusions is that the three countries that participated in this study can learn from one another. Beneficence based approaches do not necessarily have to be at odds with autonomy based approaches if autonomy is not understood as an individual capacity to make rational decisions but rather as an interpersonal quality within the caregiver–patient relationship.

Areas for further research

Discussions are underway to develop ideas for cross cultural research which addresses the four areas identified within this report. Both departments have a track record of conducting interdisciplinary research, and of designing and conducting studies which use a range of methodologies: these will be essential in order to gain a deeper understanding of the issues involved in this field. In particular, it is seen as important to undertake both detailed qualitative studies of the decision making process surrounding end of life care and large scale cross cultural surveys of views/ attitudes to further explore the themes identified in this report. In the short term, one possibility is to design a project for submission to the Cross Council Programme of Ageing: The New Dynamics of Ageing, with a view to examining how people in late old age and their informal care givers plan for conceptualise and plan for the end of their lives, how care providers seek to relieve suffering in this group, and how the balance between 'care' and 'control' is managed in everyday practice.

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