

EACME Newsletter

European Association of Centres of Medical Ethics

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SPECIAL ISSUE: PERSPECTIVES ON ASSISTED DYING IN EUROPE

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CONTENTS

Guest editorial	1
J. Hewitt	
Dealing with Requests for Physician Assisted Suicide of Psychiatric Patients in the Netherlands Development of a Training Module	2
E. Ettema, A. Ruissen and G. Widdershoven	
Conference Report	
Ethics and evidence in end-of-life decision making	4
A. Lindblad	
Assisted dying in Turkey	5
Ö. Yücel	
Euthanasia and the Law in the UK	6
A. Smith	
End of Life Issues in Neo-Natal Care in Turkey	7
T. Ozdogan	
The Attitude of the International Institutions towards Euthanasia in Europe	9
D. Fieldsend	
Assistance au suicide en Suisse	11
Les elements principaux	
J. Martin	
Perspectives on Assisted Suicide in the UK: The Dichotomy between Physical and Psychological Suffering	12
J. Hewitt	
Transnational issues of Assisted Dying	14
Ch. Rehmann- Sutter	
Physician Assisted Suicide: The present situation in Germany – The evolution of a pragmatic and evidence-based approach	15
M. Wulf M. Stratling	
Deadline Next Newsletter + EACME Conference 2014	17

GUEST EDITORIAL

Perspectives on Assisted Dying in Europe

Death may be seen as the greatest of harms or conversely, as a release from greater harms of suffering and indignity. The way in which we view death will of course influence our beliefs about the moral rightness or wrongness of assisted dying. It is perhaps one of the most important ethical debates of the 21st Century, and one which has provoked the general public, health care clinicians and ethicists alike to examine the traditional role of medicine in reversing the trajectory towards death, to a one which instead concerns itself with responding to the expressed desires of people with regard to the end of suffering, even where those desires include death.

There appears to be a growth in permissive views towards assisted dying in many countries in Europe. It is possible to posit a number of reasons for a growth in libertarian views towards a right to die. Many Western countries have seen a change towards a secularisation of values, an increased emphasis on self-determination and a decrease in absolute faith in medical paternalism. Technological advances in medicine have meant that people are now living longer, but not necessarily healthier or happier lives. The availability of a wider range of treatments and life-sustaining technologies has given rise to medical dilemmas in terms of withholding and withdrawing treatment, which did not exist to cause concern for the predecessors of contemporary medicine. Our increased ability to keep people alive in circumstances of extreme debility or advanced disease has in itself contributed to our obligation to discuss when life may not be the best option or in the person's best interests.

There are however equally plausible arguments that caution us to examine the potential dangers of judging some lives as not being worth living. Coercion to die

can never be acceptable, but what counts as coercion may be more subtle and difficult to legislate against. Those who oppose assisted dying warn of the potential for the most vulnerable in our societies to feel that their burden of care is too great and therefore, where an option to die is available, such people may feel obligated to do so. Slippery slope arguments have also been posited, whereby the temptation to de-prioritise certain groups due to scant resources may give rise to active euthanizing of those whose care is most costly.

In this Newsletter, we seek to examine some of these views as reflected in the cultural norms of different countries in Europe. The totality of Europe is by no means represented here, but each brief article provides a fascinating glimpse into many of the key elements of the assisted dying debate. Assisted suicide, passive and active euthanasia are discussed. Important issues of cogent legislation, protection of the vulnerable and the limits of medical autonomy are explored across the life-span in relation to neonates, competent and incompetent adults, persons with mental illness and the elderly. The policies of each country both challenge and inform legal statutes in other cultures. The topic of transnational dying creates particular challenges for all of us, in terms of the increased burden this places upon countries who are willing to assist non-nationals to die, and the obligations of countries who do not allow assisted suicide but whose citizens are served by such a system.

Perhaps what is most compelling in the perspectives set out in this Newsletter is the general commonality of endorsement of supporting a right to die in certain circumstances of extreme suffering. Importantly however, opposing arguments are also set out, which remind us of the weight of the issue at hand and the significance of providing assistance to an end which can never be reversed.

It has been a great privilege for me to have been involved in this Special Issue on assisted dying and it is with much gratitude that I thank all the contributors for providing such important insights and valuable debate.

Best Wishes

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DEALING WITH REQUESTS FOR PHYSICIAN ASSISTED SUICIDE OF PSYCHIATRIC PATIENTS IN THE NETHERLANDS

Development of a Training Module

In the Netherlands, the *Termination of Life on Request and Assisted Suicide Act (WTL)* provides procedures for the termination of life on request and assisted suicide. In order not to be prosecuted, physicians have to act in accordance with the statutory due care criteria. The physician must: a) be satisfied that the patient's request is voluntary and well-considered; b) be satisfied that the patient's suffering is unbearable, with no prospect of improvement; c) have informed the patient about his situation and his prospects; d) have come to the conclusion together with the patient that there is no reasonable alternative in the patient's situation; e) consult at least one other independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled; f) have terminated the patient's life or provided assistance with suicide with due medical care and attention.

Although the law does not distinguish between somatic and mental suffering, Physician Assisted Suicide (PAS) rarely occurs in psychiatric healthcare.¹ In psychiatry, a patient's wish to hasten death is often caused by the patient's mental disease. In that case, the patient is considered not to have the mental capacity to determine his own wishes freely and not to have a full understanding of his disease. Therefore, a request for PAS of a psychiatric patient is and must be primarily understood as a request for helping to live. This does not take away, however, that psychiatric patients may suffer unbearably with no prospect of improvement and have a genuine wish to die. In these cases, there may be a situation in which PAS is a legally and morally justifiable option.

In recent years, the issue of PAS in psychiatry has received increasing attention in the Netherlands, indicating a concern that the restrictive attitude of professionals regarding PAS in psychiatry does not do justice to psychiatric patients who suffer unbearably and have no prospect of improvement. Psychiatric patients may end up in degrading situations which seldom result in suicide. Because of this situation, many psychiatrists struggle with the ethical complexity of the issue and feel insecure about how to deal with a serious wish to die of a psychiatric patient.

Against this background, we did a review of the ethical literature concerning PAS of psychiatric patients.

¹ In the Netherlands, the due care criteria equally apply for PAS and euthanasia. With regard to psychiatry, however, the Dutch ethical and juridical literature speaks mainly of PAS. We follow here the use of 'PAS'.

We also interviewed psychiatrists in order to investigate the values and norms that are at stake in dealing with a request for PAS and in what respect cases in which the psychiatrist grants the request for PAS differ from cases in which the psychiatrist does not grant the request. The results are used as input for a training module to support psychiatrists in dealing with requests for PAS in psychiatry.

Arguments contra PAS in psychiatry

The ethical and philosophical literature presents arguments pro and contra PAS in psychiatry. The main arguments contra PAS in psychiatry are the following.

1 The wish to die is a symptom of the psychiatric disorder. A request for PAS should therefore be understood within the pathological context of the patient. As it is hardly possible to distinguish with certainty between suicidal behavior and a justified request for PAS, granting PAS can never be part of good psychiatric care.

2 Psychiatric classifications are necessarily disputable. A psychiatric disorder can only be tentatively objectified in terms of criteria and measurable parameters. Even if there is consensus about a classification, the presence of a biological substrate and the role of psychosocial and societal factors remains largely unclear. A psychiatric classification can therefore not be a ground for PAS.

3 Course, treatment and prognosis are uncertain. Psychiatric patients generally have a long life expectancy, varyingly suffer from their disorder and may profit from future treatments – for example on the basis of research on neurobiological aspects of psychiatric disorders. As future treatment cannot be excluded, a psychiatrist cannot grant PAS for a psychiatric patient.

4 Vulnerable patients need to be protected. Psychiatrists deal every day with patients who think about death, have a desire for death or express a wish to die. These patients have the right that their thoughts, desires and expressions are reviewed, treated and in dangerous situations restrained. The duty of the psychiatrist is not to facilitate a hastened death but to ameliorate the situation as much as possible.

5 The safety of fellow patients is at stake. Granting a request for PAS may induce strong feelings of unsafety to other psychiatric patients. This unsafety cannot be entirely removed, whether the PAS takes place inside or outside the psychiatric institution. A psychiatrist who grants a request for PAS therefore introduces an unacceptable risk of serious harm to other psychiatric patients.

Arguments pro PAS in psychiatry

The main arguments pro PAS in psychiatry mentioned in the literature are the following.

1 The law is equal for everyone. Although the Dutch law on euthanasia does not distinguish between somatic and mental suffering, Physician Assisted

Suicide rarely occurs in psychiatry. Like somatic patients, psychiatric patients may suffer unbearably with no prospect of improvement and have a genuine wish to die. If the law is equal for everyone, then PAS should be an option in these cases.

2 Psychic suffering can be terrible. Suffering from a severe psychiatric disorder can be so unbearable that the patient ends up in a degenerating, inhuman situation. If this is the case, and the patient has a voluntary and well-considered request for PAS, and there is no reasonable alternative to relieve the suffering, PAS is ethically justifiable.

3 Violent and denigrating suicides should be prevented. In the Netherlands, each year circa 1500 people commit suicide, about half of them previously known to Mental Health Care. Although it is unclear how many of them had a serious request for PAS suicide, there is an overlap between the groups. Granting the requests for PAS will therefore decrease the number of violent suicides.

4 Good care implies providing hope for a dignified death. The promise to eventually grant a patient's request for PAS may increase the patient's peacefulness and trust which, in turn, may decrease the urge of the patient's wish to die. A positive reaction to a patient's request for PAS may even contribute to a situation in which the patient ultimately abandons his request for PAS.

5 Justice must be done to the disorder as well as to the person. The psychiatrist should acknowledge both the psychiatric condition of the patient and the patient as a person. If it is no longer realistic that the patient's situation will improve, and the patient suffers unbearably and has a well-considered request for PAS, then this human being should be helped to finish his or her life.

Experiences and moral concerns of psychiatrists

From the interviews, we learned that the moral arguments in the literature play an important role in dealing with a request or PAS in practice. For every request for PAS, the psychiatrist has to determine the extent to which the arguments mentioned above apply to the situation of the patient. This implies that the arguments are not used by psychiatrists to defend a general position towards PAS, but are used to come to a judgment in the context of a concrete case. Dealing with a request for PAS in psychiatry therefore not only requires awareness of the arguments pro and contra but also requires moral sensitivity in applying these arguments.

The interviews show that psychiatrists consider it very important that assessment of a request for PAS is conducted with due care. Although many psychiatrists are positive about the legislation as well as the guideline of the Netherlands psychiatric association, they also need support, for example in determining whether suffering is unbearable or not. Psychiatrists also emphasize the importance of becoming more aware of

their own values, norms and limitations with regard to PAS in psychiatry.

The interviews show that insight into ethical arguments for and against PAS in psychiatry is relevant in psychiatric practice, not in order for the psychiatrist to take a stance in the debate, but as input to the deliberation about the individual patient's request. In the training module, we will specifically address the issues raised in the interviews, in order to provide psychiatrists with support in dealing with a request of PAS by a psychiatric patient.

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CONFERENCE REPORT: ETHICS AND EVIDENCE IN END-OF-LIFE DECISION MAKING

April 3rd. Arriving at the Institute for Medical Ethics and History of Medicine in Bochum for the conference "Ethics and evidence in end-of-life decision making". The venue is a brick-stone mining tower dated 1877. In the old days, the mine was 670 meters deep. Today the surrounding garden is green and lush, bathing in sunlight. On a nearby football field the game is on.

The conference is organized as final symposium by the North Rhine-Westphalia Junior Research Group "Medical ethics at the end of life: norm and empiricism" (head: Dr. Jan Schildmann) which has been funded by the Ministry of Innovation, Science and Research in North Rhine-Westphalia and the Ruhr University Bochum. It holds an ambitious programme covering empirical, normative and methodological aspects of end-of-life decisions (EOLD). On this first day the main focus is on empirical research, starting out with past and current practices of euthanasia, physician-assisted suicide and palliative sedation in the Netherlands as described by Agnes van der Heide (Rotterdam). After actual practices, attention slightly shifts to involve the decision-making process foregoing every EOLD. Two recent German projects on the subject are presented by Eva Winkler (Heidelberg) and Jan Schildmann (Bochum). It is interesting data, which among other things indicate that if physician and patient have different treatment goals, the patient is less likely to be involved in the decision-making process. Also, criteria for physicians' decision-making are suggested, involving medical as well as non-medical aspects.

In the second session, Sebastian Wäscher (Bochum) presents a qualitative study performed in an oncology clinic, involving observations, interviews, focus groups and ethical interventions (the latter yet to be implemented). This starts a lively discussion on the role of interventions and methods for follow-up. Next in line of speakers is Ruth Horn (Oxford), highlighting differences in attitudes towards advanced directives in England vs. France. Finally, Hilde Buiting (Rotterdam) presents qualitative data suggesting that chemotherapy in advanced cancer may play a key role for patients to maintain hope. The audience is definitely in a debating mood now, and questions of overtreatment and clinical practice are lively discussed.

After well-deserved coffee, Jochen Vollmann (Bochum) gives an elegant speech against the development of palliative care exceptionalism, claiming that an increasing demand of palliative care calls for a more generalist approach, as well as underlining that suffering is not limited to end of life alone. Interestingly, given the theme of the conference, Prof. Vollmann is the first speaker to mention the word "death" in his presentation. The session is closed by Markus Zimmermann-Acklin (Fribourg), focusing on allocation justice and care for patients at the end of life. The subject reanimates the discussion about overtreatment and the role of chemotherapy in advanced cancer, but then, all of a sudden, the first day of conference is over and we stroll out in the lovely spring evening for buffet and drinks.

April 4th. Grey skies, cherry trees in bloom. In the mining tower, focus is shifting towards methodological aspects of empirical ethics. Jonathan Ives (Birmingham) opens the first session by sharing thoughts about practical and pragmatic bioethics. Next in line is Michael Dunn (Oxford), highlighting the normative tensions built into empirical research. This track is followed by Sabine Salloch (Bochum), presenting ideas on the selection of a normative framework for empirical-ethical studies and exemplifying these with experiences from a recent project. Further thoughts on empirical ethics are given by Marcel Mertz (Cologne).

After a tasty Italian lunch in the garden, it is time to discuss clinical and ethical interventions to improve end-of-life practice. Bert Molewijk (Amsterdam/Oslo) introduces moral case deliberation as a method for improving decision-making among health care professionals in end-of-life care, followed by Massimo Costantini (Genoa) sharing his experiences from a project aiming at improving quality of life at the end of life by importing a hospice model of care into a hospital setting. Finally, Jennifer Mack (Boston) presents interesting data indicating that in patients with advanced cancer, end-of-life discussions in an earlier

stage is associated with less aggressive treatment in the final days of life and a higher use of hospice services.

A round table discussion on future challenges regarding end-of-life decision-making with Anne Slowther (Warwick) and Guy Widdershoven (Amsterdam) closes this well-organized two-day conference. I leave the ethics tower with some of my newly found colleagues, feeling both inspired and grateful over the exchange of ideas and experiences that has just taken place.

So, before bringing this short report to a conclusion, I wish to say THANK YOU to the organizing team, especially Ms Verena Sandow, Dr Jan Schildmann, Dr Sabine Salloch, Mr Sebastian Wäscher and Professor Jochen Vollmann, for the making of this stimulating and creative event.

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ASSISTED DYING IN TURKEY

In Turkey, assisted dying is discussed, focusing on euthanasia especially. Assisted suicide is a crime according to the Turkish Criminal Code. Apart from illegality of that, there is no concrete demand for assisted suicide among patients and patients' relatives. Health professionals do not support assisted suicide either. However, many health professionals support euthanasia².

Euthanasia is divided into active and passive euthanasia. Active euthanasia is punished like murder. It is not allowed in Turkish law. It is clearly indicated in the Directive of Patients' Rights (DPR). According to the Article 13 of DPR, euthanasia is forbidden. The right to life cannot be given up for medical reasons (or any other reasons). The life of a person cannot be ended, regardless of the person's own wishes, or of the wishes of another. In this article, it is not specified which type of euthanasia is prohibited. However, there is a right to refuse and stop medical treatment, provided in the DPR. According to Art. 25 of DPR, except for obligatory legal cases, on the condition that patient is responsible for the negative results, the

² Muslu, Mert N.: "Türkiye'de Gizlice Ötanazi mi Yapılıyor", Habertürk, 09.04.2013, <http://www.haberturk.com/polemik/haber/834422-turkiyede-gizlice-otanazi-mi-yapiliyor> 20.11.2013.

patient has the right to refuse planned medical treatment, and to stop continuing medical treatment. In this case, results of non-treatment should be explained to the patient or his/her legal representatives or relatives, and a written document showing this fact should be received from them. The existence of the right to refuse and stop medical treatment indicates that passive euthanasia is not illegal³. However, health professionals avoid realising passive euthanasia due to concern about becoming responsible for death. This is not completely irrational because of a contrasting article of DPR. Art. 24 of DPR states that a patient is not allowed to remove his/her consent for medical treatment during treatment, if there is a life-threatening danger. As two equal regulations conflict with each other, there is a legal gap. International agreements, which are concerned with fundamental rights and freedoms, have superiority to the national regulations, constitutionally. The Convention on Human Rights and Biomedicine prescribes that patient can remove his/her consent at any time. They expect a definite regulation, which clearly allows for passive euthanasia. Passive euthanasia does not prevent or end pain, but it pays respect to the patient's will and accepts the patient's autonomy. Active euthanasia ends all pain, but there is no way back in this case.

Doctors have a duty to make patients live, but patients have a right to self-determination. Contrasting views should be balanced in the light of law and ethics. There is an argument against euthanasia, in that the provision of euthanasia could be easily misused and patients murdered for financial benefits. This stems from a lack of confidence in the system of justice, health, and more broadly in the political system. If patients have mental health problems, the issue of euthanasia becomes more difficult. The question then is whether to endorse living with pain or death without suffering. Now, ethics and law must reply this question, should there be a right to die?⁴

The patient could make a testamentary disposition, providing for future loss of autonomy (e.g. loss of consciousness) and the kind of treatments that could be exercised. Also, patients could appoint a representative, who might make decisions about the medical treatment of the patient when the patient loses consciousness. However, according to the Art. 24 of DPR, when a patient is not conscious, doctors are entitled to administer treatment.

In Turkey, sometimes patients demand active or passive euthanasia, but these demands are not always

³ See Aktaş, İsmail: "Git Evinde Öl", Hürriyet, 09.11.2010, <http://www.hurriyet.com.tr/gundem/16249894.asp> 20.11.2013.

⁴ Erşan, Mesude: "Ötanazi cinayet mi kurtuluş mu", Hürriyet, 08.11.2009, <http://www.hurriyet.com.tr/pazar/12887661.asp> 20.11.2013.

accepted. For example, in 2009 a 22 year old girl was struggling against leukaemia. Her family wanted to take her home from hospital. Physicians did not accept their plea and her family turned off her life-support system⁵. Nevertheless, there is an opinion amongst people that euthanasia is exercised de facto. This is difficult to state with certainty but it can be said that there is an arbitral practice in this case.

The bottom line is the legality of euthanasia. De facto exercise of euthanasia shows that people need such assisted dying. However, euthanasia or assisted dying should be legal and open to scrutiny, not arbitrarily decided in secret.

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EUTHANASIA AND THE LAW IN THE UK

The legal and ethical considerations in respect of euthanasia in the UK have yet to be legislated upon by Parliament, the Supreme law making body.⁶ Consequently, the law is somewhat confusing and does not adequately address the complexity of the main issues, as it has developed through case law made by an unelected judiciary.

From a legal viewpoint, within the English legal system murder is a crime committed when a person causes the death of a human being with intention to kill or to cause grievous bodily harm.⁷ The definition has not been updated in any significant format since its inception and motive is irrelevant. The definition of euthanasia, derived from Greek and meaning 'Easy death', is deemed to be the painless killing of a patient suffering from an incurable and painful disease or in an irreversible coma⁸. It is therefore apparent from these definitions that legally, euthanasia is murder. The issue then for consideration is whether and how the law makers have dealt with the killing of a person when motive is relevant.

Due to the fact that euthanasia is classified as murder within the English legal system, criminal prosecutions against those involved in the death of persons have

⁵ See Aksoyer, Ali et al.: "Ailesi kanser hastası kızlarına ötanazi uyguladı", *Hürriyet*, 31.10.2009, <http://www.hurriyet.com.tr/gundem/12820337.asp> 20.11.2013.

⁶ Subject to devolved powers in Northern Ireland, Scotland, Wales in certain areas and EU law

⁷ LJ Coke 1797 although updated to modern language

⁸ Oxford English Dictionary

been brought before the courts for their consideration. If legislation is absent or does not cover the issue in question, as often occurs in matters of healthcare law, judges have no choice but to decide the case in question, thereby making law on the matter. Consequently, the legal status of various facets of euthanasia have been debated upon in the courts in an ad hoc manner, dealing with issues as they arise, with judicial decisions hoping to satisfy both legal and ethical concerns. These decisions create legal precedents which, in the absence of either a higher court overruling the decision or Parliament enacting legislation, form binding law within our legal system.

Case law has set a legal precedent that sets out that euthanasia in all its forms (voluntary, involuntary or non-voluntary), if carried out in an active form i.e. death caused by a deliberate action such as smothering, injection, high doses of medication is, to all intents and purposes, classified as murder, and therefore is unlawful.⁹ This would, at face value, appear non-problematic and suggest that the medical professional is not entitled to actively and intentionally end the suffering of their patients, for fear of reprisal within the legal system. However, two courses of action i.e. the Doctrine of Double Effect and that of Passive euthanasia, have been sanctioned by the judiciary in conjunction with verdicts of juries, and require further discussion below as they form part of the law on euthanasia with England and Wales.

The Doctrine of Double effect applies in many contexts where there may be both a good and bad effect of an action. Within the medical context this applies where a medical professional wishes to lessen a patient's pain by administering drugs (a good effect) but where the drugs effectively kill the patient (the bad effect). This principle has been considered by the courts and ultimately sanctioned as being acceptable, and not therefore, deemed to be euthanasia.

In the first case of this kind, in *R v Adams* [1957]¹⁰ Dr Adams was prosecuted for the murder of a terminally ill patient. Judge Devlin firstly stated that "If the acts done are intended to kill and do kill it does not matter if a life is cut short by weeks or months, it is just as much murder as if it were cut short by years" but then he qualified this by stating "The doctor is entitled to relieve pain and suffering even if the measures he takes may incidentally shorten life". The bad effect of causing death was considered to be a secondary intention of the doctor rather than the primary intention of relieving pain. Consequently Dr Adams was acquitted by a jury. More recent cases illustrating this principle include *R v*

⁹ Lord Goff of Chieveley in *Airedale NHS Trust v Bland* [1993] A.C. 789

¹⁰ Crim LR 365

Carr [1986]¹¹ and *R v Moor* [1989]¹² where both had admitted to giving lethal doses of painkillers but were subsequently acquitted by juries. A distinction may be drawn with the case of *R v Cox* [1992]¹³ where Dr Cox was convicted by a jury of attempted murder of a patient but where it was acknowledged that the drugs administered had no pain relieving effect. To this end therefore, there was no double effect, the sole intention of Dr Cox was to hasten the patient's death.

To this extent the law seems settled on this principle at the current time, although whether such an issue should have been and remain governed by principle handed down from an unelected judiciary remains open to debate.

As mentioned previously, active euthanasia is unlawful in the UK. However, the principle of passive euthanasia has also been debated through the judicial system. The judiciary have ruled that passive euthanasia is not actually euthanasia at all as there is no intention to bring about the death of a patient. Passive euthanasia may be seen as withdrawal of treatment or as non-treatment of a patient, with the ultimate consequence being the death of that patient. The key case discussing this principle is that of *Airedale NHS Trust v Bland* [1993]¹⁴. Tony Bland was a young football supporter of Liverpool FC and was crushed during the FA cup semi-final match at Hillsborough stadium in 1989. Consequently he had been in a Persistent Vegetative State (PVS) since that time until the case was ultimately decided in 1993. The question that was put to the court was whether the medical profession could legally remove the artificial feeding and hydration and allow him to die without fear of criminal prosecution. The Law Lords held that in this type of scenario, the medical profession would be entitled to remove the tubes hydrating and feeding Mr Bland as they no longer owed him a duty of care. If no duty of care was owed, then no action need be taken and their omission to feed and hydrate him would be allowed, ultimately leading to his death. They stated that an omission (or failure to act) cannot be deemed as euthanasia but stressed in their judgment that Parliament should enact legislation on this contentious matter ("I have no doubt that it is for Parliament, not the courts, to decide the broader issues which this case raises"¹⁵).

In conclusion, no clarifying legislation has been passed on the issue of euthanasia or assisted dying (although Private Members Bills have been proposed but not

¹¹ acquitted of attempted murder - Sunday Times 30 November 1986

¹² Crim L.R. 2000 Jul 568-590

¹³ Unreported, Ognall J., Winchester Crown Court, 18 September 1992

¹⁴ A.C. 789

¹⁵ Lord Browne-Wilkinson

completed in respect of Assisted Dying¹⁶,¹⁷,¹⁸ and Attorney General Guidelines to Prosecutors issued in February 2010 in respect of assisted suicide¹⁹). If one considers why Parliament has been and remains reluctant to enact law on this complex matter, one must consider that such a contentious issue will divide opinion which also divides voters. However, Parliament has had to deal with contentious issues in the past (Abortion Act 1967, Human Reproductive Cloning Act 2001) rather than allowing an unelected judiciary to make law. Other countries (e.g. the Netherlands, Belgium, Switzerland) have seen fit to enact law on the matter and one may argue that now is the time for our legislators to join the debate.

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END OF LIFE ISSUES IN NEO-NATAL CARE IN TURKEY

When I conducted a search about euthanasia of the newborn in Turkey, I came across an article written by one of our ethics professors who is the head of the current Turkish Bioethics Society. It was published nearly 2 decades ago and gave the picture very broadly²⁰. There is a little progress on the idea of euthanasia in our country since then. At present, euthanasia is neither accepted nor authorised in Turkey.

As a neonatologist in Turkey for 13 years I have faced lots of end of life issues for newborn infants. I say issues, because we in general do not share decisions with families about their infant or child. This paternalistic behaviour is still active among Turkish physicians. The current regulations for Turkish patients' rights state that a patient has the right to reject the beginning of treatment in a serious illness. In practice, it does not work as reported in detail recently²¹.

Since the palliative care facilities are limited, going home and dying there is the only option left for terminal adult cancer patients. Most of the time the decision

¹⁶ Patient (Assisted Dying) Bill 2003

¹⁷ Assisted Dying for the Terminally Ill Bill 2004

¹⁸ Assisted Dying Bill 2006

¹⁹ http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html

²⁰ Oguz NY. Euthanasia In Turkey: Cultural and religious perspectives. *Eubios Journal of Asian and International Bioethics* 6 (1996), 170-1.

²¹ Sert G, Guven T. Examining the ethico-legal aspects of the right to refuse treatment in Turkey. *J Med Ethics* 2013;39:632-635.

maker is the health professional and the family member of the patient. Actually this is a kind of passive euthanasia, reflecting voiceless agreement between the parties. Here comes the problem of medical morality/honesty, the truth telling and trustworthiness in medical professionalism²². I think we need more and more education on the medical professionalism basis for both medical students and physicians.

This is the situation for competent adult patients, but what about neonatal patients? Why do people behave differently if we say to them "take your infant to home for end-of-life care"?

The end-of-life decisions for newborns are very challenging all around the world and are so in Turkey. For the last 10 years, together with the advances in technology, neonatal intensive care unit (NICU) facilities are increasing in Turkey. The families can find NICU beds for their infants in a private hospital paid for by the Government, when the beds in Government and university hospitals are occupied. But the dilemmas regarding the end-of-life decisions are continued in any case, because withholding and withdrawing medical treatment are not implemented interventions in our NICUs in general. For example, a severely hypoxic infant was treated in a private hospital NICU for 8 months. The infant was neither offered transfer to a palliative care unit nor a pediatric intensive care unit (PICU). The number of PICU beds are in shortage and we do not have neonatal and paediatric palliative care units. Actually the idea of palliative care, withholding and withdrawing medical treatment, are not usually discussed among neonatologists.

The Turkish Neonatal Society held a workshop about neonatal ethical problems in our country, which aimed to increase the ethical knowledge of health professionals in neonatal medicine and for the provision of guidelines²³.

In a study from Turkey, data was collected from nurses and doctors, using a standardized questionnaire adapted from the EURONIC study. The study showed that 75 % of the contributors agreed that everything possible should be done to ensure a neonate's survival regardless of the prognosis. The conclusions of the study appear to show that sanctity of life is more important than quality of life for the Turkish health professionals, in contrast to their European colleagues. The answer to the question "In the course of your professional life, have you ever decided, by yourself, to set limits on intensive interventions?" was "yes" in

²² Swick, H. M. (2000). Toward a normative definition of medical professionalism. *Academic Medicine*, 75,612–616.

²³ The Turkish Neonatal Society Bulletin, 2013;25:19.

40.0% of participants²⁴. In spite of this answer, we do not have a 'do not resuscitate order' (DR) and this answer remains an "off the record order" among the health professionals.

The participation of the families in the decision was not clear in the study, but I know that those decisions are not talked about with families in practice. The families usually cannot express their ideas about the best interests of their infant at the end-of-life situation. For example, one mother said to me "I do not know what is best for my daughter". Another mother said that it would be best for her (severely hypoxic) son to die but that she cannot express this. As time passed, the mother began to stop the visits to her son and a big problem remains to be solved.

Sometimes the health professionals do not allow the families to express their thoughts because they believe that the family cannot understand anything. So, they do not need to explain the infant's situation in detail.

I feel as if we are making dysthanasia (exaggerated prolongation of agony, suffering, and death of the patient or merciless prolongation of life) for patients while trying to avoid withholding and withdrawing medical interventions²⁵.

It is clear that we need a humane approach to end-of-life decisions and to gain this approach it is necessary extend the topic beyond the questionnaire studies.

It seems that the key point is not religion in end-of-life issues, because families have reported that they found comfort in their belief in God in USA²⁶ and the majority of the people in Turkey are Muslims and therefore believe in God. Therefore the difference in beliefs about end of life decisions must stem from our causes. I think that it is due to evolution in the way of thinking, which we need to achieve.

In 2008, the Turkish Medical Association published a guideline about ethical issues and I hope it is used widespread among health professionals²⁷.

In conclusion, we are at the beginning of many of the ethical issues as the health professionals and we need more collaboration with ethicists. Hospital Ethics Committees must be established and these subjects

²⁴ Bilgen H, Topuzoğlu A, Kuşçu K, Altuncu E, Özek E. End-of-life decisions in the newborn period: attitudes and practices of doctors and nurses. *Turk J Pediatr* 2009; 51: 248-256

²⁵ Mercurio MR, Murray PD, Gross I. Unilateral Pediatric "Do Not Attempt Resuscitation" Orders: The Pros, the Cons, and a Proposed Approach *Pediatrics* 2014;133;S37

²⁶ Brosig CL, Pierucci RL, Kupst MJ, Leuthner SR. Infant end-of-life care: the parents' perspective. *Journal of Perinatology* 2007; 27: 510–516

²⁷ Turkish Medical Association Ethical Report 2008;30-34.

<http://www.ttb.org.tr>

must be discussed between the related parties several times, again and again.

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THE ATTITUDE OF THE INTERNATIONAL INSTITUTIONS TOWARDS EUTHANASIA IN EUROPE

For more than two millennia, going back at least to the famous 5th century BC Greek father of medical ethics, Hippocrates, and lasting until the end of the twentieth century, a near universal taboo forbidding doctors to deliberately kill their patients was maintained in all national jurisdictions in Europe²⁸.

A mercifully brief exception to this was introduced during the Nazi era when doctors were not just allowed, but instructed by the state, to kill people considered not fit to live by reason of infirmity, age or handicaps of various kinds (both mental and physical). There has also been a special exception in the case of Switzerland allowing assistance (but not direct administration of the lethal act) in suicide (not restricted to doctors) provided it is not carried out for selfish motives.²⁹

To clarify, this taboo was on deliberate killing. It did not prevent doctors from ceasing the aggressive treatment of diseases once there was no longer any hope of achieving a cure, even if this might mean that death would take its natural course a few days earlier; nor to giving priority to controlling pain in the terminal stages of an illness, even if the high doses of opiates required for this might occasionally mean that death arrived a little earlier.

The basis for this taboo was quite clear; the 'right to life' is one of the most fundamental of human rights, quite literally none of the other rights can be exercised without it. The framers of the Universal Declaration of Human Rights³⁰ and the European Convention on

²⁸ The original text included '*I will give no deadly medicine to any one if asked, nor suggest any such counsel*'.

²⁹ Criminal Law & Assisted Suicide in Switzerland by Prof Dr Christian Schwarzenegger & Sarah J Summers 3rd February 2005 paper to UK House of Lords Hearing, downloadable at: <http://www.rwi.uzh.ch/lehreforschung/alphabetisch/schwarzenegger/publikationen/assisted-suicide-Switzerland.pdf>

³⁰ UN Universal Declaration of Human Rights, Article 3

Human Rights³¹ were very clear that the states who were party to these treaties should do their utmost to prevent the deliberate taking of human life through the actions of another human being – whether an agent of the state or a private individual citizen. Doctors fall somewhere between the two – they are often regarded as private liberal professionals, but in many states their services are paid for from the public purse, or they are actual public employees.

Recent developments

Since the turn of the twenty-first century a tiny minority of European states (three in all) have broken ranks and introduced laws legalising the deliberate taking of life by doctors (commonly referred to as 'euthanasia') in certain defined circumstances.

The first of these was the Netherlands. The Dutch parliament adopted a new law legalising euthanasia in April 2001³² although because the Dutch Supreme Court had held as early as 1984 in the Alkmaar case³³ that a doctor who kills a patient may in certain circumstances successfully invoke the defence of necessity, euthanasia had already become common practice in the Netherlands before that.

The Netherlands' neighbour Belgium followed suit in May 2002 and Luxembourg in 2008, but in the latter case only after a constitutional crisis had been provoked when the Grand Duke (the sovereign monarch of that country) refused for reasons of conscience to sign the parliamentary legislative proposal into law.

However, it must be remembered that we are talking here about only three nations in a continent which has forty-seven states in membership of the Council of Europe, and twenty-eight in the case of the European Union. The overwhelming majority view remains that doctors should not be authorised to kill their patients in any circumstances.

Arguments for and against legalisation

Protagonists of euthanasia often begin by citing unsupportable suffering as the reason why euthanasia should be allowed, which most people think refers to unbearable pain. In response, palliative care (in which the prime treatment goal is effective pain management, rather than curative) is advanced as the solution and its wider availability is advocated. However, if that response is successful, the argument is moved on from preventing suffering to promoting autonomy. It is argued that a patient's right to free choice is being

³¹ Council of Europe Convention for the Protection of Human Rights and Fundamental Freedoms, Article 2

³² Termination of Life on Request and Assisted Suicide (Review Procedures) Act" from 2002.

³³ Euthanasia: law and practice in The Netherlands by Sjeff Gevers, British Medical Bulletin 1996;52 (No. 2)

attacked if the range of choices available is restricted by ruling out the option of choosing death. It would not be fair to make the patient plead special circumstances like unbearable pain in order to justify their choice. In fact, in states where euthanasia has been legalised pain is not given as the prime reason for patients seeking it. Rather it is the perceived 'loss of dignity' involved in becoming dependent on others for the basic necessities of life or no longer being able to take part in enjoyable activities³⁴.

Contra arguments are concerned with the potential ideological coercion of certain vulnerable groups (e.g. the elderly) who may feel pressured to die. If euthanasia is 'routinized', as the UN report referred to below³⁵ feared, there might be a risk that it develops from being a 'right to die' to becoming a 'duty to die', especially for those only being kept alive by the benefit of expensive medical treatment in an age of restricted budgets. The current effort to make palliative care more widely available might then be reduced if there is legal access to the cheaper alternative of euthanasia.

European legislation

In the UK, assisted dying is currently not supported by law. However, in the Netherlands and Belgium, statutes are clearly set out that permit such assistance in defined circumstances. The law in both Belgium and the Netherlands states that assistance should only be given to a competent adult, after a period of reflection where free and informed written consent has been obtained. In the Netherlands, there is also special provision for euthanasia to be requested by 12 to 18 year olds. Terminally ill patients are covered by both laws, but in Belgium there is also provision (subject to the consent of a second doctor) for cases where the patient is not likely to die in the near future.

Critical opposition

The most vigorous criticisms of liberal laws which allow assisted dying (such as those of the Netherlands), have been recorded by the responsible Committee of the United Nations³⁶ including concern that systems

³⁴As in previous years, the three most frequently mentioned end-of-life concerns were: decreasing ability to participate in activities that made life enjoyable (90.1%), loss of autonomy (88.7%), and loss of dignity (74.6%).' From "Fourteenth Annual Report on Oregon's Death with Dignity Act", The Oregon Department of Human Services, Feb. 29, 2012

³⁵Concluding observations of the UN Human Rights Committee : Netherlands. 27/08/2001. (CCPR/CO/72/NET) available at <http://www.unhchr.ch/tbs/doc.nsf/385c2add1632f4a8c12565a9004dc311/dbab71d01e02db11c1256a950041d732?OpenDocument&HighLight=0.euthanasia>

³⁶Concluding observations of the UN Human Rights Committee : Netherlands. 27/08/2001. (CCPR/CO/72/NET) available at <http://www.unhchr.ch/tbs/doc.nsf/385c2add1632f4a8c12565a9004dc>

might fail to detect and prevent situations where undue pressure could lead to [requirements for free informed consent, being circumvented and that, with the passage of time, such a practice might lead to routinization and insensitivity to the strict application of the requirements in a way not anticipated.

The Committee reported that more than 2,000 cases of euthanasia and assisted suicide (or a combination of both) were reported to the review committee in the year 2000 and that the review committee came to a negative assessment only in three cases. The large numbers involved raised doubts whether the present system is only being used in extreme cases in which all the substantive conditions are scrupulously maintained. The Committee, having taken full note of the monitoring task of the review committee, was also concerned about the fact that it exercises only an *ex post* control, not being able to prevent the termination of life when the statutory conditions are not fulfilled.

Liberal laws on assisted dying have also given rise to debate at the Council of Europe³⁷ where its Parliamentary Assembly adopted a Resolution and a Recommendation to the Committee of Ministers in 1999³⁸ which the Committee of Ministers later largely adopted at their 790th meeting on 26th March 2002 as their official policy.³⁹ The Committee of Ministers endorsed paragraph 9 (c) of the Assembly Recommendation, to "*encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects...by upholding the prohibition against intentionally taking the life of terminally ill or dying persons, while:*

- i. recognising that the right to life, especially with regard to a terminally ill or dying person, is guaranteed by the member states, in accordance with Article 2 of the European Convention on Human Rights which states that 'no one shall be deprived of his life intentionally';*
- ii. recognising that a terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person;*
- iii. recognising that a terminally ill or dying person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death.*"⁴⁰

An attempt in 2003 by Swiss MP Dick Marty to have this official Council of Europe policy position challenged by the Parliamentary Assembly stalled for

[311/dbab71d01e02db11c1256a950041d732?OpenDocument&HighLight=0.euthanasia](http://www.unhchr.ch/tbs/doc.nsf/385c2add1632f4a8c12565a9004dc311/dbab71d01e02db11c1256a950041d732?OpenDocument&HighLight=0.euthanasia)

³⁷The international body representing 47 states of the wider Europe, uniting EU member states with all other states on the continent (with the exception of Belarus).

³⁸Protection of the human rights and dignity of the terminally ill and the dying – Parliamentary Assembly Recommendation 1418 (1999)

³⁹Council of Europe CM/AS (2002)Rec1418finalE / 26 March 2002

⁴⁰Ibid, paragraph 5

the best part of a year and was then rejected at a plenary session in 2004.

As recently as January last year, this position was reaffirmed by the Parliamentary Assembly when it adopted an amendment to a Resolution stating that: *'Euthanasia, in the sense of the intentional killing by act or omission of a dependent human being for his or her alleged benefit, must always be prohibited'*⁴¹.

Conclusions

The debate on assisted dying in Europe is not straightforward and this has been recognised by European legislation. Arguments for legalisation include reference to the suffering of unbearable pain and loss of dignity. However, contra arguments which relate to the potential coercion of vulnerable groups can be seen in the statements made by the United Nations and the Council of Europe, who have expressed strong concerns regarding potential abuse of routinized assisted dying.

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ASSISTANCE AU SUICIDE EN SUISSE – LES ELEMENTS PRINCIPAUX

Dans nos sociétés, le fait qu'il n'y ait pas lieu de punir les suicidants est aujourd'hui unanimement reconnu. On peut parler d'un droit à l'intention de se suicider et à la réalisation de cette intention. C'est la traduction de ce que, sous réserve d'actes illicites, l'Etat n'a pas à interférer dans la manière dont un individu doué de discernement gère son existence. Etant souligné qu'il s'agit d'un *droit-liberté* et pas d'un *droit-créance*, à savoir : personne ne saurait requérir de la part d'autres, notamment des pouvoirs publics, qu'ils mettent à sa disposition les moyens de le faire.

Des différences de culture civique d'un pays à l'autre (appréciation des conditions de légitimité de l'intervention de l'Etat). En Suisse, le respect de l'Etat est un principe fort ; néanmoins, le citoyen est très attentif à ne pas lui donner des prérogatives indues, qui ne seraient pas indispensables pour la conduite de la nation. Alors que, nous paraît-il, dans des pays comme la France, on tend à se tourner très vite vers l'Etat dans des situations délicates, en

⁴¹ Protecting human rights and dignity by taking into account the previously expressed wishes of patients - Parliamentary Assembly Resolution 1859 (2012)

pensant trop absolument à notre sens qu'il serait garant de la prise des bonnes décisions. En Suisse, nous ne le pensons pas quand sont concernés essentiellement des rapports privés entre personnes qui ont leur discernement. Nous ne voulons pas d'un Etat qui entre indûment dans les foyers ; il ne saurait y intervenir légitimement que s'il y a tort pour autrui. En particulier, les pouvoirs publics n'ont pas à « faire la morale ».

La situation légale suisse. Elle est particulière et fondée sur une disposition fondamentalement ouverte, l'article 115 du Code pénal entré en vigueur en 1943, qui a la teneur suivante : *« Incitation et assistance au suicide : Celui qui, poussé par un mobile égoïste, aura incité une personne au suicide, ou lui aura prêté assistance en vue du suicide, sera, si le suicide a été consommé ou tenté, puni de la réclusion pour cinq ans au plus ou de l'emprisonnement ».*

Dans sa simplicité, cet article est libéral ; il s'applique à tous ceux qui sont dans le pays, ce qui explique qu'on ait pu voir un certain développement du « tourisme du suicide » ; on admet en effet que toute personne qui se trouve dans notre pays peut y exercer les libertés reconnues par la législation.

Par contre, l'euthanasie, même à titre compassionnel (ce que le Code pénal appelle à son article 114 meurtre sur la demande de la victime) reste elle interdite (contrairement à ce qui vaut aux Pays-Bas, en Belgique et au Luxembourg). Pour la Commission nationale suisse d'éthique, il est délicat d'enfreindre le tabou du meurtre Ce qui l'a amenée, dans sa prise de position 9/2005, et compte tenu du fait que la grande majorité des situations peuvent être résolues par l'accès à l'assistance au suicide, à estimer qu'on pouvait laisser à un stade ultérieur le débat sur l'euthanasie active directe.

Un chemin de crête délicat. Si la large majorité des Suisses veulent conserver le statut actuel libéral relatif à l'assistance au suicide, il convient de souligner que les pouvoirs publics et les institutions en général ne sauraient en aucune manière avoir l'air d'en faire la promotion. La question se pose devant les demandes de certains d'une réglementation plus précise de cette assistance. Si les pouvoirs publics émettent des textes détaillés à ce propos, pensera-t-on qu'ils en légitiment formellement la pratique ? Quid du risque d'en faire un acte « normal », de routine ? Tout en respectant la liberté des personnes, il importe que les institutions évitent toute démarche susceptible d'être interprétée comme une caution du suicide.

Par ailleurs, il importe aussi d'éviter que, sous prétexte de protection de citoyens (qui pourtant sont dans leur bon sens), on en vienne à mettre sans raison

suffisante des obstacles ou délais disproportionnés à l'exercice par ces personnes de droits fondamentaux comme leur libre détermination.

Prises de position d'instances éthiques.

La Commission nationale suisse d'éthique (CNE) s'est beaucoup penchée sur les questions liées à l'assistance au suicide et a publié deux rapports substantiels (9/2005 et 13/2006 – lectures recommandées !). Dans le document 9/2005, relevons :

Recommandation 8 – Hôpitaux et établissements médico-sociaux : (a) Institutions de long séjour : Dans la mesure où un résident demande le suicide assisté et qu'il ne dispose pas d'un lieu de vie autre que la dite institution, il devrait pouvoir accomplir son acte en ce lieu, si cela est possible ; (b) Hôpitaux de soins aigus : Chaque institution doit se déterminer clairement quant à l'éventualité d'admettre le suicide assisté. Cette institution doit pouvoir justifier son choix envers les patients.

Recommandation 9 – Professionnels de santé : « Les médecins ainsi que le personnel soignant font face à un conflit d'éthique professionnelle du fait que leurs professions impliquent un engagement pour la vie et non pour la mort. Lorsque les médecins pratiquent néanmoins l'aide au suicide, ils le font de leur propre chef (...) Les professionnels de la santé ne doivent encourir aucune désapprobation morale ni aucune sanction professionnelle du fait de leur détermination, en conscience, en faveur ou contre l'assistance au suicide. Les professionnels de santé doivent être adéquatement formés aux soins en fin de vie. Cette formation devrait traiter des questions éthiques et des dilemmes que posent les situations de suicide et de suicide assisté ».

L'Académie suisse des sciences médicales a pris position pour la dernière fois en 2012 : « La mission des médecins prenant en charge des patients en fin de vie consiste à soulager et accompagner le patient. Il n'est pas de leur devoir de proposer une assistance au suicide. Toutefois, un patient en fin de vie ne supportant plus sa situation peut exprimer son désir de mourir et persister dans ce désir [et] le médecin peut se retrouver face à un conflit difficile à gérer. D'une part, l'assistance au suicide ne fait pas partie de l'activité médicale. D'autre part, le respect de la volonté du patient est fondamental dans la relation médecin-patient. Un tel dilemme exige une décision morale personnelle du médecin qui doit être respectée en tant que telle ».

Plusieurs hôpitaux, notamment universitaires, et des associations de homes pour personnes âgées dépendantes ont élaboré des recommandations/guidelines précisant dans quelles

conditions les patients peuvent faire recours, dans leurs murs, à une organisation d'assistance au suicide.

A propos de prévention du suicide. Il est clair que la médecine et la santé publique ont parmi leurs missions de faire œuvre de prévention du suicide. C'est un problème auquel il convient de consacrer des ressources humaines et matérielles et qu'il faut étudier par la recherche scientifique. Cela étant, comment nier qu'il y a des différences significatives entre le geste suicidaire de l'individu jeune ou adulte qui a devant lui, potentiellement, un avenir statistiquement long et qualitativement prometteur (malgré les difficultés qui peuvent surgir ponctuellement), et l'envie de voir sa vie se terminer d'une personne âgée et malade ; d'une personne qui a bénéficié de l'essentiel des possibilités de l'existence et pour qui le futur est fait de grande dépendance, de douleur et souvent de perte des repères relationnels et de solitude ?

Pratiquement. Actuellement, il y a en Suisse environ 400 suicides assistés par an, soit 0,65 % de l'ensemble des décès. Les chiffres montrent une certaine augmentation d'une année à l'autre mais on ne peut pas parler d'évolution « épidémique ».

Les deux principales organisations qui offrent une aide au suicide sont les associations « Exit-Suisse romande », qui compte quelque 19'000 membres, et « Exit-Deutsche Schweiz », avec 70'000 membres. Comparant les chiffres qui précèdent, on voit que c'est une petite minorité des membres qui vont faire usage de l'option du suicide. Toutefois, les enquêtes d'opinion montrent que ces personnes sont rassurées/tranquillisées par l'idée qu'elle pourraient, si elles le veulent, prendre librement une telle décision (d'autres sondages montrent que 75% des Suisses, dans la population générale, souhaitent que soit maintenue cette liberté). Enfin, pour requérir l'assistance d'Exit, il faut en principe en avoir été membre depuis trois mois.

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PERSPECTIVES ON ASSISTED SUICIDE IN THE UK: THE DICHOTOMY BETWEEN PHYSICAL AND PSYCHOLOGICAL SUFFERING

The question of how best to respond to suicidal persons creates an ethical quandary for the medical profession and the wider public alike. For some, the

notion that suicide could ever be rational is a contradiction in terms, and the desire for death is interpreted as clear evidence of mental illness. Traditionally, preserving life rather than causing death has been the province of medicine and the permissibility of suicide within this value-structure is not easily reconciled with the healing goals of medicine. Where sympathy has been shown towards the notion of rational suicide in the UK, this has been primarily in relation to physical disease, terminal states and chronic pain. It has not been considered to be a coherent or genuine choice for those who are deemed to be suffering from mental illness.

Suicide has not been a criminal offence in the United Kingdom since 1961, when the common law felony of self-murder was repealed. However, psychiatry has maintained its position that suicidal persons often suffer from some form of disease or irrational drive towards self-destruction, which must be prevented. Therefore, although suicide is not illegal in the UK, it is still lawfully preventable where it is considered to stem from mental disorder.

Quality of life issues have increasingly been discussed in relation to rational suicide and are often linked to concepts of suffering, which are usually conceptualised as physical in nature. Quality of life arguments contend that life is only valuable in so much as it retains value for the holder. Suicide may therefore be morally permissible where quality of life has become so reduced, that the person would rather be dead than continue with a life of suffering. The suffering associated with terminal illness and physical pain has been viewed as legitimately influencing a person's desire to die. Psychological suffering is however rarely given equal weight. It is typically seen as transitory and irrational; the person's distress is only the product of current cognitive distortions, which can either be reasoned against or treated with psychotropic medication.

Public perceptions of rational suicide in the UK

There appears to be a growing trend towards a libertarian position on suicide in the UK linked to secularisation of Western values, longer life-spans and an increasing focus on individual freedom of choice. This growing trend towards a more permissive attitude is illustrated in recent attempts to legalise assisted suicide, through individual challenges to UK courts and private members' bills, by the growth of suicide tourism and by medical and philosophical literature that argues for the legalisation of voluntary euthanasia. Libertarian claims of a right to die have become gradually more insistent.

Suicide is not however always practically possible for some persons and a right to die does not include assistance to die within the UK, whatever the person's

circumstances. It has been argued by individuals who desire to die but who require assistance to do so, that the current law is essentially unjust and enforces unbearable suffering. The notion that persons have a right to die in circumstances of unendurable physical suffering has increasingly come to the fore over the last decade in Britain, with certain highly publicised cases such as Diane Pretty, (a motor-neurone sufferer who lost her legal case in the UK to prevent prosecution of her husband should he assist her suicide) and more recently, Tony Nicklinson, who was left paralysed with locked-in syndrome following a catastrophic stroke and who sought High Court authorization of a medically assisted suicide. Although these cases (and others publicised by the media) have yet to successfully change the law with regard to assisted suicide in the UK, they have galvanised public debate on the rational nature of suicide in certain circumstances of unendurable suffering. These high profile cases have challenged primacy of life claims based on moral or religious grounds and prohibitions advocated by those who fear potential abuses that may arise if certain lives are deemed not worth living by external judgements sanctioned by law. Continued media attention given to 'right to die' cases has led to discussions about quality versus sanctity of life and body ownership versus state interference, in a wider arena outside of the privileged domain of medicine. The widespread reporting of such cases has challenged the public to engage in a hitherto taboo subject and has opened up discussion into the reasonableness of terminating life in circumstances of catastrophic and irreversible physical impairment.

Despite the growing media attention and commensurate body of literature debating rational suicide in physical illness, there has however been little discussion in the public domain of the views of people with mental illness with regard to a right to die. It is possible to pick out at least three possible reasons for this omission: The first two reasons are closely linked and stem from public misconceptions about the mentally ill and a consequent reluctance on the part of mental health service-user advocates to potentially reinforce negative stereotypes of mental illness. The third reason may be attributable to a prevailing dualism in public opinion.

Mental illness remains highly stigmatised in the UK. Media reports often depict people with severe mental illness as highly likely to be unpredictable as a consequence of their mental illness. Misconceptions about the general irrationality and riskiness of people with mental illness may well have resulted in a view that the desires and actions of people with mental illness are likely to be incomprehensible to the wider public and therefore such people are best left to the care of psychiatry.

Dualistic notions of suffering have significance for the legitimacy of claims that psychological pain can be grounds for rational suicide. The idea that pain is either real (physical) or imagined (mental) is one that is widely held within public perception (and by some healthcare professionals). Mental states of chronic suffering have not generally received the same sympathies or credibility as physical conditions of suffering. Rarely has psychological suffering been seen as a reasonable inclusion for rational suicide, either because it is seen as being insubstantial and ephemeral or because it is attributed to an underlying mental illness which is remediable.

There is however arguably an essential injustice in giving greater weight to physical above psychological pain. Subjective satisfaction with quality of life is significantly affected by chronic mental illness. Quality of life studies show that serious mental illness leads to impairments in many aspects of life, including physical and cognitive functioning, mood state, social and occupational roles, and economic stability. The experience of chronic mental illness for some people may be one of repeated relapse, continuous psychiatric surveillance, unwanted intervention and stigma from without and within the psychiatric system. People may become hopeless because they despair about their future lives with mental illness. Hopelessness experienced as a result of a realistic perspective on the course, costs and consequences of living with serious mental illness would seem a reasonable response in some circumstances where treatments have proved ineffective and remission or recovery has not occurred.

What then should count as good evidence of a person's suffering and be significant to the rational suicide debate in the circumstance of mental illness? It would seem in answer that the only means of addressing the whole experience is to take a whole view of persons as unified in body and mind. As such, internal mental phenomena must given equal weight as physical properties. Since subjective experience is by nature internal and individual, this can only be known fully to the person and only revealed through the person's narrative.

Should some persons with mental illness then be included in the class of cases in which rational suicide is a justifiable option? The only persons however who can give good reasons for suicide in this context are those who experience mental illness. There are no lives that can be judged not worth living by objectively discernible criteria, only persons who judge their suffering as not worthwhile.

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TRANSNATIONAL ISSUES OF ASSISTED DYING

As a Swiss philosopher now working as a bioethicist at a North German medical school and as a frequent visitor to the UK, I see a multitude of ethical issues in the transnational dimension of assisted dying. Some issues are worrying even to those whose attitude to assisted dying is otherwise liberal. People who cannot get assistance to die at home see themselves compelled to travel to Switzerland to end their days there with the assistance of one of the organizations, such as *Dignitas*, whose *raison d'être* is to assist the suicides of both nationals and visitors from abroad. We need more views from non-Swiss countries on the ethics of the practices of *transnational assisted dying* (TAD), including their governance.⁴² Not all of these issues might be visible within the Swiss domestic perspective to which I was devoted, when a few years ago I was chairing the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE).

According to the statistics published by *Dignitas*, the yearly number of suicides facilitated for non Swiss residents, since the first single foreign person from Germany died with *Dignitas* in 1999, has continually increased to 197 persons in the year 2013. Applicants came mainly from Germany (840 in total over the years), the UK (244), France (159), and Italy (69) but also from other European countries and even from overseas.⁴³ At present two other Swiss organizations offer assisted suicides for non-residents (*Ex International* and *Eternal Spirit*), one of them recently established, who however did not publish numbers. The phenomenon of TAD in Switzerland is expanding. There are internationally active organizations who support a right to die as a human right under Art. 8 ECHR (such as *Dignitas* itself) or, on the other side, who protect and defend the sanctity of life (such as the *Alliance Defending Freedom*). Therefore TAD is not only to be seen as a "Swiss" issue. Obviously, more questions need to be discussed than the question of whether to allow or to ban certain practices at the end of life in one country, if applicants arrive from another. What is salient for the individuals and for their families who live in situations when a patient travels to Switzerland? What moral considerations are helpful to

⁴² Instead of the derogatory term "suicide tourism" I prefer the neutral "transnational assisted dying".

⁴³ See the statistics sheet at: <http://dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2013.pdf>

clarify the issues? How should the terms and conditions be set, and how should the procedures be monitored and improved? How should countries collaborate?

For obvious reasons, Switzerland has a special responsibility for developing, implementing and overseeing internationally fair procedures, since (i) it is the only country that allows organizations (not only physicians and individuals) to provide assisted death, (ii) Switzerland has no legal restrictions that exclude non-residents, (iii) most other countries are much more restrictive, and therefore (iv) the numbers of those travelling to Switzerland with the sole purpose to die has been constantly increasing. Recently, in *Gross v Switzerland [2013]*, the European Court of Human Rights has decided that Switzerland must issue clear guidance detailing the circumstances under which physicians may prescribe lethal drugs to individuals who have a well-settled wish to die.⁴⁴ In some other morally controversial biomedical practices banned on one country, the possibility to travel to another European country where the practice is tolerated might be an acceptable way around developing properly permissive domestic legislation – at least for the time being – if only a very few individuals are concerned. I ask myself whether this is also the case for dying.

One can make the obvious argument in favour of harmonization of differing legalizations, in one way or the other. I am however not so convinced that this is really a way forward, since there are important cultural differences that play a role and lead to different moral assessments at different places. And one can make a very strong argument in favor of allowing for ways of assisted dying that are acceptable in the country where the patient lives. If going to a foreign country to die becomes an explicitly tolerated practice it may look like “outsourcing” what would be disturbing at home.⁴⁵

But I think that we need to know more about the circumstances of those individuals and families who opt for TAD. What are their own ethical considerations? What are their needs? They cannot die at home; their loved-ones might not all be able to be present. And they might be forced to act prematurely, as long as they are still able to travel. What are the locally available alternatives and why do they reject them?

As also the ECHR ruling clearly indicates, Switzerland needs to improve its legal oversight of organized assistance to suicide, both for residents and for non-

⁴⁴ *Gross v Switzerland [2013]* ECHR 67810/10. See the discussion of the case by Isra Black: Existential Suffering and the Extent of the Right to Physician-Assisted Suicide in Switzerland. *Medical Law Review* 22 (2014): 109-118.

⁴⁵ We have made that point in: Christoph Rehmann-Sutter, Lynn Hagger: Organised Assistance to Suicide in England? *Health Care Analysis* 19 (2011): 85-104.

residents. In several years of work, the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) has produced an elaborated and well-balanced policy proposal, which would clarify what is lawful in the practice of right-to-die organizations who offer suicide assistance under the rather terse ruling of Art. 115 of the Swiss penal law, which excludes assistance to suicide only if it is done for selfish motives. Both this law (unintentionally) and the NEK-CNE policy proposal (intentionally) would apply also to non-Swiss residents. The latter proposal would allow assistance to suicide if it abides by duty-of-care criteria in the process of evaluation of the assistance-to-die requests.⁴⁶ It would not establish a right to an assisted death but a right to be treated fairly in the application procedure. For several – purely domestic – political reasons no regulation that would complement the Art. 115 has yet been implemented.

I therefore propose to take a second look both at the issues and at that proposal. And we also need a discussion about the different circumstances of TAD in the different “sender” countries.

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PHYSICIAN ASSISTED SUICIDE:

The present situation in Germany – The evolution of a pragmatic and evidence-based approach

As in most other Western countries, the *public* debate in Germany on physician-assisted suicide is subject to considerable controversy. Contrary to often held beliefs however, assisted suicide in German law is *not* illegal. Therefore, it is in principle *not* subject to criminal prosecution or other legal sanctions.

The German Chamber of Physicians (Deutsche Bundesärztekammer, BÄK) in 2011 issued revised recommendations, aiming to outlaw the active participation of *doctors* in assisted suicide^{47 48}. Such

⁴⁶ Swiss National Advisory Commission on Biomedical Ethics: Opinions Nr. 9 (2005) and 13 (2006). Available on www.nek-cne.ch (also in English).

⁴⁷ Deutsche Bundesärztekammer (Edit.), Grundsätze der Bundesärztekammer zur ärztlichen Sterbebegleitung, *Deutsches Ärzteblatt* 2011: 346ff.

⁴⁸ Deutsche Bundesärztekammer (Edit.), (Muster)Berufssordnung für die in Deutschland tätigen Ärztinnen und Ärzte ... in der Fassung

professional regulations however, are only “subsidiary” and subservient to the common / general law. In practice the BÄK-recommendation on (physician) assisted suicide is therefore largely irrelevant: It is not legally binding and cannot be enforced. Consequently, more than half of the *regional* chambers of physicians in the German Federation (Landesärztekammern, LÄKs), which are actually responsible, refrained to (fully) adopt or implement the BÄK-recommendation. Not a single chamber since tried to actively enforce it. This remarkable, still somewhat contradictory situation is based on a growing acknowledgement among the health-care professions and the wider public in Germany of the complex and often “sobering” facts behind this phenomenon^{49 50}. There seems to be a gradually increasing consensus and commitment that these need to be addressed in a pragmatic, un-ideological and pluralistic way:

- Despite best palliative care, two-digit percentages of all dying patients suffer distressing symptoms, which cannot be sufficiently controlled.
- The prevalence of palliative care patients, who ultimately require and receive “terminal sedation” (which has a significant “overlap” with “assisted dying”) is about the same.
- The numbers of patients, who - even in such “specialized” settings - ultimately request and receive some form of having their life actively and “prematurely” ended, is in a low one-digit percent-range (~1 - 3%).
- It is plausible that across the wider population, notably among the elderly, the chronically ill and the severely disabled, similar (and probably even higher) prevalence and severities of morbidity and “premature” deaths apply:
 - It can therefore be safely assumed that somewhere between above 1 % and up to 3% of all severely ill and (pre)terminal patients ultimately decide

der Beschlüsse des 114. Deutscher Ärztetages in Kiel, Deutsches Ärzteblatt 2011, S. 1980 ff.

⁴⁹ Strätling Meinolfus W., Assistierter Suizid – Grundsätzlich „keine ärztliche Aufgabe“ ? Medizinrecht - MedR (2012) 30: 283 -289. [Assisted Suicide and doctors’ duties – incompatible ? MedR – German Journal of Medical Jurisprudence 30: 283 -289].

⁵⁰ Strätling Meinolfus W., Gesundheitsökonomische Aspekte bei Entscheidungen am Lebensende, Mythos Palliativmedizin, Klinische „Ethikberatung“ und Behandlungsbegrenzung bei schweren Gehirnschädigungen – Kritische Hinweise zu vier medizinischen und ethischen Kernaussagen der Deutschen Bundesärztekammer zur ärztlichen Sterbebegleitung, Medizinrecht - MedR (2012) 30: 428 - 436. [Resource Allocation and End-of-Life Decision Making, “Myths” surrounding Palliative Care, Clinical “Ethics Consultation” and withdrawing and withholding treatment in severe brain damage – A critique of four medical and ethical core-recommendations of the German Chamber of Physicians on End of Life Care. MedR – German Journal of Medical Jurisprudence 30: 428 – 436].

to end their lives, suffering or “bad deaths”.

- They probably also often receive consensual assistance.
- These findings also correlate with all the other evidence available on a wide range of related or similar practices and phenomena of “end-of-life decision-making” [e.g. “euthanasia”; general epidemiology, etiology and phenomenology of suicide; coroner’s data on unclear / “unnatural” deaths; “overlaps” with accepted forms of medical end-of-life decisions (e.g. withholding / withdrawing futile treatment, palliative sedation etc.)].
- Consequently, the phenomenon is apparently a “baseline phenomenon”: It (already) is very much within the “empirically normal spread” of human deaths and end-of-life decisions.
- Applying historic and trans-cultural comparisons, it probably always was.
- The influences of cultural or legal aspects are overestimated: With the exception of strong religious beliefs, significant interactions between end-of-life choices and general socio-cultural backgrounds, economic conditions or historic traditions can usually not be proven.
- In most European countries “assisted suicide” apparently either isn’t illegal, or is “tacitly tolerated” and not prosecuted. In the UK, for example, assisted suicide is presently illegal. In most cases, however, its prosecution is not deemed as in the “public interest”⁵¹ [5]. There is no comparative evidence to suggest that such differences in legislation have any significant (practical or empirical) implications, either on the field of health care, or of legal administration.
- A “slippery slope”, leading to problematic increases of the relevant practices, or even their abuse, has never materialized.
- The philosophical, ethical and political debate is consistently “pluralistic”: Both, promoting and maintaining good care as (hopefully) an alternative in many cases, and the demand of “freedom of choice”, notably in the event of otherwise un-controllable suffering and loss of dignity, are supported.
- Forcing doctors or carers to abandon patients, who for understandable reasons contemplate suicide, can hardly be deemed “ethical”, or in the “public interest”: There is convincing

⁵¹ Director of Public Prosecutions (Edit.), [Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide](http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html) (February 2010): http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html.

casuistic evidence to suggest that many patients may otherwise subject themselves and others to considerable, additional, tragic and preventable suffering (“collateral damage”, e.g. by “amateur” or particularly violent techniques, or by seeking “shadowy” or “semi-professional” assistants).

- Politically, in all Western societies there are broad majorities among the public in favor of allowing and facilitating, or at least of tolerating end-of-life choices. For a multitude of reasons, this consensus most notably applies to “assisted suicide”. The phenomenon therefore is clearly nothing “militant”, but politically entirely “mainstream”, pragmatic and based on a very broad, pluralistic consensus.
- Among “vulnerable groups” the majority actually perceive the option of assisted suicide not as a “threat”, but as a reassuring alternative in case their situation should become unbearable. They do not perceive the position of doctors as in any significant way compromised. Unsurprisingly therefore, only about 1:10 of all documented initial requests for ending lives prematurely are eventually followed through.
- Among doctors usually more than a third would be happy to make themselves available for assistance. A broad majority would be comfortable with tolerating the practice.
- All legislation proposed or implemented so far has guaranteed the right of individual doctors and carers to conscientiously object to participate.

Conclusions:

There is objectively not much – if anything – to be “prevented”. The problem cannot be ignored: In all European Countries it affects thousands of individuals every year. There is convincing evidence for improvements on all levels, once differentiated procedures are put in place, which acknowledge realities and pluralistic attitudes within a liberal legal framework. From an ethical perspective the health-care professions should responsibly and constructively lead on working together to “pave” the way forward. We do need to sensibly and urgently address and settle the issues arising and pacify the debate. To this aim the evolution of the situation in Germany holds many lessons, which may also be of international interest.

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Dr. M. “Wulf“ M Stratling is a senior doctor and clinical ethicist, based in Cardiff. The “condensed” scientific survey presented here has recently been published in Germany. Its’ findings are by and large also applicable to the situation throughout Europe, including the UK.

DEADLINE NEXT NEWSLETTER

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