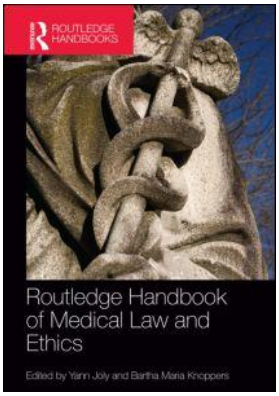

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End of life

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End of life

Chris Gastmans and Herman Nys

8.1 Introduction

Treatment decisions at the end of life are common in contemporary clinical practice. According to Broeckaert and the Flemish Palliative Care Federation (2009), treatment decisions at the end of life, in principle, can be grouped into three categories. The first group encompasses decisions whether to initiate or withhold, continue or withdraw curative or life-sustaining treatments (e.g. cardiopulmonary resuscitation, artificial ventilation, dialysis, artificial nutrition and hydration). In this group, non-treatment decisions refer to 'withdrawing or withholding a curative or life-sustaining treatment, because in the given situation this treatment is deemed to be no longer meaningful or effective' (Broeckaert and the Flemish Palliative Care Federation 2009: 30–2). According to the British Medical Association (2007), treatment is usually unable to produce the desired benefit either because it cannot achieve its physiological aim or because the burdens of the treatment are considered to outweigh the benefits for the particular individual. This is called 'futile' treatment. Refusal of treatment occurs when the patient requests curative or life-sustaining treatment to be withdrawn or withheld.

The second group of treatment decisions according to Broeckaert and the Flemish Palliative Care Federation's (2009) conceptual framework refers to decisions made to alleviate pain and other symptoms with, for example, opioids, benzodiazepines or barbiturates. In this group, the focus of the decisions shifts from a curative and life-sustaining approach to a palliative approach. Pain control refers to 'the intentional administration of analgesics and/or other drugs in dosages and combinations required to adequately relieve pain' (Broeckaert and the Flemish Palliative Care Federation 2009: 32–3). A specific form of pain control is palliative sedation, 'the intentional administration of sedative drugs in dosages and combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms' (Broeckaert 2002: 246).

The third group of treatment decisions at the end of life addresses the use of lethal medication. Voluntary euthanasia is defined in the Netherlands, Belgium and Luxembourg – three countries where euthanasia is legalised – as the intentional termination of a patient's life by someone other than the patient, at the patient's request. Assisted suicide is 'intentionally assisting

a person, at this person's request, to terminate his or her life' (Broeckaert and the Flemish Palliative Care Federation 2009: 34–5). Non-voluntary euthanasia involves someone intentionally terminating the life of a patient, but not at the patient's request.

Thus the complex decision-making surrounding the end of life cannot be considered purely clinical; rather it also has an ethical dimension. Treatment decisions are also influenced by the legal context of a particular country (e.g. the *Patient Self-determination Act* (1991) in the US, the legalisation of euthanasia in the Netherlands, Belgium and Luxembourg) (Lewy 2011) and by the country's cultural values (Cohen *et al.* 2013; Gysels *et al.* 2012).

In this chapter, we provide a selected overview of legal and ethical frameworks that address some of the above-mentioned treatment decisions at the end of life. First, we give an overview of legal approaches to end-of-life treatment decisions from an international perspective. Second, we illustrate two major ethical approaches – principlism and care ethics – through a case analysis of euthanasia for patients with advanced dementia. This section centres on the topic of advance euthanasia directives in order to make our ethical evaluation more concrete. We conclude this chapter with an overview of some current and emerging ethical and legal issues in end-of-life care.

8.2 Legal frameworks on treatment decisions at the end of life: an international perspective

There exist no legally binding international rules dealing specifically with treatment decisions at the end of life. This is not surprising, as the legal context of a particular country influences, more than any other medical decision, treatment decisions at the end of life (see section 8.1). Therefore we will discuss the treatment decisions at the end of life within the framework of international human rights law and – given our background – especially, but not limited to, European human rights law. The *European Convention on Human Rights* (ECHR) 1950 of the Council of Europe and the jurisprudence of the European Court of Human Rights (ECtHR) are inexhaustible sources of information and inspiration regarding health and human rights law (Hendriks 2012). Crucial human rights regarding treatment decisions at the end of life are the right to life, the right to be safeguarded from inhuman or degrading treatment and the right to protection of one's private life (Dorscheidt 2012).

8.2.1 The right to life

The *Universal Declaration of Human Rights* 1948 (UDHR) confirmed the protection of all human life as a basic rule in response to the atrocities committed before and during the Second World War. Article 3 of the UDHR stipulates that '[e]veryone has the right to life, liberty and security of persons'. The *International Covenant on Civil and Political Rights* 1966 later adopted a legally binding equivalent of this provision. Article 6(1) of this *Covenant* states that '[e]very human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.' The rhetoric used in this article expresses that the right to life is the most essential human right. Because this provision does not refer to medical decisions at the end of life, it remains unclear how such decisions relate to article 6(1) of the *Covenant*. According to Dorscheidt (2012), at issue is whether it is possible to waive the right to life. Dinstein (1981) sees possibilities for legislation on euthanasia only if it provides guarantees for an authentic request to die, as well as the specific way in which the patient can admissibly abandon his right to life.

From a European perspective, the right to life is laid down in article 2 of the ECHR:

> Everyone's right to life shall be protected by law. Nobody shall be deprived of his life intentionally save in the execution of a court's sentence following his conviction of a crime for which this penalty is provided by law.

During the drafting process, it was not foreseen that the interpretation of this article would relate to treatment decisions at the end of life. Indeed, for many years, the jurisprudence of the ECtHR offered no indication that any such interpretation would arise. However, this has changed in the last decade. In the case of *Glass* v. *The United Kingdom* (Application No. 61827/00) [2004] ECHR 102 (*Glass*), a mother filed *inter alia* a complaint under article 2 of the ECHR against the Portsmouth Hospitals National Health Service Trust and its physicians. She alleged they put her ill son's life at risk by administering to him an adult dose of a sedative and pain relief medication (diamorphine) and that they placed a DNR order in his medical file without her consent or knowledge. The ECtHR did not deny that the acts and omissions of healthcare professionals in certain circumstances may engage states parties' responsibilities under the ECHR (para. 71). However, if a state party has made adequate provisions to secure high professional standards for healthcare workers and to protect the lives of patients, matters of error of professional judgment (even if established) in treating a patient are not sufficient in themselves to call that state to account for its obligation under article 2 of the ECHR to protect life. Ultimately, the ECtHR found this complaint ill-founded, and therefore inadmissible.

The judgment in *Pretty* v. *The United Kingdom* (Application No. 2346/02) [2002] ECHR 427 (*Pretty*) was the first explicit ruling of the ECtHR on the relationship between deliberate ending of life at request and article 2 of the ECHR. Diane Pretty suffered from motor neurone disease (MND), a progressive neurodegenerative disorder of the motoric cells of the central nervous system. In time, a patient with MND will experience severe breathing difficulties, eventually resulting in death by suffocation. To prevent serious deterioration, Pretty wanted to end her life in a humane and dignified way. Due to her poor physical condition, she was unable to end her life alone and wanted to enlist her husband's help in ending her suffering. However, assisted suicide is a criminal offence in the UK. Pretty therefore requested the Director of Public Prosecutions to declare that her husband would not be prosecuted if he helped her to die. This request was denied. An appeal to the Divisional Court and later to the House of Lords did not succeed either. Finally she presented her case to the ECtHR, where she argued that the British judicial authorities' refusal to grant her husband immunity from prosecution constituted a violation of, among others, article 2 of the ECHR. According to Mrs Pretty, article 2 not only protected the right to life, but also guaranteed the right to choose whether or not to continue living. Pretty was convinced that the article included the right to die in order to prevent unbearable suffering and indignity.

From the point of view of the ECtHR, article 2 leaves no room for doubt:

> Article 2 cannot, without distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die; nor can it create a right to self-determination in the sense of conferring on an individual an entitlement to choose death rather than life. The Court accordingly finds that no right to die, whether at the hands of a third person or with the assistance of a public authority, can be derived from article 2 of the Convention.
>
> *(*Pretty, *paras 39–40)*

Although in some countries assisted suicide is not punishable in specific circumstances, article 2 of the ECHR holds no obligation for the UK to accept a similar criminal regime regarding such conduct. It is considered to fall under a state party's 'margin of appreciation' to address such an act in a way that corresponds with national criminal law, and having regard to the state's responsibilities under the ECHR. Consequently, the ECtHR concluded there was no violation of article 2.

8.2.2 Treatment decisions at the end of life and freedom from inhuman or degrading treatment

The issue at stake is whether the fundamental right to protection against inhuman or degrading treatment plays a role in establishing the legal admissibility of treatment decisions at the end of life, as stated in article 7 of the *International Covenant on Civil and Political Rights* and article 3 of the ECHR. Can the state be held responsible for an individual's suffering due to his state of health, or even a continuation of life-sustaining treatment? In *Pretty,* the applicant further argued that her suffering constituted degrading treatment within the meaning of article 3 of the ECHR. Although she admitted that the state bore no direct responsibility for this treatment, she argued the state must not only refrain from such treatment, but also has a duty to protect its civilians against it. Therefore the UK would be obliged to take measures to protect her against further suffering.

However, the ECtHR concluded that article 3 was not violated. The refusal of the UK authorities to grant Pretty's husband immunity from prosecution was not equal to inhuman or degrading treatment for which the state bears responsibility for failing to protect Pretty from the suffering she must face. The ECtHR was unwilling to force the UK to permit actions that end life. No such positive obligation for a state can be derived from article 3 of the ECHR, no more than can a duty for the UK to declare that Pretty's husband will not be prosecuted if he assisted his wife in ending her life.

8.2.3 Treatment decisions at the end of life and the right to privacy

According to article 8(1) of the ECHR, '[e]veryone has the right to respect for his private and family life, his home and his correspondence'. The right to respect for his private life is especially important with regard to treatment decisions at the end of life.

First, the right to respect for private life underpins the right to give or refuse consent for any medical treatment, including at the end of life. In *Glass,* the ECtHR held that the decision to impose medical treatment on a critically ill 12-year-old boy in defiance of his mother's objections interfered with the child's right to respect for his private life, particularly his right to physical integrity. Such interference is generally admissible only if it occurs after free, expressed and informed consent. The Court observed that the boy's mother had clearly withdrawn her consent while the physicians should have respected her change of mind and refrained from intensively attempting to overcome her opposition. As a result, the ECtHR concluded the authorities' decision to override the mother's objection to the proposed treatment, in absence of a court authorisation, resulted in a breach of article 8 of the ECHR. Moreover, in *Pretty*, the ECtHR stated that the very essence of the ECHR is respect for human dignity and human freedom. Without in any way negating the principle of sanctity of life protected under the ECHR, the ECtHR considered that it was under article 8 that notions of the quality of life took on significance.

In an era of growing medical sophistication combined with longer life expectancies, many people feel they should not be forced to linger on in old age or in states of advanced physical

or mental decrepitude, which may conflict with strongly held ideas of personal identity. The ECtHR regards the freedom to refuse medical treatment, even if it concerns potentially life-saving medical treatment, vital to the principles of self-determination and personal autonomy articulated in *Jehovah's Witnesses of Moscow and Others* v. *Russia* (Application No. 302/02) 10 June 2010 (para. 135). After *Pretty*, the ECtHR repeated this point of view in several other judgments, the most recent being in *Gross* v. *Switzerland* (Application No. 67810/10) [2013] ECHR 429 (*Gross*). In *Gross,* the ECtHR held that a competent adult patient has the right to make choices according to his own view and values, regardless of how irrational, unwise or imprudent such choices may appear to others. Therefore the state must refrain from interfering with individual freedom of choice in the sphere of healthcare, for such interference would only lessen, rather than enhance, the value of life. The ECtHR clearly sympathises with the view that a person's authentic decision to end his life is part of his private life, as observed by Dorscheidt (2012).

Second, the right to private life is relevant to assisted suicide. In the *Pretty* case, the applicant, Diane Pretty, also relied on article 8 (1) of the ECHR and her right to self-determination. Pretty argued that the Director of Public Prosecutions' refusal to grant her husband the requested immunity, as well as the British ban on assisted suicide, constituted violations of her right to privacy and freedom to prevent her life from ending in an undignified way. However, the ECtHR dismissed Pretty's application based on article 8(1) of the ECHR. The ECtHR did not want to affirm that Pretty's situation was indeed an infringement of her private life. Rather, it held that the right to privacy is not absolute. In the ECtHR's view, the UK is permitted to create criminal law regulations, regulating behaviour which endangers people's lives or safety. The greater the danger, the more the idea of personal autonomy must be considered inferior to the interest of public health or public safety. Regardless of the circumstances that befall the terminally ill, their vulnerability justifies the criminalisation of assisted suicide in the UK. Therefore the ECtHR concluded that the criminalisation of assisted suicide in the UK serves a legitimate purpose and constituted a necessary interference with Pretty's right to privacy based on article 8(2) of the ECHR.

Another case on assisted suicide decided by the ECtHR is *Koch* v. *Germany* (Application No. 497/09) 19 July 2012. Mrs Koch suffered from total sensorimotor quadriplegia after falling in front of her doorstep. She was almost completely paralysed and needed artificial ventilation, constant care and assistance from nursing staff. She further suffered from spasms. However, according to her medical assessment, she had a life expectancy of at least fifteen more years. Nonetheless, she wished to end what was, in her view, an undignified life, by committing suicide with her husband's, the applicant, help. She requested the Federal Institute for Drugs and Medical Devices authorise her to obtain 15 grams of pentobarbital of sodium, a lethal dose of medication that would enable her to commit suicide at her home. The Federal Institute refused to grant her authorisation, relying on section 5(1)(6) of the German *Narcotics Act*. Consequently, together with her husband, she travelled to Switzerland where she died after committing assisted suicide with the help of a Swiss assisted-suicide organization. Her husband applied to the ECtHR claiming the refusal to provide his late wife with a lethal dose of drugs allowing her to end her life violated both their right to respect for private and family life. Relying on its case law, the ECtHR concluded the Federal Institute's decision to reject Mrs Koch's request did interfere with the applicant's right to respect for his private life under article 8 of the ECHR (para. 54). However, the state's decision ultimately fell within its margin of appreciation. Relying on comparative research, the ECtHR found that the majority of member states do not allow any form of assistance to suicide (para. 70). Only four states have allowed medical practitioners to prescribe a lethal drug to enable a

patient to end his life. It follows that the states parties to the ECHR are far from reaching a consensus on the issue. Consequently, states enjoy a considerable margin of appreciation in this context.

Third, article 8 of the ECHR is relevant in determining the legal requirements for obtaining medication to end one's own life (suicide), as demonstrated by *Gross* and *Haas* v. *Switzerland* (Application No. 31322/07) 20 January 2011 (*Haas*). For approximately twenty years, Haas suffered from a severe bipolar affective disorder. As a result of his condition, Haas felt he could no longer live in a dignified manner and attempted suicide twice. Subsequently, he decided to obtain sodium pentobarbital (SPB), a substance that would enable him to end his life safely and with dignity. Since the substance was only available through prescription, he unsuccessfully approached several psychiatrists to obtain a prescription. Later, he approached various federal and cantonal authorities (Federal Departments of Justice and Public Health and the Department of Health of the Canton of Zurich), seeking permission to obtain SPB from a pharmacy without a prescription. The Federal Department of the Interior and the Zurich Administrative Court rejected both his application and appeal. Haas finally appealed to the Federal Court, but his action failed. Before the ECtHR, Haas complained about the conditions to obtaining SPB, specifically a medical prescription based on a psychiatric assessment. Relying on article 8 of the ECHR, he alleged that since those conditions could not be met in his case, the right to which he considered himself entitled to, namely choosing the time and manner of his death, was not respected. He submitted that, in an exceptional situation such as his, the state ought to guarantee his access to the necessary medical products for suicide. In light of its case law, the ECtHR considered that an individual's right to decide by what means and at what point his life will end – provided he is capable of freely reaching a decision on the question and acting in consequence – is one aspect of the right to respect for private life within the meaning of article 8 of the ECHR.

According to the ECtHR, the issue was whether, under article 8, the state must ensure that the applicant can obtain a lethal substance without a medical prescription in order to commit suicide painlessly, by way of derogation from the legislation (*Haas,* para. 52). Although the ECtHR was sympathetic to Haas' wish to commit suicide in a safe and dignified manner without unnecessary pain and suffering, it nevertheless believed Swiss regulations, specifically the requirement to obtain a medical prescription, pursued the legitimate aims of protecting individuals from hasty decisions and preventing abuse. In particular, the ECtHR supported regulations ensuring that a patient lacking discernment does not obtain a lethal dose of SPB.

The ECtHR went on to consider such regulations all the more necessary in a jurisdiction such as Switzerland, where legislation and practice allow for relatively easy access to assisted suicide (*Haas,* para. 57). Therefore, where a country adopts a liberal approach in this respect, implementing preventive measures to counteract abuse is necessary. The introduction of such measures is also intended to prevent organizations providing suicide assistance from acting unlawfully, in secret and with significant risks of abuse. Therefore the ECtHR concluded that even assuming states have a positive obligation to facilitate suicide with dignity, the Swiss authorities complied with their obligation in the present case (*Haas*, para. 61). Hence there was no violation of article 8 of the ECHR.

Similarly, *Gross* also dealt with article 8 of the ECHR and the accessibility of SPB as a means of putting an end to one's life in their own dignified way. For many years, Gross expressed her wish to end her life. She explained she was becoming increasingly frail as time passed and was unwilling to continue suffering the decline of her physical and mental faculties. In 2005, following a failed suicide attempt, she received inpatient treatment for six months in a psychiatric hospital. This treatment did not alter her wish to die. Therefore she contacted an assisted death

organization, EXIT, for support. However, she was informed that it would be difficult to find a medical practitioner who would be willing to provide her with a medical prescription for the lethal drug.

Upon examining Gross, one psychiatrist was convinced she was able to form her own judgment. He further noted that her wish to die was reasoned and well-considered, had persisted for several years and was not based on any psychiatric illness. From a clinical point of view, the psychiatrist did not object to prescribing Gross a lethal dose of SPB. However, he refrained from issuing the prescription himself: he did not want to confuse the roles of medical expert and treating physician. Afterwards, a physician stated that she would be ready to examine Gross and to consider her request to issue the required prescription, provided that her counsel could guarantee that she would not risk any consequences from the point of view of the code of professional medical conduct. When her counsel replied that he could not give such a guarantee, the physician declined the request, as she did not want to be drawn into lengthy legal proceedings.

Gross then submitted a request to the Health Board of the Canton of Zurich for 15 grams of SPB in order to commit suicide. She submitted that she could not reasonably be expected to continue her search for a physician who was ready to issue the required medical prescription. The Health Board refused her request and all of her subsequent appeals against this decision failed. Before the ECtHR, Gross argued that by depriving her of a lethal dose of sodium pentobarbital, the Swiss authorities violated her right to decide by what means and at what point her life would end. Once again, referring to its case law, the ECtHR considered that Gross' wish to be provided with the lethal dose indeed fell within the scope of her right to respect for her private life under article 8 of the ECHR (para. 60). However, the ECtHR identified a significant difference with the *Haas* case. In the former case, the ECtHR considered that it was appropriate to examine Haas' request to obtain access to sodium pentobarbital without a medical prescription from the perspective of a positive obligation on the state to take the necessary measures to permit a dignified suicide. Inversely, the *Gross* case raised the question of whether the state had failed to provide sufficient guidelines defining if and, in the case of the affirmative, under which circumstances medical practitioners were authorised to issue a medical prescription to a person in Mrs Gross' condition (para. 63).

The ECtHR observed that pursuant to article 115 of the Swiss *Criminal Code* 1937, inciting and assisting suicide are punishable only where the perpetrator of such acts is driven to commit them by 'selfish motives'. Under the case law of the Swiss Federal Supreme Court, a doctor is entitled to prescribe SPB in order to allow his patient to commit suicide, provided that conditions outlined in the Federal Supreme Court's case law are fulfilled. The ECtHR noted that the Federal Supreme Court referred to the medical ethics guidelines on the care of patients at the end of their life, which were issued by a non-governmental organization and did not have the formal quality of law. However, the ECtHR observed that these guidelines only apply to patients whose doctor determined that their death was imminent. Because Gross was not suffering from a terminal illness, her case did not fall within this scope. Moreover, the Swiss government did not rely on any other principles or standards in outlining under what circumstances a doctor is entitled to prescribe SPB for a patient who, like Gross, was not suffering from a terminal illness. Therefore the ECtHR considered the paucity in clear legal guidelines would likely have a chilling effect on doctors who would otherwise be inclined to provide someone like Mrs Gross with the requested medical prescription. Two doctors previously consulted by the applicant had confirmed this prediction – both declined the applicant's request on the grounds that they felt the medical

practitioners' code of conduct prevented them from prescribing the drug, fearing possible professional consequences as a result of lengthy judicial proceedings. Had there been state-approved guidelines defining when it was permissible for doctors to prescribe lethal doses for assisted suicide, Gross, and patients like her, would have been spared a state of anguish and uncertainty (para. 66).

The ECtHR sympathised with Mrs Gross, acknowledging the anguish she must have endured waiting for a decision allowing her request. At issue was under what circumstances medical practitioners were justified in issuing the requested prescription in cases where an individual has come to a serious decision, in the exercise of their free will, to end his or her life, but where death would not otherwise be imminent as a result of a specific medical condition. The ECtHR concluded that Swiss law, while providing for the possibility of obtaining a lethal dose of sodium pentobarbital with a medical prescription, did not provide sufficient and clear guidelines as to the extent of this possibility, which violated the applicant's right under article 8 of the ECHR.

The four to three decision in this case demonstrates the lack of consensus among the judges of the ECtHR on this matter.

Finally, the right to respect for family life protected by article 8 of the ECHR may also be relevant when treatment decisions at the end of life are taken, as demonstrated by *Lind* v. *Russia* (Application No. 25664/05) 6 December 2007 (*Lind*). In *Lind,* the Applicant, a Russian prisoner, complained that he was not allowed to visit or say goodbye to his dying father because the Russian authorities had denied his multiple requests and appeals to be released. The ECtHR had already affirmed that the refusal of leave to visit an ailing relative or to attend a relative's funeral constituted an interference with the right to respect for family life (*Ploski* v. *Poland* (Application No. 26761/95) 12 November 200 cited in *Lind*, para. 92). However, article 8 of the ECHR does not give a detained person an unconditional right to leave to visit a sick relative or attend a relative's funeral: domestic authorities must assess each request based on its own merits (*Lind*, para. 94).

In *Lind*, the applicant's father was dying of cancer in The Hague, and had requested euthanasia, which was scheduled for 29 September 2005. This was the distinguishing feature of this case: the date of the applicant's father's death was known in advance and he was to die within a matter of days. Therefore it was truly the applicant's last opportunity to see his father. Moreover, given the applicant's father's grave condition, it was unrealistic to expect him to visit his son in detention. Taking into account these exceptional circumstances and the humanitarian considerations involved, the ECtHR believed the domestic authorities should have examined the applicant's request for release with particular attention and scrutiny. However, the ECtHR considered the domestic authorities better placed to assess the matter. Consequently, the ECtHR was unable to find that, in refusing to release the applicant, the domestic authorities exceeded their margin of appreciation (*Lind*, para. 97). Nonetheless, respect for his family life required that, once his application for release had been rejected, the applicant be provided with an alternative opportunity to bid farewell to his dying father, opportunity he was given by being allowed to talk on the phone to his father. However, the conversation had to be in Russian, lasted a minute and was interrupted by the facility administration without any explanation from the government. The ECtHR considered that this one minute conversation in a language which the applicant's father had difficulty understanding did not provide a meaningful opportunity for the applicant to bid farewell to his dying father (*Lind*, para. 98). For these reasons, the ECtHR concluded that the domestic authorities had failed to secure respect for the applicant's family life as required by article 8 ECHR.

8.3 Ethical approaches to end-of-life care: euthanasia for patients with advanced dementia as a case study[1]

Since 2002, euthanasia within a number of patient categories has been legalised in Belgium and the Netherlands, provided that strict due care criteria are applied. Section 2 of the *Belgian Act on Euthanasia* 2002 defines euthanasia as 'intentionally terminating life by someone other than the person concerned, at the latter's request' (Nys 2002: 182). This definition is commonly known as the 'Dutch definition' of euthanasia. Ironically, the Dutch Act on euthanasia, the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* 2002, does not contain this definition and the word 'euthanasia' is not even mentioned in the text of the Act. The Act always refers to 'termination of life on request', without defining the notion. Since termination of life on request coincides with what is labelled as euthanasia in the *Belgian Act*, both Acts have the same field of application. The *Belgian Act on Euthanasia* does not allow euthanising persons with severe dementia as decreed in an advance euthanasia directive. However, bills to extend to this possibility have unsuccessfully been presented to the Belgian parliament.

By contrast, in the Netherlands, euthanasia of persons with severe dementia, as decreed in an advance euthanasia directive, is allowed by law (*Termination of Life on Request and Assistance with Suicide (Review Procedures) Act*). The implementation of euthanasia in this patient population, however, is under discussion (Sheldon 2011). To our knowledge, no official documents on the ethics of euthanasia for patients with dementia exist. Despite this, some empirical (Rurup *et al.* 2005; Rurup *et al.* 2006a; Rurup *et al.* 2006b; De Boer *et al.* 2010a; De Boer *et al.* 2010b; De Boer *et al.* 2011) and philosophical (Hertogh *et al.* 2007; Gastmans and De Lepeleire 2010; Draper *et al.* 2010; Gastmans and Denier 2010; Sharp 2012; Gastmans 2013; Den Hartogh 2013; Nys 2013) studies on the issue have been conducted. The topic of advance euthanasia directives for patients with dementia enables us to present two influential ethical approaches to end-of-life care: the principles-oriented autonomy approach that generally favours the use of advance euthanasia directives on the one hand, and the care-oriented relational approach that mostly criticises advance euthanasia directives on the other hand.

8.3.1 Principles-oriented autonomy approach

Today's elderly generation regards the prospect of progressing dementia in their own way. The elderly often associate dignity with autonomy, independence and preserving one's intellectual powers (Woolhead *et al.* 2004). Some individuals believe that the fear of losing one's intellectual capacities, and the risk of being handed over to the will of others when one becomes incompetent, are notable reasons for requesting euthanasia via an advance euthanasia directive (Hardwig 2013; Den Hartogh 2013). These advance directives rely on the authority of the competent pre-dementia person (the 'then' self) to govern the welfare of the incompetent person with dementia (the 'now' self) (Dworkin 1993, 2006; Draper *et al.* 2010). Proponents of this 'precedent autonomy or critical interest' approach underline the stewardship responsibility of the 'then' self for the journey into forgetfulness (Dworkin 1993, 2006; Post 1995). As a consequence, post-dementia decisions should be based on historical lifetime values and beliefs. De Boer *et al.* (2010a: 204) clarify:

> [T]he decisions made by a competent individual as laid down in the advance directive represent the individual's appraisal of where his/her critical interests lie, and should therefore prevail above the preferences of the person with dementia.

1 The following sections build on the already published work of the authors.

An important presupposition of this approach is that individuals are perfectly capable of determining their wishes concerning their end-of-life care individually and cognitively, and in such a way that advance directives unambiguously tell caregivers what to do. Persons are, in this approach, mainly considered as beings with thoughts, intelligence, reason, reflection and consciousness (Hughes 2001). Decision aids serve to facilitate the development of advance directives, providing neutral information about the dementia process such that an informed decision can be made (Levi and Green 2010).

Respect for autonomy – one of the four principles of biomedical ethics described by Beauchamp and Childress (2012) – largely covers moral reasoning on advance euthanasia directives. The literature describes autonomy as the right to self-determination and individual choice (Den Hartogh 2013). Respect for autonomy is founded on the ideal of the autonomous agent. As an autonomous person, one is entitled to act in accordance with a freely self-chosen and informed plan. In line with this philosophical viewpoint, advance euthanasia directives are considered instruments that enable, and indeed legitimise, autonomous wishes concerning a dignified end of life.

8.3.2 Care-oriented relational approach

While the principle of respect for autonomy generally leads to an argument in favour of advance euthanasia directives, questions arise about its applicability to cases involving dementia patients. Because dementia is marked by progressive deterioration, affecting both the memory and reasoning capabilities, dementia patients fall short of the ideal of the autonomous agent that grounds the principle of respect for autonomy. Hence, according to the proponents of the care-oriented relational approach, ethical reflection on the end-of-life of persons with dementia should not start from the ideal of the autonomous agent but from the relational context in which dementia care practices are embedded.

The caregiving relationship often involves entering into a relationship with a vulnerable human being – in this case, a person with dementia who is in need of care. However, it is not always clear what care needs a particular person with dementia might have. Finding the right answer is not the result of a general and abstract balancing of principles or of logical deduction. Rather, the right answer is reached through a shared dialogical process of interpretation and mutual understanding that takes place within the care relationship (Widdershoven and Berghmans 2001). Based on this relational approach to dementia care, some problems arise in using advance euthanasia directives (Hertogh *et al*. 2007; Hertogh 2009; Gastmans and De Lepeleire 2010; Gastmans and Denier 2010; Gastmans 2013).

The first group of problems relates to interpreting patients' wishes. As many authors have already pointed out, clearly expressing one's wishes and thoughts can be difficult. However, interpreting the meaning of a patient's wishes can be an even more difficult task for people such as family members, caregivers, etc. A patient's wishes cannot be assumed or implicitly deduced from an advance directive which attempts to clarify for all those involved what must be done for the patient throughout the consecutive stages of care. What a patient would have wanted under specific circumstances needs to be constructed through fairly elaborate interpretative processes, based on what we know of his or her life, previous pronouncements (e.g. as reported in advance directives) and the patient's actual reactions to concrete proposals (Agich 2003). Even if persons with dementia might be incompetent, they still have the capacity to experience their life and the context wherein it is embedded (De Boer *et al*. 2010a). Hence contemporary preferences, needs and desires, coupled with the present well-being of the person with dementia, should be the main foci for substituted decision-making. This perspective on the relationship between the

'then' self that existed prior to the onset of dementia and the 'now' self that lives almost entirely in the present without any connection to the past, is known as the so called 'experiential interest approach' (Dresser 1995; Draper *et al.* 2010).

Even if, as in advance euthanasia directives, the proposed medical intervention (euthanasia) is clear, communication and interpretation are still needed. Most notably, the difficulty resides in determining the moment when euthanasia should be performed. Suppose, for instance, that a person diagnosed with early dementia clearly states a wish to be euthanised the moment he can no longer recognise his child. This advance euthanasia directive is not self-executing. The physician must determine whether this person's actual situation indeed matches the circumstances specified in the advance directive. This is very difficult for even the most carefully formulated specifications about the chosen moment of death (Widdershoven and Berghmans 2001; Hertogh *et al.* 2007). For example, how should one determine the act of recognition? Surely there are many ways of recognising a person. Where should the line be drawn (Widdershoven and Berghmans 2001)? The progressive developmental stages of dementia itself can render it almost impossible to determine the moment of death in such cases: patients can still have good moments from time to time, no matter how diminished these may be (Gastmans and Denier 2010).

This brings us to the category of problems with future forecasting. They refer to the fact that a person's preferences and values can change. Individuals are able to constructively adapt to even the most severe debilities. Previously communicated wishes may not reflect a change of heart (Hertogh 2009). The issue of irreversibility is more pronounced when dementia patients are involved, as it is impossible to reconsider the decisions outlined in one's advance euthanasia directive. It may be that the aforementioned person with an advance euthanasia directive resists when the procedure is performed. How is such resistance to be handled? Thus physicians and proxies are faced with the dilemma of balancing the current preferences and experiences of the person with dementia against the patient's earlier opinions laid out in a now-forgotten advance directive (Widdershoven and Berghmans 2001; Hertogh *et al.* 2007; Gastmans and Denier 2010; De Boer *et al.* 2010a). Following the 'experiential interest approach', the well-being and interests of the 'now' self are of moral significance, and the absolute primacy of precedent autonomy seems to be wrong (Post 1995). Goering clarifies:

> This does not mean that we should never make plans for our future-selves; rather, it means that we should take care to provide for flexibility in any advance directive, with the recognition that our values or priorities may change, and due to declining decisional capacities, those judgements may need to be made by others in conjunction with our future-selves, rather than solely and individually by our presently competent selves.
>
> *(Goering 2007: 63)*

Another challenge is the difficulty in respecting patient autonomy when it conflicts with the wishes of relatives, friends and caregivers. It seems in the case of advance euthanasia directives, supporting the respect for autonomy principle is much more complicated. People's wishes and values are very often of a pre-reflexive and emotional kind. Without sufficient attention to emotional cues from patients with dementia such as feelings of grief or resistance, relevant third parties (e.g. relatives, friends, caregivers) risk facing a situation in which the patient can easily draft an advance euthanasia directive on their personal computer while in a state of panic or depression, or having little or unclear information about the course of dementia. In this case, advance euthanasia directives could even increase the vulnerability of the patient, as they do not reflect the well-informed wish of the patient (Gastmans and Denier 2010).

Finally, a patient's decision to write an advance euthanasia directive has important implications for all parties involved in the patient's care (Hertogh *et al.* 2007). Because the timing of the euthanasia procedure must be made by someone other than the patient (e.g. the physician), dissensions can arise between the parties involved. Thus to what extent can our fellow man be given the responsibility to ensure that our right of self-determination is respected? The above-mentioned scenario clearly demonstrates a contradiction in the autonomy approach when applied to advance euthanasia directives in persons with dementia.

This critical discussion culminates in the basic problem weakening the use of advance euthanasia directives: the lack of communication and shared understanding between the demented patient, on the one hand, and the caregivers, on the other hand. Margaret Battin confirms:

> To end the life of a patient, even if fully legal, is not an easy process for a physician. We can assume it would be even more difficult when it is no longer possible for the physician to discuss the issue rationally with the patient and to have the patient's wish explicitly confirmed, and especially difficult when there is no evidence of current suffering other than the fact of having dementia disease.
>
> *(2007: 59)*

This observation is confirmed by studies from the Netherlands where, despite the legal recognition of advance euthanasia directives for persons with dementia, euthanasia occurs very rarely or even not at all in this patient group (De Boer *et al.* 2010b; Rurup *et al.* 2006a; Rurup *et al.* 2006b; De Boer *et al.* 2011). Dutch researchers concluded:

> [C]ommunication and interpretation are crucial in determining the circumstances as well as the exact moment of performing euthanasia and this cannot be captured in or replaced by advance euthanasia directives. This is precisely what seems to cause the fundamental problem of complying with advance euthanasia directives in cases of severe dementia.
>
> *(De Boer et al. 2010b: 261)*

According to Hertogh (2009), euthanasia for persons with severe dementia on the basis of an advance euthanasia directive seems to be equivalent to attempting to operate in the dark. He refers to a fundamental vulnerability that confronts physicians if the dialogical and interpretative aspects of end-of-life care are no longer present, and which becomes clear when caring for severely ill demented patients who are unable to discuss their euthanasia requests as formulated in advance euthanasia directives.

Given the above-mentioned difficulties that arise from conceptualising advance euthanasia directives within a principles-oriented autonomy approach, some authors suggest a care-oriented relational approach instead (Hertogh 2009; De Boer *et al.* 2010a; Gastmans and Denier 2010). According to them, taking into account the dialogical and interpretative nature of ethical decision-making should be a standard and indispensable element of good dementia care. As Moody says, '[t]he heart of the matter is not to be found in the legal instrument as much as in the process of communication and negotiation which leads up to the result' (Moody 1992: 92).

In the care-oriented relational approach, the patient's best interest should not solely focus on the patient's wishes as an isolated individual. Rather, the patient's best interest should always start with listening to the concerns expressed by the patient, close relatives, caregivers, etc. because they reflect the rich relational context in which the person's care must take shape. Understanding persons implies an understanding of the relational stories in which these persons are embedded (Hughes 2001), and shared decision-making describes a participatory process involving all

parties. There will never be a legal instrument that supplants this demanding process of communication and interpretation inherent to shared decision-making. Therefore certain authors suggest that advance euthanasia directives have as their purpose to facilitate, but not replace, ethical dialogue and the interpretation process among all decision-makers involved (Widdershoven and Berghmans 2001; Tulsky 2005).

8.4 Current and emerging legal and ethical issues in end-of-life care

In this section, we present two controversial topics frequently discussed in current end-of-life debates: end-of-life decision-making concerning severely ill newborns and the status of conscientious objections in end-of-life care.

8.4.1 End-of-life care of severely ill newborns

Neonatology specialises in treating newborns with diverse, life-threatening conditions. This can include full-term babies with multiple congenital disorders, babies who suffer from complications during delivery or extremely pre-term newborns (<26 weeks) hovering between life and death. In such cases, the spectrum of medical possibilities applied within the field of neonatology demands that positive and negative aspects of decisions, and their subsequent effects, are constantly weighed. On the one hand, it is possible to save lives and to treat children who would certainly have died in previous times. On the other hand, it remains to be asked whether life-sustaining treatment is justifiable if it will result in poor quality of life for the child (Walther 2005). In our ethical and legal exploration of these questions, we largely rely on the reports published by the Nuffield Council on Bioethics (2006), the Health Council of the Netherlands (2007) and the Committee on Fetus and Newborn of the American Academy of Pediatrics (2007, reaffirmed 2010).

8.4.1.1 The boundaries of viability

Neonatal intensive care allows for the control and support of the baby's vital functions – blood pressure, respiration, temperature, nutrition – and can provide a substitute intrauterine environment. Many newborns benefit from interventions without which their lives would have taken a different course (Nuffield Council 2006; Sauer 2001).

The perceived benefits of these interventions are complicated when babies suffer from serious disorders. Newborns with severe chromosomal disorders such as trisomy 13 will certainly die regardless of the treatment. Others, for instance those with serious brain damage or organ failure, can stay alive only with life-prolonging treatment. In these two cases, physicians and parents often opt for pain and comfort management available through palliative care, in combination with withholding/withdrawing life-sustaining medical treatments. For most of these children, this results in a dignified end of life (Nuffield Council 2006; Verhagen and Sauer 2005a; Sauer 2001).

Sometimes, however, the true extent and impact of a disorder becomes clear only later on, when the baby's life no longer depends on the application of life-sustaining medical treatment. This category of patients includes viable newborns who are likely to suffer from severely limiting physical and cognitive disorders such as cystic leukomalacia, a serious form of epidermolysis bullosa, etc. In such situations, the question of whether active termination of life is justifiable becomes relevant (Nuffield Council 2006; Verhagen and Sauer 2005a). In this context, the Dutch

Groningen Protocol 2005 (Verhagen and Sauer 2005a; Verhagen and Sauer 2005b) provoked a worldwide ethical debate concerning the question of whether it is sometimes, in very exceptional cases, justified to terminate the life of severely ill newborns (Hanson 2009; Jotkowitz *et al*. 2008; Kodish 2008; Lindemann and Verkerk 2008; Kon 2007, 2008; Chervenak *et al*. 2006; Manninen 2006; Feudtner 2005).

8.4.1.2 Legal and self-regulating framework

No jurisdiction explicitly allows active termination of newborn babies. However, in most countries, non-initiation or withdrawal of life-sustaining medical treatments are legal under specific circumstances (Sauer *et al*. 2013). In the Netherlands, active termination is tolerated within the self-regulating framework of the Groningen Protocol (Verhagen and Sauer 2005b). In 2005, the Dutch Pediatric Association and the Public Prosecutors approved the Groningen Protocol (developed in 2002 by physicians from the University Medical Centre in Groningen) for nationwide application. Key elements from the procedure include: parental consent; clear description of diagnosis and prognosis; approval from a team of physicians, of which at least one is not directly involved in the care for the patient; and legal supervision *a posteriori* (Verhagen and Sauer 2005b). In 2007, the Minister of Justice and the Secretary of State for Health approved a regulation establishing a Central Committee of Experts on late term abortion and termination of life of newborns (*Staatscourant* 2007), requiring the notification of this Committee in either case. The Committee evaluates whether the criteria of due care contained in the Groningen Protocol is respected and informs the Public Prosecutor of the results. Uncertainty regarding which cases should be presented to the Committee has resulted in low reporting rates. Consensus among the medical professions is lacking (Verhagen 2013). Very recently, however, the Royal Dutch Medical Association (KNMG) published a document containing '[c]lear criteria for medical end-of-life decisions for newborn infants with very serious birth defects' (KNMG 2013). It is expected that this document will enhance transparency in the medical practice and provide more efficient legal control (Verhagen 2013). A brief explanation of parts of this document is provided by the KNMG:

- *Decision-making and the role of parents*. Doctors are expected to communicate with parents openly, directly and regularly. Parental input is a vital part of the decision-making process, particularly where the prognosis is uncertain. Parental permission is always required for the treatment of a newborn baby. Where treatment is medically futile, doctors may – following consultation – decide independently to suspend or to not provide such treatment. This is because the doctor's primary duty of care is towards the infant, and the treatment provided must not harm or prolong harm or suffering.
- *Suspending nutritional support*. If there is no longer any justification for providing life-prolonging treatment to a baby, it will also be unacceptable to continue administering fluids and nutrition. Doctors may allow parents time to understand and accept as best they can that treatment is to be suspended. However, there will be a time limit as to how long physicians can accommodate parents' desire to continue treatment once it has been established that such treatment is medically futile.
- *Gasping and administering of muscle relaxants*. Newborn infants may be visibly suffering if they are gasping for air. Once it has been decided to withhold further treatment, the position paper states that administering muscle relaxants is justified where:

- the baby is gasping, visibly suffering, and pain relief is not sufficiently effective. Deliberate ending of life will then be justified and must be reported to the Central Committee of Experts for assessment. The position paper provides a clear framework for subsequent assessment of the appropriateness of this action;
- if the dying process is underway but is so prolonged that it is causing serious distress to the parents. Such a situation must also be reported. Justification on these grounds needs to be added to the criteria under the Regulation for the Central Committee of Experts;
- if the baby was already receiving muscle relaxants as part of its treatment. Continuing to administer this treatment may be regarded as normal palliative care if suspending it and waiting for its effects to wear off is deemed unsuitable, for instance in the interests of preventing serious discomfort or to ensure that the infant can die in his/her parents' arms. Its purpose is not to end life and thus it need not be reported to the committee of experts. This would constitute a natural death and the municipal forensic pathologist is not required to report it to the Central Committee of Experts.

(2013: 2)

8.4.1.3 Constant and unbearable suffering, pain and palliative care

An important element in the discussion regarding end-of-life care of severely ill newborns involves the aspect of unbearable suffering that cannot be alleviated. The unbearable character of suffering has to be identified objectively. In the case of newborn babies, two problems arise.

Firstly, it is difficult to objectively identify the unbearable character of suffering. Suffering is a personal matter and whether or not it is unbearable is a matter of individual experience and expression of the person concerned. A newborn baby, however, cannot express the unbearable character of a specific condition (Verhagen *et al.* 2007).

Secondly, we run into the problem of identifying future suffering. With newborn babies, health professionals are forced to undertake the difficult task of reflecting upon the levels of unbearable suffering that is expected in the child's future (chronic pain, dependency because of a serious sensomotoric disorder, verbal or non-verbal communication inabilities, the burdens of necessary future treatments, etc.) (Kompanje *et al.* 2005). It is extremely difficult for physicians and other health professionals to assess whether and to what extent there will be unbearable suffering in the future. Research shows that when asked about their quality of life in adulthood, people born with complex or life-threatening conditions – for instance with spina bifida or with extremely low birth weight – have a higher assessment of their quality of life than initially predicted by physicians or even their parents at birth (Payot and Barrington 2011; Bellieni and Buonocore 2009; Health Council of the Netherlands 2007). It is clear that the concept of 'constant and unbearable suffering' is indeed variable, according to personal accounts of competent, terminally ill patients who are able to explain the dimensions and character of their suffering (Kluge 2009; Kompanje *et al.* 2005).

The great difficulty of *assessing* whether and to what extent newborns suffer unbearably does not imply, however, that they cannot *actually* suffer seriously from their condition (Liben *et al.* 2008; Nuffield Council on Bioethics 2006). Measuring scales exist to assess pain and discomfort in newborns. These scales are based on behavioural signs that indicate pain vis-à-vis facial expressions, vocal, non-verbal expressions of pain, bodily movements and positions, physiological changes like pulse rate or breathing frequency, and hormonal response to pain and stress (Verhagen *et al.* 2007; Hunt 2006). Despite these measuring scales, pain continues to be difficult

to assess with precision and can remain inadequately treated in some cases (Liben *et al*. 2008). Hence more needs to be done to apply current knowledge about how to assess, prevent and treat pain for babies receiving intensive care.

There is wide consensus among physicians and nurses that palliative care can contribute in an important way to a dignified end of life for newborn babies, especially through adequate pain control (including palliative sedation), non-initiation or withdrawal of life-sustaining medical treatment and maintaining a supporting and comforting parental presence (Kilby *et al*. 2011; Committee on Fetus and Newborn 2007, reaffirmed 2010; Liben *et al*. 2008; Health Council of the Netherlands 2007; Nuffield Council on Bioethics 2006; Walther 2005). In detecting an underutilisation of palliative care for newborns broadly, Liben *et al*. (2008) point out that there is still an important social responsibility left partially unfulfilled.

8.4.1.4 Non-initiation and withdrawal of life-sustaining medical treatment: respect for a dignified process of dying

Although prolonging life is usually in a patient's best interests, there is a wide consensus among ethicists that 'survival of the newborn' is not the most important goal in neonatology. Sometimes, it is the primary responsibility of parents and care providers to allow for a dignified process of dying.

According to Walter (1988), the central end of medicine is to promote and enhance the (potential) purposefulness of physical and personal life. Physicians promote health, prevent death, perform surgery, relieve pain … in order for patients to continue in some fashion to pursue values that transcend physical life. This proposal addresses the *raison d'être* of medical interventions and its limits, and provides some insight into the general meaning of the terms 'benefits', 'burdens' and 'best interests' of severely ill newborns. Thus, if neonatology can intervene to ameliorate the quality of the child's condition and the (potential) pursuit of life's goals, then such an intervention can be considered a benefit to the patient and in his/her best interests. On the other hand, when a medical intervention is burdensome to the life treated, then it is contrary to the best interests and is even harmful to the child. In such cases, medicine has reached its limits on the basis of its own purpose and thus should not intervene except to palliate and comfort the severely ill newborn (Porta and Frader 2007; Meulenbergs and Schotsmans 2001; Walter 1988). Hence, from this perspective, initiation of and continuing life-sustaining medical treatments can only be considered when a specific objective is in view, when there is a reasonable chance that this objective can be attained with the therapy (effectivity) and when the application of the therapy does not pose an excessive burden on the child (Nuffield Council on Bioethics 2006; Health Council of the Netherlands 2007; Committee on Fetus and Newborn 2007, reaffirmed 2010).

8.4.1.5 Active termination of life: quality of life and respect for autonomy

Authors who support active termination of life in newborn babies mostly rely on value arguments that prioritise quality of life and respect for autonomy. In caring for severely ill newborns, it is the parents' and care providers' responsibility to bring about the best possible quality of life for the child and ensure his/her well-being. However, other ethicists argue that applying quality-of-life arguments in the decision-making process regarding end-of-life care for these children is problematic. In this context, six reasons are identified in the literature.

First, it is only possible for the person concerned to assess quality of life. Notwithstanding that standard (health-related) quality of life measures generally include objective components, quality of life is inherently subjective (Kluge 2009). Mere knowledge of a person's physical and mental limitations does not provide insight into what quality can be attached to such a life or what this life actually means for the person concerned (Kon 2007).

Second, it is not clear which criteria should be used to assess another person's quality of life. For instance, is it reasonable to compare the quality of life for a severely ill newborn baby with that of a healthy child? Doing so would shed a negative light on the life of a handicapped or ill person from the start (Meulenbergs and Schotsmans 2001).

Third, assessing future quality of life introduces uncertainty, especially in the case of extremely premature babies. Is it reasonable, in such cases, to base one's judgment on a 'worst-case scenario' (Health Council of the Netherlands 2007; Chervenak *et al.* 2006)?

Fourth, it is possible that the interests – as well as the fears and opinions – of parents, relatives and society become key factors in assessing quality of life and treatment decisions for the child (Bellieni and Buonocore 2009; Chervenak *et al.* 2006).

Fifth, quality-of-life reasoning happens to equate 'being handicapped' or 'living with a disorder' too readily with 'being unhappy'. It is questionable at least, whether this is indeed the case. After all, it should not be forgotten that people's sense of well-being is closely correlated to feelings of acceptance, and living in a social environment that enhances people's abilities despite physical limitations. Although it can be difficult to live with a handicap or disease, it is not by definition the case that everyone with a handicap is unhappy. Rather the immediate environment and society at large play a major part in this (Shildrick 2008).

Finally, we should not forget that discussions regarding the low quality of certain lives, implying that these people would be better off if they did not exist at all, are disparaging and offensive towards people who live with such deficiencies (De Wert 1991).

Another point that complicates the proactive life-termination argument in newborns is that a newborn child cannot express autonomous will in a clear and straightforward manner. Parents and care providers must interpret the child's actual condition and what the future situation will be in light of prognostic uncertainty. As already mentioned, such an interpretation is very delicate, given the short- and long-term consequences. Hence scholars argue that parents and care providers cannot rely on the principle of respect for autonomy in order to legitimise the active termination of a severely ill, newborn life (Kon 2007; Kodish 2008; Paris 2011). Respect for autonomy cannot result in an absolute disposal of the life of another person who is unable to give informed consent, which is in this case the severely ill newborn (Callahan 1991; Nuffield Council on Bioethics 2006; Jotkowitz *et al.* 2008). The problematic use of quality-of-life and respect-for-autonomy arguments as reported in current ethics literature confirms the lack of consensus among ethicists on active life-termination in newborns.

8.4.2 End-of-life care and conscientious objections

End-of-life care is closely related to the moral attitudes of the persons involved – both patient and caregiver – and their way of experiencing meaningfulness. In fact, all caring behaviour at the end of life is interwoven with normative and existential elements. As an important aspect of a free society, moral pluralism implies that citizens have the opportunity to orient their lives – including the last stages – on the basis of specific religious and philosophical convictions. Worldviews appeal to what we value and hope for in life, not only with our knowledge and

technical expertise. Similarly, it is quite clear that end-of-life care is about more than the efficient organization of care procedures and scientific know-how. Dealing with illness and death affects people in their deepest and most intimate being; it touches the most profound part of their lives. Different worldviews – Christian, Jewish, Islamic, humanist, atheistic, etc. – provide a great deal of inspiration for dealing with these sorts of human experiences and the normative questions they raise. This multifaceted variety of worldviews attempts to formulate answers to fundamental questions and enriches pluralist societies.

8.4.2.1 Moral pluralism and conscientious objections

Current literature on end-of-life care shows an increasing interest in culturally sensitive issues, including their link with religious and philosophical foundations (Andrew *et al.* 2013; Denier and Gastmans 2013; Gysels *et al.* 2012; Evans *et al.* 2012a; Evans *et al.* 2012b). Responses to conscientious objections among end-of-life care providers offer interesting analyses of the relationships between culture, religion and end-of-life care delivery (Wernow and Gastmans 2010). Moral pluralism can complicate end-of-life care when caregivers object to providing certain legal but morally controversial services, such as euthanasia or physician-assisted suicide (White and Brody 2011). The appropriateness of conscientious objections by caregivers remains controversial. Some authors suggest that such disputes arise in a healthy pluralistic society. Others see it as an unfortunate clash of patient versus caregiver autonomy, undue patient burden or the impugning of the caregiver's moral integrity (Wicclair 2006).

To begin, we review Benjamin's three conceptions of conscience. They include '(1) moral sense – an inner sense that distinguishes right acts from wrong; (2) internalized social norms – the internalization of parental and social norms; and (3) sense of integrity – the exercise and expression of a reflective sense of integrity' (Benjamin 2004: 513). In view of the complexity and prevalence of medical end-of-life decisions, it seems important to identify the primary positions and the ethical arguments upon which conscientious objections in these discussions are based.

8.4.2.2 Three positions

A review of ethical literature addressing conscientious objections by caregivers in medical end-of-life decisions reveals common ethical characteristics that correspond to three primary positions. The first position commonly holds that socio-cultural conventions do not serve as a valid basis or warrant overriding conscientious objections to end-of-life procedures that impugn the moral integrity of care providers (Wildes 1993; Boyle 1994; Wear *et al.* 1994; Engelhardt 1997; Peppin 1997; Pellegrino 2002; Orr 2007; Elshtain 2008; Sulmasy 2008; Hardt 2008). Defenders of this first position commonly claim that the right to personal conscientious objection to end-of-life procedures is compatible with their professional obligations. Their claim is based upon the belief that those objections are informed and guided by personal normative values and principles. They assert that professional and personal obligations of care are holistic in nature and argue that any attempt at dichotomisation violates individual identity. That is, when the conscientious individual is compelled to act against the dictates of his or her conscience, their very notion of personal identity, from which professional obligation derives, is violated (Engelhardt 1997; Peppin 1997; Pellegrino 2002).

Proponents agree, however, that an obligation to continue care for the patient extends until a third party arranges for the transfer of the patient's care to another caregiver, whose objections

are disclosed to the appropriate interested parties, such as patients or employers. Some decline any cooperation in areas of objection, such as patient's referral, when matters of conscientious objection arise (Peppin 1997; Engelhardt 1997; Pellegrino 2002). Others in this cluster maintain that, under the condition of proper intent, a referral of patients to accommodating caregivers remains compatible with patients' normative values and principles (Wildes 1993; Wear *et al.* 1994; Orr 2007; Sulmasy 2008; Elshtain 2008). A proper intent of referral facilitates a release of the patient from their care, but is not intended to assist the objectionable act. Like other authors, Hardt (2008) contends that a discussion about moral commitments at the outset of the physician–patient relationship might mitigate future burdens for both.

The second position maintains that personal conscientious objection is compatible with professional obligations so long as the conventional standards of society permit such objection (Wicclair 2000, 2006, 2007, 2008; Davis 2004; Charo 2005; Dresser 2005; Lawrence and Curlin 2007; Glenn and Boyce 2007; Brock 2008). Three conditions are necessary to claim a conscientious objection under this second position: the objector must be willing to disclose their objections to interested parties in a timely manner; there must be a willingness to cooperate in the referral of the patient to a professional who will accommodate the patient's requests; and the objection must not pose undue burdens on interested parties including the patient or their family.

The third position claims that socio-cultural conventions derived from professional standards of practice serve as a valid basis to override conscientious objection to end-of-life procedures (Rhodes 2006; Savulescu 2006, 2007; Adams 2007). According to this position, conscientious objection to end-of-life procedures, such as physician aid in dying or euthanasia where legally permissible, is strictly based upon personal moral preference. It is therefore incompatible with the caregiver's professional obligation to render service to society. Advocates of the third position may temporarily tolerate the practice of conscientious objection but insist it should not be an undue burden to the parties of interest. They also demand disclosure of possible objectionable end-of-life practices to their patients prior to such circumstances and insist on the patient's referral in light of their objections. Temporary toleration should not be construed as an admission of validity or support for conscientious objection; rather, toleration should be maintained until conscientious objections are made illegal (Rhodes 2006; Savulescu 2006, 2007; Adams 2007).

8.4.2.3 Recommendations

The heart of the dispute surrounding conscientious objection appears unsolvable. It is a conflict between proponents of conscientious objection, who view moral truth as a divinely given *a priori* where conscience is part of the identity of the whole person, and those who view conscience as merely a personally acquired social construct. However, both groups share some common ground. All three positions agree that the patient should be respectfully and adequately informed about the caregiver's conscientious objection to some end-of-life procedures. Almost all authors agree that the best time to disclose conscientious objection is at the beginning of the patient–caregiver relationship or, in less optimal circumstances, when conscientious objection arises at the point of request. It appears that all groups would affirm cooperation in proper access to the patient's medical data at transfer and that care should continue during this transfer. From these observations, four recommendations follow: (1) caregivers with conscientious objection should clearly disclose procedures considered morally objectionable to all primary parties of interest; (2) caregivers should have a clearly developed rationale for their objection and inform patients and institutions; (3) caregivers should determine and disclose the extent to which they will cooperate

in facilitating transfer of care, including medical information, assurance of continuum of care during the transfer process, and development of referral mechanisms; (4) caregivers should consider avenues of practice that minimise their exercise of conscientious objection. In following these recommendations, caregivers enhance the patient care experience both professionally and legally.

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