The relation between cultural values, euthanasia, and spiritual care in the Netherlands

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KEY WORDS
dying, euthanasia, Netherlands, palliative care, spirituality

ABSTRACT
The aim of this paper is to gain some understanding of euthanasia as a Dutch cultural practice, focusing on value orientations that lie beneath the surface of what is made visible in the many national surveys done in the Netherlands. In order to reach this aim, I take 2 steps. In the first place, I give a short sketch of euthanasia as it is understood and practiced in the Netherlands. This is followed by a cultural analysis by the American-Dutch historian James Kennedy who studied the euthanasia debate in the Netherlands from the 1960s until 1985. Having arrived at some cultural understanding of Dutch mentality, I dive deeper into the understanding of the Dutch value orientations by focusing on the dimension of spiritual care at the end of life. After having defined the concept of spirituality, I sketch the contemporary state of affairs in this area and report how spiritual care in the Netherlands is understood and practiced by discussing the consensus-based Dutch guideline on spiritual care in palliative care, recent research on hope among palliative care patients in the Netherlands, and an often used Dutch tool for spiritual care: the *Ars moriendi* model. I end this contribution by sketching how I think that spiritual care at the end of life should be developed further in the Netherlands from a palliative care perspective.

Introduction

End-of-life issues belong to the most sensitive topics of discussion in health care ethics, dividing people and nations across Europe and the world. In-end-of-life practices, however, are based on moral understandings that are articulated in moral choices. In order to understand the moral choices of people, communities, or even countries, one has to understand the cultural context in which these have been developed. Understanding a culture, however, is not as easy as it seems at first sight. In anthropology, for example, a number of different theoretical models have been developed, understanding culture as comparable to an iceberg, an onion, or composed of different layers. Common to these theoretical models is the idea that the most powerful elements of culture are those which are not visible, but lie beneath the surface. This dimension of value orientations is hard to grasp or describe, but works as the hidden basis of visible practices and traditions.

The aim of this paper was to gain some understanding of euthanasia as a Dutch cultural practice, focusing on what lies beneath the surface of what is made visible in the many national surveys that have been taking place in the Netherlands. In order to reach this aim, I take 2 steps. In the first place, I give a short sketch of euthanasia as it is understood and practiced in the Netherlands. This is followed by a cultural analysis by the American-Dutch historian James Kennedy who studied the euthanasia debate in the Netherlands from the 1960s until 1985. Having arrived at some cultural understanding of Dutch mentality, I dive deeper into the understanding of the Dutch value orientations by focusing on the dimension of spiritual care at the end of life. After having defined the concept of spirituality, I sketch the contemporary state of affairs in this area and report how spiritual care in the Netherlands is understood and practiced by discussing the consensus-based Dutch guideline on spiritual care in palliative care, recent research on hope among palliative care patients in the Netherlands, and an often used Dutch tool for spiritual care: the *Ars moriendi* model. I end this contribution by sketching how I think that spiritual care at the end of life should be developed further in the Netherlands from a palliative care perspective.
Understanding euthanasia in the Netherlands

The definition and practice of euthanasia

In 1985, after 20 years of discussion in society, the State Commission of The Netherlands formulated a definition of euthanasia that has been the official Dutch definition ever since: “the intentional termination of the life of a person at his/her explicit request by someone else than the person concerned.” With this definition, an attempt was made to gain some clarity about the many ways in which euthanasia had been (and still is) defined in the debates: being either active or passive, voluntary or involuntary, direct or indirect, and intentional or unintentional. According to the Dutch legislation, euthanasia is always active, intentional, and direct, and it can be called euthanasia only if it follows a voluntary request of a mentally competent patient.

Killing a fellow citizen is a serious crime in the Netherlands, and this law refers to the physicians as well. Physicians, however, may be exempted from persecution if they follow a number of requirements that are listed in article 2 of the 2001 Termination of Life on Request and Assisted Suicide Act, including: 1) the physician held the conviction that the request by the patient was voluntary and well considered; 2) the patient’s suffering was lasting and unbearable; 3) the physician had informed the patient about their situation and prospects; 4) the physician agreed with the patient that there was no other reasonable solution; 5) the physician consulted at least one other independent physician who saw the patient; and 6) the physician terminated the life or assisted in the suicide with due care. In 2015, 5516 patient lives were terminated by euthanasia, which was 3.9% of all deaths, the ratio between the estimated number of long-term requests and actual euthanasia cases almost being 10 to 1.9

Although the Dutch legal requirements seem to function in practice, in the literature there is much unclarity about what is meant by unbearable suffering. In an integrative literature review, Dees et al10 defined unbearable suffering in the context of a request for euthanasia as “a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person’s mind”. By defining unbearableness as a “profound personal experience” and something “in the person’s mind”, it becomes a category which is directly related to spirituality, since it is directly connected to the personal way in which people find meaning in life. The personal way in which people deal with suffering is confirmed by the research of Ruijs et al11,12 who have developed a way to measure unbearable suffering. According to their findings, 94% of patients with a euthanasia request report unbearable suffering, and 87% of patients without a euthanasia request also did so (n = 64). Ruijs et al11,12 found that those who asked for euthanasia often had a euthanasia declaration (77%) and sometimes a higher education (35%). When asked about the sources that helped the patients to bear suffering, people mostly reported family and proxies (69%), and faith and trust in God (40%).

What is behind the decisions of some people to choose active termination of life, and what values are underlying the Dutch mentality that has made possible a legal arrangement that is different from almost every other country in the world?

The mentality underlying euthanasia developments

In an interesting study the American-Dutch historian James Kennedy asked himself why the Netherlands was the first country in the world where euthanasia was legalized, in opposition to the surrounding countries.13,14 In order to answer this question, Kennedy analyzed the euthanasia debate as it developed in the Netherlands from the 1960s until 2015. In his research, he distinguished 3 factors that fostered the developments towards the euthanasia legislation that was enacted in 2002: the typical Dutch mentality; a health care system based on solidarity which secures that there is no economic pressure to let people die; and a minority of Christian political parties in Dutch parliament. Although this last fact seems to endorse the idea that religiousness is a buffer against the development of euthanasia legislation, the history of the Dutch debate is more complicated, also showing Christian theologians to be proponents of self-determination in matters of life and death. More interesting for the understanding of Dutch culture is the typical mentality that Kennedy assigns to the Dutch, and which is expressed in 5 arguments that were often used in favor of euthanasia.

In the first place, according to Kennedy, in the 1960s, a strong feeling arose that there should be no subject that could not be spoken of and discussed in public. People became more open about subjects that traditionally were more or less taboos, like sexuality and death. This movement that was strong in the North Atlantic world, was particularly well developed in the Netherlands. Probably endorsed by the Protestant culture of confession and openness, people thought it a good thing to talk about, for example, the question whether one should have the right to end one’s life when it was no longer considered to be worth living. From a psychological point of view, this openness was considered to be a healthy thing because taboos generate guilt and guilt may lead to depression.

In the second place, euthanasia was considered to be inevitable because of modern medical power. In 1969, the psychiatrist and phenomenologist Jan Hendrik van den Berg published a small but influential book, “Medical power and medical ethics”, in which he pleaded for the possibility to have physician-assisted dying.15 His line of reasoning was very simple: if medicine has the power to prolong life, and this sometimes leads to ethically problematic situations, it should also have the courage to end life. Because the Netherlands is a small country often following
In fact, the Dutch pragmatic way of solving controversial issues is a way of dealing with cultural authenticity, and inner motivations. This is visible in the great surveys that have been added a paragraph to the definition in which the factual occurrence of physician-assisted dying. These surveys formed the empirical basis for the Dutch legislation in this area. Understanding Dutch culture and the mentality underlying the special way this country deals with end-of-life issues is not the same thing as justifying the moral choices that have been made. In fact, the Dutch pragmatic way of solving controversial issues is a way of dealing with cultural and moral pluralism. It is based on the idea that in order to be able to live together with differences, the state should enable and regulate a variety of moral positions rather than endorse a specific position. In the end, of course, this liberal idea is also a moral position.

Having understood the general mentality of the Dutch underlying the societal debate that paved the way for the first euthanasia legislation in the world, what can we say about the spirituality of patients in the Netherlands? Although there has been a number of euthanasia surveys in the Netherlands from 1990, the relation between euthanasia and spirituality has never been researched thoroughly. The first reason for this might be the dominant liberal idea in the Netherlands that spirituality belongs to the private sphere of citizens, which should be exempt from any political influence. The second reason might be the fact that spirituality was no theme of serious medical research in the period from 1990 to 2010. Although in the past years this has changed, until now there has been no research that can help us further. I therefore had to use a different strategy to gain some insight into the spirituality of Dutch patients, as presented below.

Understanding spiritual care in the Netherlands

Defining spirituality According to international organizations such as the World Health Organization and the European Association for Palliative Care (EAPC), palliative care should be focusing on physical, psychosocial, and spiritual problems and needs. However, there are many misconceptions about this last dimension of care. One of the most widespread misconceptions is the idea that spirituality is something for religious people only. Although the concept of spirituality as it is generally understood in the North Atlantic world has its roots in the Christian tradition, the way it is used in palliative care is far from exclusively religious. In order to clarify this field, a number of consensus conferences were organized both in the United States and Europe. In a consensus meeting in 2010, the EAPC Taskforce spiritual care arrived at the following consensus definition:

**Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.**

The above definition builds on the definition that was agreed upon in the 2009 consensus conference in the United States. In order to give a more concrete idea of in how many ways spirituality may be encountered, the EAPC taskforce added a paragraph to the definition in which it stated that the spiritual field is multidimensional, comprising: 1) existential challenges (eg, questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy); 2) value-based considerations and attitudes (what is most important for each person, such as relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself); 3) religious considerations and foundations (faith,
beliefs, and practices, the relationship with God or the ultimate).

When spirituality is approached in this way, it is clear that religiousness is only one of many ways to articulate spirituality. And like any articulation of spirituality, also this one is largely defined by cultural factors. Historically, for many centuries the Netherlands has been divided into a large majority of Roman Catholics living in the south and a majority of Protestants living in the north of the country. In the years 1966, 1979, 1996, 2006, and 2016, large surveys were undertaken to follow the cultural developments in the Netherlands as regards religion and philosophy of life. According to these studies, in 1966 almost half of the Dutch population (47%) reported to believe in a personal God, followed by 31% of the people that were not sure about who or what God was, but still said to believe in something higher. Only 16% of the Dutch considered themselves to be agnostic, and a minority of 6% called themselves atheists. After gradual developments that have taken place for over half a century, the situation has completely changed. According to the latest report, in 2016, a minority of 14% of the Dutch believed in a personal God, 28% of the population believed in some higher power, 34% of the Dutch considered themselves agnostic, and the percentage of atheists increased to 24%. A large majority of the Dutch (82%) never or almost never visits a church or a religious service. Accordingly, to a large majority of people, Christianity has become “an unknown or exotic world”. What does spiritual care in palliative care look like in such a cultural context?

A multidisciplinary guideline for spiritual care When in 2006 a comprehensive volume of interdisciplin ary guidelines for palliative care was published, there was no mention of spiritual care at all. Nevertheless, the volume contained a guideline on existential crisis. Noticing the reductionist, instrumental, and problem-oriented character of such an approach to spirituality, a small interdisciplinary group of health care professionals began to develop the first consensus-based interdisciplinary guideline for spiritual care in palliative care. This guideline was primarily intended for physicians and nurses, but was designed to build bridges between other disciplines as well, including social workers, psychologists, and chaplains. After 4 years of drafting and consensus rounds, the final text was published in 2010.

The guideline offers practical guidance to distinguish between: 1) situations in which ordinary attention to patient’s spiritual questions is part of good care; 2) situations in which patient asks for accompaniment in spiritual issues or are going through a normal struggle where guidance by an expert can be valuable; and 3) situations in which a process of wrestling with spiritual questions has led to an existential crisis that needs intervention by a chaplain, social worker, or psychologist.

In the guideline, spiritual care is seen as the most intimate and hidden dimension of care, less measurable than physical and psychosocial care, but continuously in a relation of mutual influence of these dimensions. One of the tools used to gain access to the dimension of spiritual care is the approach worked out by the German chaplain Erhard Weiher, who has distinguished between different layers of meaning that interconnect in every conversation: the physical level in which a sentence is seen as referring to something verifiable or factual; the psychological level where one is sensitive to what thoughts, images, or feelings are hidden in an expression; the social level which leads to an understanding of the social environment in which a person is embedded, expressing a part of his or her identity; and a spiritual level that refers to the ultimate concerns, inspirations, and existential meaning expressed. In the guideline, physicians and nurses learn how to use the first 3 levels in order to come to the fourth.

Next to the approach of Weiher, the guideline offers a number of other instruments that are helpful in practice to have conversations with patients on spiritual issues, such as the 3 questions of the Mount Vernon Cancer Network, and the Ars moriendi model. A characteristic of the guideline is that it contains an approach to spiritual care that is open to all patients and their families, either religious or not. Because of this open character, the guideline played an important role in making spiritual care acceptable to professionals who were less open to the idea of mixing up medical science with religion.

This inclusive approach to spiritual care—conceiving itself as broader than, but including, religious care—is characteristic of the developments in Dutch palliative care, as it is reflected in a number of research projects that have been done in the last few years, on spiritual care at the end of life in Dutch nursing homes, spiritual coping of cancer patients, the screening of spiritual needs of hospitalized patients by nurses, the role of spirituality in the adjustment to cancer, and the training of spiritual care in palliative care in teaching hospitals in the Netherlands.

We will finally look at 2 of these projects in which the value orientations of patients are integrated in palliative care: the work of Erik Olsman on hope, and the Ars moriendi model.

The dynamics of hope in palliative care In a recent study, the Dutch researcher Erik Olsman interviewed 29 Dutch palliative patients (as well as their caregivers) in order to understand the dynamics of hope, hopelessness, and despair in this population. Some of the patients were interviewed more than once. Of these patients, 48% reported to be not spiritual, 28% considered themselves to be monotheistic, and 24% said they had a spiritual belief not related to one God. Studying a traditionally Christian subject, such as hope, in a multicultural and secularized context, such
as the Dutch one, Olsman found that hope still is an important force in these patients, although it is in many cases not articulated in a religious way. Hope in Dutch palliative patients may have a number of objects, which may differ over time and develop in various ways. Sometimes people hope for different things simultaneously, and these hopes may coexist or alternate like different voices in a singing choir.

By studying the secularized polyphony of hope, Olsman has contributed to re-integrating a spiritual theme in a secularized medical context. Apart from studying the role of hope in the lives of palliative patients, Olsman also researched the way this theme is framed and discussed in health care.35

The most dominant perspective on hope is the realistic perspective that is often adopted by physicians and nurses. Both disciplines are focused on doing what is needed and avoiding futile treatments. Since hope for recovery can be destroyed after disclosure of a bad prognosis, the most important goal for those who adopt the realistic perspective is to adjust hope to the truth. According to the second perspective on hope that we find in the literature and which is of a more psychological origin, hope is seen as a coping strategy. Hope is considered to be important in order to have courage, a positive attitude, and motivation to undergo therapy. Hope should be helpful rather than truthful, and the main goal of people following this functional strategy is to foster hope. The third perspective on hope is closest to the traditional way hope is understood in spiritual traditions. In this narrative perspective, hope is to be fostered to the degree that it is valuable and meaningful to the patient. The major goal in this approach is to look for meaning rather than good outcomes or coping.

Olsman’s research is helpful for integrating spirituality in a medical context. A good caregiver should be able to work with the 3 perspectives, attuning to the needs of the patient and balancing between compassion and empowerment according to what Olsman calls “an ethics of hope”.26

In this approach, the 3 perspectives on hope play a central role because of the many voices in patients that articulate aspects of hope.

Towards a new Ars moriendi  This idea of more than one inner voice in patients—the so-called polyphonic self—also plays a central role in an often used model for spiritual care that was developed in the Netherlands, and which is based on the 15th century Ars moriendi (art of dying) tradition.28,37 According to this approach, the major goal of spiritual care is to help the patient develop “inner space”, a metaphor referring to the inner freedom of a person, being sovereign in relation to the feelings, thoughts, and attitudes that are elicited by a situation. This focus on inner space is important to deal with a number of tensions in which patients find themselves and which are connected to central issues such as patient autonomy, pain control, saying goodbye, looking back upon one’s life, and the question of hope.

The Ars moriendi model has proved to be a helpful tool for patients to organize their thoughts,38 and for caregivers such as physicians to get a grip on a dimension of care that many find difficult to gain access to.39 It has been developed in such a way that it addresses important themes against the background of bigger cultural developments.40 With respect to euthanasia, for example, in the Ars moriendi model, an important question is how to develop the inner space or inner freedom to make a good decision in the tension between doing and undergoing. Patients, family members, and caregivers are inclined to intervention, action, and control because of the culture of control they are living in. This cultural context compromises patient autonomy, since it pushes all those who are concerned in the same direction without thinking about possible alternatives.

**Conclusion: directions for the future**  The developments in the Netherlands that have led to the practice of euthanasia are based on a culture in which value orientations like openness, freedom, transparency, mercy, authenticity, equality, self-determination, and responsibility play a central role. The way these values are understood and interrelated can be understood against the historical background of the secularization process and emancipation from traditional hierarchical and religious structures. In such a context, spiritual care has been developed as a way of supporting patients in their personal search for meaning, purpose, and transcendence, which can be articulated either in a religious or secular way. Helpful in this context is the work of Olsman on hope and the framework of a new Ars moriendi in which the inner space of the patients and of formal and informal caregivers play a central role. In these approaches, for many people, the moral evaluation of the practice of euthanasia has shifted from the outcome to the quality of the process leading to the outcome. In this process, spiritual care still plays a role, although it is framed and understood differently as in more traditional religious ways.

In Dutch discussions, euthanasia is increasingly seen by the general public as a patient right (which it is not) rather than as the last option when there seem to be no more alternatives to relieve suffering. However, from an ethical perspective and in line with the central value of freedom, one could critically ask how free the patient’s and their families are when they formulate a euthanasia request.41 In this respect the Ars moriendi model is a promising tool to discuss openly with patients and families to what extent they might be subject to cultural pressure regarding, for example, an individualistic view on autonomy and a tendency to do rather than undergo.42 Discussing these tensions in an open and democratic way (without moralizing) fits very well into the cultural climate of the Netherlands that Kennedy analyzed so well. At the same time, it offers
a tool for further development of the central value of (inner) freedom, which is conceptualized in the metaphor of “inner space”. Although in the contemporary Dutch neoliberal climate, pressure groups like Right-to-Die-NL will continue to push the boundaries of euthanasia towards inclusion of people with intellectual disabilities or people who are tired of living, and a minority of people will continue the possibility of choosing their own way of dying, for the majority of Dutch patients the development of spiritual care focused on the development of inner freedom might help decrease the inner and cultural pressure that leads to asking physicians to end their lives. In this way, the further development of spiritual care might contribute to the protection of current legal status of euthanasia as a nonmedical action that is still under penal law and reserved for rare situations of extreme suffering. Although this situation is still contrary to how palliative care is understood by the World Health Organization and the European Association for Palliative Care, one may hope that the further development of spiritual care might contribute to help patients and their families develop inner freedom and strength to live life until the very end.

REFERENCES