



Article

“If Only I Could Start All over . . . ” A Case Study of Spiritual Care Provision to a Patient with a Psychiatric Disorder Requesting Physician-Assisted Dying in The Netherlands

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Abstract: In a growing number of countries, legislation permits physicians—under strict conditions—to grant a request for physician-assisted dying (PAD). Legally allowing for the possibility of granting such a request is in accordance with central humanistic values such as respect for autonomy and self-determination. The Netherlands is one of few countries where severe suffering from a psychiatric illness qualifies as a ground for a request for PAD. Central in this article is a case description of spiritual care provision in the Netherlands by a humanist healthcare chaplain to a patient requesting PAD because of psychiatric suffering. We discuss what we may learn from the case description about how spiritual caregivers may support patients who express a wish to die, and about their contribution to the care for patients with a psychiatric disorder who request PAD.

Keywords: spiritual care; physician-assisted dying; secular chaplaincy; humanist spiritual care; The Netherlands; euthanasia



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1. Introduction

In a growing number of countries, legislation permits physicians—under strict conditions—to grant a request for physician-assisted dying (PAD) from a patient (Emanuel et al. 2016). In four of these countries—Belgium, the Netherlands, Luxembourg, and Canada—the suffering underlying these requests may stem from a psychiatric illness (Emanuel et al. 2016). In the Netherlands, the conditions a physician must adhere to in the context of PAD are called the due care criteria. Although a guideline has been issued specifically for PAD based on psychiatric suffering (Levensbeëindiging op Verzoek bij Patiënten met een Psychische Stoornis [Termination of Life on Request from Patients with Mental Disorders] 2018), the more substantive of these criteria still seem to be more difficult to assess when the request was made in relation to suffering from a psychiatric illness (Evenblij et al. 2019). According to one of the criteria, the physician should be convinced that the request by the patient is voluntary and well-considered. There is discussion about how mental illness affects the ability of patients to have a well-considered wish to die, and about the possibility of distinguishing between suicidality and a well-considered wish to die in psychiatric patients (Pronk et al. 2020). Another criterion states that the physician should be convinced that the suffering of the patient is unbearable and without prospect of improvement. For all requests for PAD, it seems difficult to assess whether suffering is unbearable: “unbearable suffering has not yet been defined adequately and views on the concept are in a state of flux” (Dees et al. 2010, p. 339). As for requests by psychiatric patients, there is also discussion about the conditions under which psychiatric suffering can qualify as irremediable (van Veen et al. 2020).

Several authors point at the existential dimension of unbearable suffering in the context of a request for PAD (Berghmans et al. 2013; Dees et al. 2010; Dees et al. 2011). In a

qualitative study among 31 Dutch patients who had requested PAD, [Dees et al. \(2011\)](#) found that all patients named existential motivations, related to unbearable suffering, for their request for PAD. Following [Geertz \(1973\)](#), worldviews may be understood as collective meaning frameworks that both describe and prescribe how to make sense of existence, in particular of existential challenges such as severe suffering. According to Geertz, religious responses to suffering characteristically emphasize how to endure suffering: “how to make of physical pain, personal loss, worldly defeat, or the helpless contemplation of others’ agony something bearable, supportable—something, as we say, sufferable” (p. 104). The notion that suffering may eventually be unendurable, and that ending life may be a valid response to such suffering, may thus conflict with traditional religious convictions. Empirical research shows that an increase in public support of PAD in various countries is correlated with a decline in religiosity ([Cohen et al. 2006](#); [Emanuel et al. 2016](#); [Halman and van Ingen 2015](#); [Marsala 2019](#)), and that religious commitment of individuals is associated with opposition to PAD ([Aghababaei 2013](#); [Cohen et al. 2006](#); [Fortuin et al. 2020](#)). Considering or approving the option to end one’s own life or request assistance with dying in the context of unbearable suffering reflects core humanistic values such as respect for autonomy and self-determination. The thought here is that the patient should have the final say if and how he or she wants to live life or end it. Considering this, PAD may be characterized as a secular practice that is in accordance with central values in humanism.

The importance of addressing the existential dimension of the suffering of patients as well as physical and psychosocial dimensions is increasingly recognized in healthcare ([LeMay and Wilson 2008](#); [Puchalski 2013](#)). Healthcare chaplains are traditionally the obvious professionals to provide care directed at existential struggles of patients. Chaplains nowadays tend to describe their work in terms of providing spiritual care rather than in terms of providing religious care ([Doehring 2015](#); [Orton 2008](#); [Pargament 2007](#)). This designation of chaplaincy underscores that chaplaincy care is not restricted to religious people, as spirituality is more and more seen as a universal human experience instead of a synonym of religion ([de Jager Meezenbroek et al. 2012](#)). Now that spiritual care is often accepted as an integral dimension of healthcare, healthcare chaplains are becoming part of healthcare teams rather than working at the margins of healthcare organizations ([Pesut et al. 2012](#)). This development is especially visible in the context of palliative care ([Puchalski et al. 2014](#)). In this context, there is also a growing body of research into spirituality, spiritual care, and the role of chaplains in care provision ([Steinhauser et al. 2017](#)). By contrast, when it comes to patients with psychiatric disorders (PPD) requesting PAD, not much is known about the (potential) role of spiritual care for these patients, about how healthcare chaplains provide spiritual care, or about how this care relates to the care provided by other healthcare professionals involved. In this article, we explore a case of spiritual care provision in the Netherlands by a humanist healthcare chaplain (LvD) to a patient requesting PAD because of psychiatric suffering. By reflecting on the case, we explore how to understand spiritual care provision to PPD who experience their suffering as unbearable, without prospect of improvement. Furthermore, we address the question of how spiritual care provision to PPD requesting PAD fits in with the care for these patients in general, in particular with the assessment of whether the patient’s request is voluntary and well-considered.

2. Results

2.1. Case Description: Introducing Anna

The following case description is based on an in-depth interview of Lisa (LvD), a healthcare chaplain in a large mental health institution in the Netherlands. Part of this case description was published previously ([van Duijvenbooden 2017](#)). The case is about the chaplaincy care that Lisa provided to Anna, a woman in her seventies, during the last two years of Anna’s life. Anna had regularly been hospitalized (both voluntarily and involuntarily) because of severe depression, suicide attempts, and manic episodes with psychotic features. Lisa met Anna when the former chaplain, who had provided chaplaincy care to Anna whenever she was confined to the institution, had retired, and Anna was once

again hospitalized after a half-hearted suicide attempt. Anna was an educated woman, which was, even though she was in an unkempt state, evident from the way in which she spoke, the vocabulary that she used, and her subtle sense of humor. She felt very much out of place in the institution and experienced every hospitalization as traumatizing. The healthcare professionals in the institution therefore always tried their best to keep Anna's hospitalizations as short as possible. As soon as her situation had somewhat stabilized, she was allowed to move back home where she would attempt to pick up her life again, supported by outreaching care. There were no people in her life with whom she had a close relationship. Repeatedly, Anna expressed her desire to die. By the time that Lisa came into contact with Anna, this desire was taken seriously into consideration within the institution, and a psychiatrist explored possibilities of PAD together with Anna.

After meeting Anna for the first time, Lisa visited Anna weekly during her stay in the institution. In the conversations with Lisa, Anna kept repeating that she could no longer deal with life and that she wanted to die: "I did not live a good life, I made the wrong choices, I want to die, this is not me!" She talked about her youth, about how beautiful and talented she had been back then, and how she had let her life slip away by making wrong choices. Anna's stories were full of guilt and self-blame, as she felt that she herself, through her own actions, had cut off the road towards a good life that lay open for her. Anna had some hope left that she would feel better once she would be allowed to go back to the apartment where she lived. When, however, she finally was discharged and had returned home, her hopes came to naught. Her despair, loneliness and depression resurged, and she kept requesting PAD. At the same time, she expressed her doubts about PAD to Lisa, who had continued her visits to Anna at Anna's home: "What should I do? Help me! I don't know, I just don't know". When Anna was eventually informed that her request for PAD had been granted, her doubts suddenly became even more severe: "I do not understand it. All the time I longed to die. I longed for liberation. And now, now that I am allowed to die, I am not sure any more. I keep thinking: if only I could start all over ...".

2.2. Lisa's Response to Anna's Story

In the interview, Lisa describes the difficulties she experienced when attempting to connect with Anna: she felt weighed down by Anna's monotonous repetition of her story of despair, guilt and self-blame. But she adds that being able to stay with tragedy, suffering, and despair, without being overwhelmed by it, is part of her professionalism as a chaplain. She describes this professional competence metaphorically in terms of cultivating "inner space", referring to the conceptualization of the term by [Leget \(2017a\)](#), and stresses that it requires hard work and discipline to maintain and cultivate inner space. Having inner space allowed Lisa to be touched by Anna's suffering and despair, without feeling desperate herself: "I could really be moved by Anna without feeling that I had to save her". The importance of having inner space becomes especially clear with respect to Anna's ambivalence about her request for PAD. Lisa never suggested that she knew what would be the right way to proceed for Anna, even though Anna repeatedly asked her: "Lisa, should I actually do it? I don't know, I don't know ...". Anna was constantly moving back and forth in her position towards PAD. On the one hand, she would declare that she had made her decision a long time ago and had no hope of recovering from her depression. On the other hand, she would stress that "somehow, I am still waiting for a miracle". In her conversations with Lisa, Anna could express these struggles, doubts and ambivalences. Religion also played a role in these struggles and ambivalences. Anna had a Christian background and she still drew strength from this background and stated that Jesus had always been her most important role model. On the other hand, she felt guilty towards Jesus because of her suicide attempts which she referred to as "having tempted death". Lisa explains her response to the ambivalence in Anna's story as follows: "The ambivalence did not have to be solved. I always felt that I just needed to follow Anna. I moved along with her, I attuned myself to her, and in turn I expressed to her how her struggles touched me".

According to Lisa, the monotony of Anna's story of despair, guilt, and self-blame not only posed a difficulty for building a connection with Anna, but also for responding to the story. Anna's lamentation about her past that she kept repeating to Lisa while she was in the institution was, in a sense, a "dead" story. Anna did not seem to have an emotional connection with what she was telling about her former self. Lisa's attempts to find openings in the story did not succeed until Anna's request for PAD had been granted and Anna's doubts about PAD intensified: "I keep thinking: if only I could start all over . . .". It seemed that Anna could not choose death because of the desire to start all over—even though it was an unrealistic one. By expressing this desire, Anna implicitly pointed at a part of her life that remained unarticulated in her dead story about her past: her unfulfilled dreams and promises, the life that she had hoped for but had never been able to live, and the deep sorrow of having lost so much. When Lisa explicitly addressed this part of Anna's life by mentioning that she sensed deep sorrow in Anna's story, Anna casually replied that actually so much had happened in her life that one might write a book about it. Lisa then proposed to do precisely that and write down Anna's life story. This idea was enthusiastically received by Anna. For months, Lisa and Anna worked on writing down Anna's life story: Lisa recorded Anna's stories, wrote them down, and read them back to Anna, while showing her own emotional response to the hardship and challenges Anna had been confronted with in her life. According to Lisa, due to her compassionate retelling of Anna's life story, Anna herself began to look compassionately at her past, at who she had been, and at the choices she had made. Her guilt and self-blame softened and mingled with an acknowledgement of the tragic aspects of her life.

2.3. *Anna's Death*

When Anna and Lisa had finished writing Anna's life story, she requested PAD again. In the process of writing her life story, Anna had obtained a clearer view of what, to her, constituted a life worth living. She also had a better understanding of how, in the course of her life, this view had slipped out of reach, and she was convinced that she would not be able to live in accordance with this view, in the first place because of her psychiatric illness. Even though being seen and affirmed by Lisa softened Anna's loneliness, Lisa's support did not result in resolving Anna's wish to die. It did, however, result in a different perception of her situation, no longer mainly colored by guilt and self-blame, but rather by acceptance of how her life had been marked by tragedy. While Anna's first request for PAD had mainly resulted from panic and desperation, her second request involved self-compassion. Anna eventually received physician-assisted suicide in the presence of the psychiatrist, a nurse, and Lisa. Lisa tells in the interview that the atmosphere was tranquil, peaceful, and "almost sacred". Anna's last words were: "I am so happy right now".

2.4. *Lisa's Work at an Organizational and Societal Level*

In relation to this case, Lisa explains in the interview that providing spiritual care to Anna is not restricted to providing individual care, but is embedded in work at an organizational and societal level. Here, Lisa sees it as her task to increase understanding of the potential ambivalence in persons who strongly express a wish to die. For care professionals and for family members of patients, it may be emotionally stressful to move along with ambivalence. Furthermore, a patient being uncertain or feeling ambivalent about a wish to die seems hard to reconcile with a positive assessment by the physician of the due care criteria concerning PAD. These criteria involve the physician being convinced that the request is well-considered and that suffering is unbearable and without prospect of improvement. Lisa points out that psychiatrists who were involved in Anna's request for PAD understood well how important it was for Anna to have a place where she could explore her doubts concerning PAD—doubts that she would not extensively discuss with psychiatrists, as this would decrease the chance that her request for PAD would be granted. As for the societal level of spiritual care, Lisa attempts to make Anna's voice heard in the public domain by publishing about the case. According to Lisa, Anna would have been

thrilled to know that her story would be published; she would feel that making her story known to a larger public would in a way do justice to her life.

3. Discussion

In this article, we described a case of chaplaincy care in the context of a request for PAD by a patient with a psychiatric disorder. We argued in the introduction that PAD can be characterized as a secular practice with a humanistic value-base that conflicts with traditional religious responses to severe suffering. Nowadays, chaplains generally present themselves as spiritual care professionals who support all people, religious and non-religious, struggling with existential issues. If chaplains are anywhere challenged to specify how the shift from chaplaincy as providing care from within religious traditions to chaplaincy as inclusive spiritual care provision plays out in practice, it is in relation to patients who request PAD or express a wish to die. We now discuss what we may learn from the case description concerning spiritual care for PPD requesting PAD.

3.1. Two Key Elements of Spiritual Care for PPD Requesting PAD

In the case description, two crucial elements of spiritual care provision to patients who express a wish to die come to the fore. First, the case description shows how meaningful it may be for patients to be able to express and explore ambivalence and doubts concerning a wish to die with a spiritual caregiver, without pressure either towards or away from PAD. Opening space for ambivalence and doubts concerning a wish to die requires of spiritual caregivers that they are able to engage with the intense suffering of others and to recognize when impulses to distance themselves from such suffering arise. In the case description, the chaplain referred to this competence in terms of cultivating “inner space”. Interestingly, [Leget \(2017b\)](#) uses the term “inner space” to describe what spiritual care may bring about for patients who express a wish to die, namely: “further development of the central value of (inner) freedom, which is conceptualized in the metaphor of ‘inner space’” (p. 266). He stresses that patients need inner space to explore how cultural pressures influence their wish to die. Similarly, in order to open space for ambivalence concerning a wish to die, spiritual caregivers need to explore what cultural or worldview discourses influence their views of PAD. In particular, this requires that they examine how the view that ending life may be a compassionate response to severe suffering relates to their worldview.

This raises the question of whether and how spiritual caregivers who reject ending life as a potentially acceptable response to unbearable suffering may ensure free expression and exploration of a wish to die by patients. The sparse existing literature on chaplaincy care for patients who requested PAD suggests that chaplains in general, including those who on religious grounds personally oppose PAD, describe their work in terms of nonjudgmental support of patients ([Carey et al. 2009](#); [Carlson et al. 2005](#); [Farley 2014](#); [Goy et al. 2006](#); [Grant 1997](#); [Rikmenspoel 2014](#)). More research is needed to find out how the worldview of spiritual caregivers influences their response to patients who experience unbearable suffering. For the chaplain in the case description, who identifies as a spiritual humanist, the view that PAD may eventually be a compassionate response to unbearable suffering is grounded in her humanist worldview. It is important to point out that the accepting attitude towards PAD of the humanist chaplain should not be ascribed to the dominant neoliberal cultural climate in the Netherlands. Humanist and neoliberal responses to unbearable suffering should not be lumped together under the same umbrella, even though humanism and neoliberalism share some common ground. For instance, the notion of autonomy that plays a role in humanist responses is a relational one, fueled by compassion and connectedness, as can be seen in the case description, whereas from a neoliberal perspective, autonomy is a purely individualistic notion.

A second element of spiritual care that can be identified in the case description as meaningful for patients who struggle with a wish to die is “listening beyond the wish to die”. Unbearable suffering may leave little room for anything but stories centering around a wish to die. Listening beyond the wish to die means listening carefully to clues in these

stories about the hopes, dreams and desires of the person who is telling the stories. Stories about a wish to die are also stories about life—about a life worth living that someone cherished but that stayed or moved out of reach. Listening beyond the wish to die may thus involve asking for and compassionately listening to “stories about life” and providing space for grief. This allows for new stories to be told or for old stories to be told in a new way, as we saw in the case description. In listening beyond the wish to die, the aim is not to move away from the wish, but to explore how it is situated in the life and biography of this unique person. The focus is on the patient as a complex human being who cannot be completely known, let alone reduced to a story about a wish to die, or a set of reasons for and against such a wish.

3.2. Outcomes of Spiritual Care for PPD Requesting PAD

On the basis of the case description, we may critically reflect on the question of what chaplains aim for when providing spiritual care to PPD requesting PAD: what are (potential) “good outcomes” of the care they provide? The case description emphasizes the need for nuanced answers, since outcomes that are often associated with spiritual care, such as spiritual well-being, meaning in life, or hopefulness, do not come to the fore in the description, and seem to clash with the persistence of the wish to die. In order to reflect further on the case in relation to the question of good outcomes of chaplaincy care for PPD requesting PAD, we turn to an inclusive conceptual understanding of chaplaincy that is based on the metaphorical explanation of existential processes as orientation processes by philosopher Charles Taylor ([Schuhmann and Damen 2018](#)). According to [Taylor \(1989\)](#), in order to orient ourselves in life, we need orienting frameworks, consisting of visions of a “good life”, a life worth living, that, to us, represent appealing and plausible answers to the question of how to live, and thus provide us with direction and meaning in life. Traditionally, worldview traditions provided people with orienting frameworks, but, in the context of secularization and pluralization, people may draw from multiple worldview traditions simultaneously, both religious and non-religious, when attempting to orient in life. When people experience disorientation, for instance due to illness or loss, chaplains provide spiritual care by supporting them in their attempts to regain a life worth living, that is, in their search for reorientation. In this view, “good outcomes” of spiritual care may be understood in terms of managing to reorient in life. In case of a request for PAD, this notion of a good outcome of spiritual care does not immediately make sense. A request for PAD indicates that, according to the patient, life is not and will not be worth living due to unbearable suffering.

Looking at the case description, we see that the patient, who was in a state of severe disorientation wherein any possibility of living a good life seemed lost when she met the chaplain, did not eventually reorient towards a vision of a life worth living as a result of spiritual care. Still, something had changed in terms of orientation, as the patient had obtained a better view of her position in life, of how she had, in the course of her life, arrived at this position, and of how her visions of a good life had slipped out of reach. The patient also had obtained a better view of the ambivalent role of her Christian background in her experience of disorientation, both providing her with strength and feeding her feelings of guilt. There was also a subtle kind of reorientation involved in the process, as being seen and affirmed by the chaplain softened the patient’s loneliness. It seems that what may be achieved in spiritual care for PPD who request for PAD are subtle forms of reorientation. Patients may gain a clearer view of what, to them, constitutes a life worth living, and of how they lost orientation, and thus a milder view of themselves and their struggles. They also may experience the goodness of building a connection with someone who looks at them compassionately. Even if spiritual care does not lead to a renewed sense that one’s life is worth living, it may result in reorientation in the sense of having clarified the underlying motivation of a patient’s wish to die. Eventually, spiritual care may result in a “good” death in the sense that the patient dies in the company of someone who has seen and affirmed the patient’s unique existence.

The idea that spiritual care for PPD requesting PAD can result in good outcomes while a wish to die persists also suggests that notions such as faith and hope— notions that may seem to be at odds with a wish to die—do play a role in spiritual care in the context of a request for PAD. [Schuhmann and Damen \(2018\)](#), in their inclusive conceptual understanding of chaplaincy, describe faith as a characteristic feature of the profession. They use work by philosopher Iris Murdoch to argue that all chaplains, irrespective of their worldview, represent the faith that, even when one experiences severe disorientation, when all good seems lost, it makes sense to keep searching for visions of the good ([Schuhmann and Damen 2018](#)). [Murdoch \(2014\)](#) writes that, both in religious and non-religious traditions, faith involves connecting “a clear-eyed contemplation of the misery and evil of the world with a sense of an uncorrupted good” (p. 59). The case description illustrates that, in the context of a request for PAD, representing faith should not be mistaken for attempting to impose on patients the view that some vision of the good may eventually be found, thus attempting to persuade them to refrain from PAD. The chaplain in the case description represents faith by attentively listening to stories of tragedy, suffering, and despair, and, at the same time, searching for openings in the stories—in other words, by “listening beyond the wish to die”, as it was described above. There is a sense of hope in listening beyond the wish to die that might be mistaken for a lack of recognition of the hopelessness in unbearable suffering ([Dees et al. 2011](#)). Listening beyond the wish to die, however, is not grounded in faith that a spiritual caregiver may instill hope in patients, but in the faith that being compassionately addressed and affirmed as a human being may be a meaningful experience, even when all hope to live a life worth living is lost. This idea fits in with a humble understanding of the role of hope in the work of spiritual caregivers ([Capps 1995](#); [Nolan 2011](#)). [Olsman \(2020\)](#) phrases this role as follows: “Hope belongs to the heart of their work, not as an object that could be offered or given to patients, but rather as something that may arise when they acknowledge patients’ despair and other tough experiences” (p. 9). The notion that spiritual caregivers need to be humble as to what they may achieve in terms of relieving unbearable suffering brings us back to the work of [Murdoch \(2014\)](#), who argues that such humility is not a sign of failure, but rather of moral accomplishment: “Humility is not a peculiar habit of self-effacement, rather..., it is selfless respect for reality and one of the most difficult and central of all the virtues” (p. 93).

3.3. *Spiritual Care for PPD Who Request PAD in Relation to the Assessment of Due Care Criteria*

What may we learn from the case description about the contribution of spiritual caregivers to the care for PPD who request PAD? While literature on spiritual care in a palliative context suggests that the work of spiritual caregivers fits neatly into the broader care provision, this is less obviously the case in the context of a request for PAD. We saw that it may be meaningful for PPD to freely express and explore ambivalence and doubts concerning their wish to die with a spiritual caregiver. A free expression of doubt is only possible if there are no negative consequences for an eventual request for PAD. This suggests that spiritual care needs to remain, at least to some extent, a “free space”, and should not be fully incorporated into the care process in which due care criteria are assessed. It can, however, also be derived from the case description that spiritual care may play a positive role concerning the assessment of at least one of the due care criteria. An outcome of spiritual care may be that patients can reconnect with their past. Exploring how a wish to die is situated in the biography of PPD may help them to take a closer look at the underlying suffering: “Unbearable suffering can only be understood in the continuum of the patients’ perspectives of the past, the present and expectations of the future” ([Dees et al. 2011](#), p. 727). Through spiritual care, a wish to die may develop into a newfound life perspective, but a wish to die that is grounded in panic and isolation may also develop into a wish to die based on self-compassion and acceptance. This shows the potential value of spiritual care, not only for PPD, but also for other caregivers involved. Although assessing the due care criteria will remain difficult when considering a request for PAD by PPD, clarifying whether the wish comes from accepting the current situation or

attempting to flee from it may aid the physicians involved when assessing the criterion of a well-considered request.

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