The Darker Side of Ageing: Towards an Ethics of Suffering that Emphasises the Primacy of Witnessing

Els van Wijngaarden¹

Received: 24 March 2021 / Accepted: 16 May 2021 / Published online: 4 August 2021
© The Author(s) 2021

Abstract

Many older adults succeed in finding meaning in life, even in deep old age. There is, however, a minority of older adults, in particular among the oldest old, who feel that life no longer makes sense: they suffer from the consequences of old age, explicated in feelings of loneliness, social isolation and disconnectedness, and fears for (further) decline and dependency. This article seeks to address this darker side of ageing. It discusses probing questions including: what can we learn from the stories of those who severely struggle with the consequences of old age? And how might these stories guide us in finding ways how we – both as fellow human beings and as a society – can face and respond to suffering in old age? To achieve this, this article first briefly outlines the scholarship on suffering and explores the idea of suffering from life in old age. Secondly, drawing on empirical work, it reflects on the phenomenological question: what is it like to suffer from life in old age? What does it mean to live with a deep sense that life is no longer worth living? Then, thirdly, building on these insights, the aim is to work towards developing an ethics of suffering that emphasises the primacy of witnessing. It is argued that in the confrontation with manifestations of meaninglessness and suffering that cannot be solved or remedied, we need bystanders who are willing to name, to narrate, to give voice and connect to these experiences of suffering.

Keywords Ageing and old age · Suffering (from life) · Tiredness of Life · Witnessing · Phenomenology · A communicative ethics

Introduction

Being 84 years old, Michael Hellgardt struggles with tinnitus, arthritis and rheumatism. The penetrating noise in his head, the pain and the tiredness dispel his joy of living. Despite his longing for death, there are also moments that

✉ Els van Wijngaarden
e.vanwijngaarden@uvh.nl

¹ Department of Care Ethics, University of Humanistic Studies, Utrecht, the Netherlands

his will to live seems stronger; especially during moments when listening to Bach, or when meeting up with loved ones, or when enjoying a nice cake in a neighbourhood cafe. But the overall felt malaise predominates. He experiences his body increasingly as a hindrance, disabling him to engage in the activities he loved. Struggling with the age-related deterioration, he feels more and more disconnected from world around him, alternately unable or unwilling to reconcile himself with his estranged and resisting body.

(based on the documentary *Full Stop*, 2020¹)

Although most older adults succeed in finding meaning in life, even in deep old age (van Campen, 2020; van Campen & Verbeek-Oudijk, 2017), there is a minority of older adults who feel that life no longer makes sense (van Wijngaarden et al., 2015). As reflected in Michael's case, those people may suffer from the consequences of old age, explicated in feelings of loneliness, social isolation and disconnectedness, and fears for (further) decline and dependency. Consequently, some older adults may develop a wish to die (McCue & Balasubramaniam, 2017; Richards, 2017) + (van Wijngaarden et al., 2016; Hartog et al., 2020). Both in Belgium and the Netherlands, multiple geriatric syndromes in combination with old-age vulnerabilities are, in some cases, evaluated as 'unbearable and incurable suffering' and in such instances the people concerned may possibly be eligible for euthanasia or physician assisted suicide (Van Den Noortgate & Van Humbeeck, 2020) + (van den Berg et al., 2020).

To refer to this age-related suffering, several phrases are used interchangeably in research, health care and the public debate, most common of which are: 'tiredness of life', 'completed life' and 'suffering from life'. In Belgium, tiredness of life is most frequently used (Van Humbeeck et al., 2019) and defined as 'suffering caused by the prospect of having to continue living with a very poor quality of life, not predominantly caused by a physical or psychiatric disease, and closely associated with a death wish' (Van Humbeeck et al., 2019). A complicating factor, however, is that in other literature, tiredness of life is associated with a clinical depression, suicide (Barnow & Linden, 1997; De Leo & Spathonis, 2003; Dennis et al., 2007) and terminal illness (Kelly et al., 2002). Moreover, this phrase suggests a one-sided focus on (physical) tiredness, while research has not only pointed out that the tiredness is multi-dimensional, but should also be seen as one constituent among others (van Wijngaarden et al., 2015). Therefore, the phrase falls short in describing the phenomenon concerned (van Wijngaarden, 2016, 255).

In 2010, the phrase 'completed life' was coined in the Dutch right-to-die debate and used to describe the situation of older persons who consider their lives to be completed and, instead of waiting for a natural death, desire to conclude it' (Peters, 2010). Lately, this phrase is taken up by a USA right-to-die movement.² Also in ageing research, the notion of 'completed life' is recently

¹ In Dutch 'Punt Uit', in Deutsch 'Schluss Aus'. For the trailer see: <https://www.youtube.com/watch?v=hgGvB83VaUI>

² For an impression of The Completed Life Initiative, founded in 2019, see: <https://completedlife.org>

suggested as a challenge to traditional ideas about later life (Gilleard, 2020). However, research has indicated that ‘completed life’ is an inappropriate frame to describe the phenomenon at stake (van Wijngaarden, 2016), demonstrating that the lived experience of the people concerned is not (or not mainly) about ‘completeness’. Instead it is rather characterised by existential suffering from a sense of disconnectedness in old age, referring to predominantly negative experiences that condition one’s quality of life (van Wijngaarden et al., 2015).

The phrase ‘suffering from life’ – introduced by the Dutch Committee Dijkhuis (2004) and adopted by The Royal Dutch Medical Association – refers to ‘suffering under the prospect of having to continue life at a profound diminished level of quality, which results in persistently recurring longing for death, without being able to determine a somatic or psychological reason’ (Dijkhuis et al., 2004). It refers to a personally experienced threat, not excluding physical, emotional, existential or social suffering. Although the concept ‘suffering from life’ does not necessarily refer to old age, and might be a bit broad, it is regularly used in this context. Drawing on empirical research, to date I regard the phrase ‘suffering from life in old age’ most suitable to describe the phenomenon concerned. It acknowledges the experienced threat that impacts people’s total state of life, and does not underestimate or cover up the level of despair in the lives of the people who consider life is no longer worth living.

In this article, I explore a probing question related to the experience of suffering from life in old age, namely: what are appropriate ways to face and respond to experiences of suffering in old age? My main aim is to establish an outline for a communicative ethics of suffering that underlines the *primacy* of witnessing as a form of care, preceding any intervention. To achieve this, this article is structured as follows: First, conceptually, I position myself within the scholarship on suffering and, more specifically, I discuss the phrase ‘suffering from life in old age’. Second, drawing on my own empirical work, I reflect on the phenomenological question: what is it like to suffer from life in old age and live with a deep sense that life is no longer worth living? Then, third, building on these insights, in the last part of this paper I work towards developing an ethics of suffering that emphasises the primacy of witnessing. I argue that in the confrontation with manifestations of meaninglessness and suffering that cannot be solved or remedied, we need bystanders (such as family, friends, neighbours, professionals and other close ones) who are willing to name, to narrate, to give voice and connect to these suffering-experiences.

Suffering from Life in Old Age

In this section I discuss the concept of suffering and the phrase ‘suffering from life in old age’. By suffering I do not mean temporarily suffering, being a very common experience in human life. Rather, in this article, I refer to long-lasting, severe suffering, most often caused by combined effects of multiple symptoms (den Hartogh, 2017). Following Fredrik Svenaeus’ phenomenological accounts

on suffering (2014, 2018), I understand suffering as ‘a threatening and alienating mood³ that involves the person’s entire lifeworld’. Since it is beyond the scope of this article to provide a full critical assessment of definitions of suffering, below I limit myself to underscoring some features that I consider crucial for our understanding of suffering in the context of ageing.

Personal Threat

One of the most regarded contributions about suffering in the context of medicine is by Eric Cassell. For him, suffering concerns the disintegration of life, the threat of one’s integrity, the destruction of the intactness of a person (Cassell, 2004: 32). It implies the belief that one’s personhood is fundamentally at risk. With reference to Heidegger, Svenaeus describes suffering basically as an experience of ‘unhomelikeness’ proposing that suffering can be conceived as ‘an alienating mood overcoming a person and engaging her in an embodied struggle to remain at home in the face of loss of meaning and purpose in life.’ (Svenaeus, 2014, 2018). Helen Black, who investigated the lived experience of suffering in old age by interviewing 40 people, underscores that suffering is an utterly personal experience. She defines suffering as ‘the visceral awareness of the self’s vulnerability to be broken or diminished at any time and in many ways.’ (Black, 2018). Hence, Black seems to start from a somewhat different conception of the human being than Cassell, not referring to suffering as a threat of ‘the integrity’ or ‘cohesiveness’ of persons. Rather she starts from the idea that all human beings should be conceived as vulnerable beings. Suffering, then, makes vulnerable people extra vulnerable, or even ‘breaks’ them, as she puts it.

Situation of Uncontrollability

To underscore that suffering always has a passive side, Frans Vosman (2017) cites Paul Ricoeur who used the term ‘passibilite’ to indicate this experience of undergoing reality. Creatures do not simply act, but always also undergo (Ricoeur, 1986, In: Vosman, 2017, 71). They not only undergo their own body turning up against them as alien. They also undergo the actions of other human individual actors as well as the influences of non-human entities such as the atmosphere, the context, institutions and other practices. In suffering, people find themselves in a situation of passivity in relation to feelings that hurt them, threatened with the unmanageable, that which one cannot control. It concerns a sense of being acted upon, being violated, being doomed just to undergo the alienating mood, unable to act. In suffering, the environment no longer conforms or supports the person in question. Rather, it has

³ Distinguished from sensations and emotions, in a phenomenological sense, ‘moods’ determine the way the whole world appears to us, opening up the world to a person in a certain tone or color. Moods interpenetrate the other dimensions of the lifeworld, shaping one’s spatial, temporal, intersubjective and embodied horizons, not just as an internal happening, but perceptual and interactive (Svenaeus, 2014, 2018; Todres et al., 2007).

changed into a hostile reality that breaks one down, lacking a place where one can withdraw, feel safe, have a sense of belonging (Vosman, 2017).

Interplay of Dimensions

Suffering is not merely a matter of pain and other physical symptoms, but in addition has psychological, social and existential dimensions. Indeed, social and existential concerns are often more prominent than physical symptoms, also in end-of-life research (Dees et al., 2011; Rodríguez-Prat et al., 2017). Moreover, suffering does not consist in symptoms. Pain, for example, can be an (important) element, but is usually not considered the cause of the suffering. To find the cause of suffering, you need to know what the pain *means* to the sufferer (den Hartogh, 2017). For whether a condition or symptom is perceived by someone as a severe threat will depend on the person one is, one's character, life history and values. The gravity of the suffering is influenced by the way people evaluate their suffering against the background of their personality characteristics, life history and core values (Cassell, 2004; den Hartogh, 2017; Svenaeus, 2018). This means that to understand suffering, we have to consider the interplay of the different elements and dimensions (rather than making lists of the symptoms) and explore the meaning that these – as a whole – have on a person's life (den Hartogh, 2017).

Beyond the Individual Domain

Among others, Vosman (2017) points our attention to the contextuality of suffering-experiences. He identifies a tendency – especially in bioethics – of the privatisation and psychologicalisation of experiences in general and of suffering-experiences more specifically (Vosman, 2017: 70). Experiences tend to be reduced to a psychological occurrence inside someone's mind (Vosman, 2017: 67). According to Vosman, this tendency is also traceable in Cassell's argument, as it contends that suffering is ultimately a personal matter, something whose present and extent can only be known to the sufferer (Cassell, 2004: 34). He argues that by wrongly understanding suffering as something that mainly occurs within an individual, more precisely in one's psyche (2017: 70), we run the risk of neglecting the multiple contextual sources of suffering. He thus makes a strong plea to understand suffering-experiences as being embodied, situated, and mediated by context and practices. Suffering should thus be understood as a socio-culturally contextualized phenomenon (Priya, 2012). Along with aspects of personhood, culture shapes the experience of suffering (Kleinman, 1988/2020; Kleinman et al., 1997): not being able to execute roles or commitments that are culturally valued due to one's illness or disability may in some cases be a key driver of the suffering.

Suffering from Life in Old Age

Suffering can be understood as an intentional state (Cassell, 2004; den Hartogh, 2017), having two aspects: the state itself and its object. This means that if you

suffer, there has to be something that you suffer from. But is it apt to invoke a category of age to which the suffering is related? Some argue that suffering in old age refers to all kinds of losses and deterioration that are, as such, not distinctive for old age. By creating a category of old age, we may not only run the risk homogenizing the people who inhabit such a category, but also stigmatizing the last phase of life (Ruddick, 2000). Therefore, it is important to underline that using the wording ‘suffering from life in old age’ is not to suggest that old age is a very distinct, separate phase of life or a source of suffering as such. Rather, with this phrase, I intend to acknowledge the accentuated struggles that people may have to face particularly during the last phase of life. These may be more typical and predictable, though by no means limited to nor always present in old age.

Among others, Erikson and Erikson (1998) have described the very last phase of life as a distinct phase. In this last phase of life people actually re-face all kinds of crises from the previous periods of life, but the confrontation with these crises is heavily intensified by a whole range of new challenges (Erikson & Erikson, 1998). As such, old age has its own burdens and existential issues (Längle, 2001). To a greater or lesser extent, the ageing process typically goes along with bodily decline and deterioration. Hence, people often have to deal with (a chain of) multi-dimensional losses: the decrease of vitality, of intensity of drives and of cognitive capacities, as well as losing control, autonomy and independence. Commonly, one also has to deal with prevailing negative social attitudes and stereotypes (understanding oneself as a burden, feeling pushed to the sidelines) which may evoke feelings of shame, isolation and loneliness. Also, undoubtedly, time and possibilities (for change) are running out (Ruddick, 2000). Although in different degrees, older adults face these challenges. Whether one flourishes or suffers in the midst of this might be related to the question of whether one is willing and/or able to stay connected or rather resists or resigns and, perhaps even more important, whether others and/or society stay connected with those who have reached deep old age (van Wijngaarden et al., 2015).

Considering these nuances, in my view the phrase ‘suffering from life in old age’ fits to describe the experienced threat that greatly impacts the existence of those who feel life is no longer worth living.

Lived Experience of Older Adults Suffering from Life

Having positioned myself in the scholarship on suffering, and discussed the phrase ‘suffering from life in old age’, in the following session, I aim to illuminate this specific suffering-experience. Drawing on previously published empirical work, I will reflect on the phenomenological question: what is it like to suffer from life in old age? What does it mean to live with a deep sense that life is no longer worth living? Over the years, I have conducted several studies in which I explored the life-world of people like Michael (van Wijngaarden et al., 2015; van Wijngaarden et al., 2016; Hartog et al., 2020). Analysing these stories brought into view several central meanings. Below, I mention four. To illustrate these meanings, I also include four typical descriptions that originate from my research, using pseudonyms. As it

is beyond of the aim and scope of this article, for methodological issues and other background information concerning the cited phenomenological studies, I refer the reader to these empirical publications.

Feeling Disconnected from One's Sense of Self(-Identity)

People who 'suffer from life in old age' often intensely suffer from a pile of different conditions such as ill-health; age-related losses; bereavement; loneliness; isolation; traumas; burdensomeness; having a low social status associated with retirement; poor economic situation due to a limited pension; lack of available meaningful projects; and/or uncertainty about the adequacy of welfare services and care arrangements (van Wijngaarden et al., 2015; Hartog et al., 2020). These different conditions lead to distinct, often intertwined dimensions of suffering.

One of the main concerns appeared to be the fear of losing one's identity (van Wijngaarden et al., 2015). Prado uses the notion of 'epistemological crisis' to refer to such fears (Prado, 1998, 23). He describes how the self-identity of ageing individuals can be severely threatened by interpretative difficulties, feeling alienated from the things that were most dear to them in life. This was reflected in my research; participants struggled with the loss of essentials that constituted their lives, such as identifying activities, capacities by which they expressed themselves, worthwhile projects that reflected their personality.

After retirement Babette (87) painted a lot. Her living room is fully decorated with all kinds of colorful paintings. All made by herself. Painting was the way for her to express herself. But when we talk about it, she sadly says: 'I can't see it anymore, I just see black.' In recent years, she's had many injections in her eyes, but it's not helping. 'Cataract has won. My world has no color anymore. I had to give up a lot: my car, later on my 45-kilometer car, my bicycle. You lose all your freedom. I can no longer help anyone, no longer write, no longer paint. At best, I can just chatter on the phone. So much is falling away...' She experiences the losses she has to bear as an assault on her identity, saying: 'Actually, I am no longer human.'

In the stories, shame and indignity were evoked by failure of living according to their own values and commitments (van Wijngaarden et al., 2015). Always having thought of themselves in terms of being in control and independent, it became very difficult – indeed almost unbearable – to recognise a growing dependence, because it contradicted their personal standard. In their view, something precious has gone that could not be regained anymore, resulting in a sense of disconnectedness from oneself. As such, these people suffered not only from a loss of autonomy but also from a loss of authenticity (Ahlzen, 2020) + (Wijngaarden, 2021).

Feeling Disconnected from One's Own Body

For the older persons who suffered from life, the body appeared in a new and threatening way: it had become a source of suffering. The deterioration, the vulnerability,

the dependency, the loss of control, the difficulty of moving, the tiredness; such age-related losses were experienced as a breakdown of ordinary life (van Wijngaarden et al., 2015). Formerly, their body had been a self-evident way of being-in-the-world. They had taken their bodily capacities for granted. But gradually, nothing could be taken for granted anymore. More and more, they were losing control over their body, which was experienced as one of the gravest crises.

The first experience of faecal incontinence was the moment, when Steven (75) strongly felt he was losing grip on his body, because things happened beyond his control. 'I went out with Anita, watching birds, and uh, I said: "Oh, I need to pee", so I walked out of the bird hide, stood there and then I peed. But then..., I'll just say it, I suddenly pooped too. I deeply, deeply cried, standing there outside in nature. I became intensely sad. (...) I do not know, I burst into tears, I felt so sad about this happening to me. (...) I had no control at all, it just happened without my involvement... I stood there and it just happened unintentionally, it just happened...

The body was no longer experienced as a potential, or capacity for being and doing. Rather the body was experienced as *non*-potential and an *incapacity* (Slatman, 2014). Indeed, they increasingly identified themselves with this deterioration process: in their view, they not only had an incapable body, the body *was* incapacity, and so they were (van Wijngaarden et al., 2015). For the people concerned this had led to an increasing dissociation from their body: they no longer felt at home in and with their body. It progressively became an enemy, an opponent, leading to a form of 'embodied dissociation'.

Feeling Disconnected from Others and the Social World

The people concerned not only lost the sense that their lives were worth living, they also had lost the sense that other people agreed that their lives are indeed worthwhile (van Wijngaarden et al., 2015). They suffered from being unable to meet the dominant socio-cultural demands (Kleinman et al., 1997) feeling side-tracked and left without meaningful roles. The experience of not being listened to anymore, not being taken seriously anymore and the lack of expressions of respect and appreciation affronted their sense of personal worthiness. They had lost the sense that their dignity was respected by others, using a discourse of not-belonging and being-an-outsider (van Wijngaarden et al., 2015).

Raised as a skipper's child, Christian (92) had also chosen a job in shipping: 'Imagine, I've seen the whole world. I have been in charge of major projects. But now, I have no influence on whatsoever. Nothing in prospect. Have you any idea how that feels?' He stares straight ahead and softly says: 'I'm nothing anymore. I'm an outsider. And when I go somewhere - to a shipyard, for example - they look at me like: what the hell is that old, decrepit man doing here? You know, that hurts a lot...'

Rather than suffering from a complete absence of interpersonal relationships, mostly, they suffered from the experience that the remaining contacts did not compensate lonely feelings anymore. The lack of reciprocity caused a deep inner existential ache and a sense of emptiness, void and disconnectedness from others (van Wijngaarden et al., 2015).

Seeing No Future Possibilities Anymore

Suffering from life in old age also has a temporal structure which qualifies the depth of the suffering-experience. In phenomenological research, temporality refers to people's sense of time and the way we experience continuities and discontinuities and how this gives meaning to life, which implies that 'the past becomes meaningful in people's lifeworld as it appears in the present, and the future becomes meaningful as it appears towards us now' (van den Berg, 1972/2013).

A majority of the older adults that I encountered during my inquiries felt hunted by bad memories. More than average, they had experienced misfortunes and pain of considerable magnitude, such as being deprived of one's children, traumatic loss of a partner, abuse, and/or traumatic war experience. These (often overwhelming) afflictions from the past still darkened the present lives of participants (van Wijngaarden et al., 2015). In other situations, the stories concerned mainly echoed the melancholy of a cherished but lost past, contributing to present suffering.

Roelof (93) feels that there is very little left over: 'My life is just trivial. Worthless futility... Life itself is no longer attractive. Eh, it does not matter anymore. I keep on doing things, because, uh, I simply need something to do. Indeed, I have to try to fill the gap by being busy. Because I always have been busy. That's why I'm always looking for something. But I'd rather prefer doing nothing... Look, I can lie down in bed and stop eating and drinking. My discipline is big enough to do so, as far as I feel. But well, I have a partner, so I have to wait. And she has a totally different opinion. She simply doesn't want to die yet, although she's highly disabled... But for me, I'm totally done with it. Life has no value anymore. When I'm dead, everything will be 'cleaned up'.'

The older adults in question not only suffered from a lost past, they also found themselves paralysed by not having any (positive) imagination of the future anymore. While human persons usually feel embedded in a (meaningful) world and oriented towards possibilities, in contrast, the lifeworlds of those concerned were often characterised by significant alterations towards future possibilities. They seemed to perceive their future as 'a dead end'. While their 'biological' time had not stopped yet, they desperately wished that their biographical time would come to an end. Indeed, they were utterly afraid of new narrative openings (Freeman, 2000; Lange, 2010). Because in their view, life could continue only in what they considered to be an 'unacceptable' manner. In a way, they sensed that they had already 'outlived' themselves (van Wijngaarden et al., 2015). Galvin and Todres (2013) have described this as if people are 'frozen in time' without meaningful invitations for the future. They miss 'a call from the future' that can constitute a sense of purpose (Galvin

& Todres, 2013). Hence, sad memories of the past, current discomfort as well as a repulsive future are presently lived as an inseparable unity, evoking a sense of hopelessness.

Applied to our attempt to understand the experience of suffering from life in old age, this shows that it is this intertwined load of past, present and anticipated sufferings that often occupies, holds, or troubles the older adults concerned.

Towards a Communicative Ethics of Suffering

Having described what suffering from life in old age may mean to those involved, I now turn to the ethical question: what are appropriate ways to approach experiences of suffering that cannot be solved or remedied? How to speak about patience and hope, for example, without downplaying the existential crises that the people in question are facing?

A phenomenology of suffering from life in old age is, at least in some sense neutral with respect to ethical questions. Scholars have argued that phenomenology is well-suited for describing the impact of certain experience in all its richness (Ricoeur, 1995). So how does one bridge between phenomenology and ethics? I follow the argument that, since ‘for phenomenology every question concerning any being whatsoever is a question about the sense of that being’, phenomenology can be accounted as an ‘unsurpassable presupposition’ of ethics (Ricoeur, 1995). This is to say that, although phenomenology does not offer causal explanations, clear solutions, nor a set of ethical principles, it can enable us to understand suffering at a deeper level. Rather than to explain *why*, it facilitates an attempt to empathically understand *how* these people are suffering. As such, it can be seen as a proto-ethical enterprise that constitutes a solid foundation for the ensuing ethical reflection that is embedded in real-life experiences and practice (Cohen, 2011; Olafson, 1998; Ricoeur, 1995).

Contemporary Ways of Approaching Suffering

Hence, grounded in a phenomenological understanding, I aim to provide some outlines for an appropriate ethical approach to the suffering-experiences concerned. But before exploring what such an ethics could entail, I first briefly map out three dominant, contemporary ways of approaching suffering thereby drawing on Svenaeus’ inquiry on suffering (2018: 28–29).

1. *Facing suffering through responsiveness/responding*: Some philosophers, theologians and other contemporary thinkers consider suffering as ‘part of life’ and *potentially* meaningful, having a purpose even if we do not understand it right away. From this perspective, despite its perils, suffering can be conceived as a positive, transformative force in life (Bohlmeijer, 2018; de Wachter, 2019; Frankl, 2011; Kierkegaard, 1997; Van Hooft, 1998; Veldman, 2019). It could possibly lead to a more authentic life for the one who suffers if one succeeds in adopting a

right attitude (Frankl, 2011; Svenaeus, 2018). Suffering might also teach a person to know and explore his own limits: learning to live with disappointments, failures and vulnerabilities (de Wachter, 2019; Kierkegaard, 1997), as well as accomplish things despite struggles (Svenaeus, 2018). As such, it can help to find one's place in life and develop one's (moral) character. Moreover, experiences of pain, loss and tragedy can be seen as carriers of a deep longing for the good (Nussbaum, 2001), as it is precisely in the confrontation with suffering and tragedy that people may discover what is of significance and value (Bohlmeijer, 2018; de Wachter, 2019; Veldman, 2019). An ethics of suffering starting from this premise tends to focus on responding by taking a right attitude and trying to be open to learn from it. A suffering person can also respond to the situation by lamenting and/or protesting against it. The response is then that the suffering has to be acknowledged, and should not be denied or ignored.

2. *Diminishing or dissolving suffering through acceptance or indifference:* A second way of understanding and approaching suffering is to develop an attitude of acceptance or indifference towards suffering (e.g. modern forms of stoicism, Buddhism, or the mindfulness movement). In a recent On Being-podcast (Tippett & Banhart, 2020), the book 'When Things Fall Apart' written by the Tibetan Buddhist teacher Chödrön, was discussed. It concerns the question of how to deal with suffering. The overall message is that, paradoxically, suffering begins to dissolve when we can efface the hope that suffering can be escaped. Indeed, to view suffering as something that can be avoided is seen as a forlorn, delusional idea based on what Banhart disputes as 'the belief in a solid, separate self'. From this perspective, to seek for some lasting security is just futile. 'Suffering is part of life. We're stuck in this together. There's nowhere to hide.' (Tippett & Banhart, 2020). It is thus only by acceptance or indifference that the impact of suffering can be diminished or dissolved.
3. *Eliminating suffering through action/activism:* On top of the abovementioned ways, there is a third way, which is probably most widespread and influential in our contemporary society; namely to understand and approach suffering as evil, meaningless and even unnecessary. If suffering lacks any purpose at all, it follows that in medicine managing, alleviating and especially eliminating pain and suffering is seen as a major ethical calling, a duty, perhaps even the most important principle (Svenaeus, 2018). Although not new (as reflected in the Hippocratic Oath), the tendency to eliminate suffering by technology and medical treatment has been significantly strengthened in contemporary times. These medical-technological transformations have great consequences for how we think about and deal with suffering. With its single-minded telos of cure, cosmopolitan medical civilisation has transformed pain, illness, and death from a personal, existential challenge into a medical-technical problem that needs action: human suffering has become a matter of techne, a treatable disorder (Illich, 1995, 2003).

All three approaches have shortcomings and pitfalls in one way or another: those who try to find meaning in suffering by responding or acceptance may tend to trivialise the apparent meaninglessness of some forms of severe suffering. When those around fail to acknowledge the meaninglessness and/or insist to extract explanations

of suffering experiences, in fact these experiences are silenced (Priya, 2012). Next, they may run the risk of interpreting the suffering in dualistic terms, due to a tendency towards a division between (bodily) sufferings and 'higher' life matters and attitudes. Furthermore, they may ignore the potential paralyzing effects of severe suffering and the fact that suffering can disable the facilitating human conditions to respond, act, choose or attune, let alone to master one's attitude.

Those, however, who deny any purpose might neglect the potential for growth in some human suffering (Svenaesus, 2018: 29). Another much-discussed criticism is that modernity has deprived suffering of its personal meaning (Bauman, 1992; Frank, 1995/2013; Illich, 1995, 2003). Whereas traditional cultures made pain tolerable by integrating it into a meaningful narrative and interpreting its necessity, a pain of modernity is that we have lost such grand narratives by dismantling them. 'The new suffering has lost its referential character' (Illich, 2003). Subsequently, this might leave us empty-handed with regard to (a) suitable (and subtle) language to interpret and communicate about these unavoidable existential challenges, (b) ways to come to terms with pain, suffering and death, and (c) ethical standards needed to deal with and accept the fragility of life (Fricker, 2007; Illich, 1995, 2003).

These approaches considered, I think it is justified to argue that there is not just one that can count as 'sufficient'. Notwithstanding the important aspects highlighted by the various approaches, they also leave crucial aspects underexposed. Suffering should not necessarily be seen as something bad or to be avoided always, neither as predominantly positive or transformative. Rather than explicitly express (or fill in for someone else) whether a suffering experience can be regarded as meaningful, meaningless, avoidable or whatever, I would urge bystanders in particular to refrain from making explanatory statements. Instead such persons should let themselves be informed by those who have suffered or are suffering severely. Consequently, in my endeavour to work towards an ethics of suffering, I presume a fruitful approach would be to put the focus on how bystanders should behave, face and respond to suffering. Also, an ethics of suffering should by no means relativize the severity of the suffering-experience; has to be reluctant in explaining the (meanings of) suffering; allow room for different interpretations; and open up ways to communicate about these existential challenges. In what now follows, I suggest that a communicative ethics of suffering that emphasises the primacy of witnessing could be an approach that meets those concerns.

Possible Outlines for a Communicative Ethics of Suffering

S. Kay Toombs (1993), who conducted in-depth phenomenological research on the experience of chronic illness, stresses the importance of recognition in the encounter with persons suffering from severe illnesses. She has argued that phenomenological research is actually indispensable to be able to help or support those who suffer as it illuminates the lived experience of suffering and enhances our understanding of it. She has stated that explicit recognition of another person's suffering requires us to bridge the gap between the separate worlds of ourselves and the other. The bystander who monitors his own reaction and feelings towards the other and his/

her suffering is better able to acknowledge and set aside any preconceived notions which may impede the ability to explore the meanings inherent in the other person's world and suffering. Only an understanding of a particular person's situation and self-understanding can enable us 'to begin the task of constructing a shared world of meaning' with a person (Toombs, 1993). If understanding fails, support is less likely to help. One cannot address a person's suffering unless attention is paid to such (shared) meaning.

The importance of recognition is also emphasised by Vosman and Baart (2009). They argue that before help or support is provided, first there is always an encounter. It is at this basic level of the encounter that decisive questions must be addressed before we can move to the moral framework of helping and support (Vosman & Baart, 2009). Following Housset, they pose that:

...only by being immediately present to oneself can one truly encounter, see and listen to another person. Only then is one able to be moved and touched. This kind of intelligence unfolds through experience rather through theoretical reasoning or observation. It does not analyse, separate and distinguish; instead, it allows life to show itself (2009: 26).

It is about truly seeing, listening, and being moved by the encounter, and about being present to this movement. Indeed, they argue, if we are moved by meeting someone who suffers, we should refrain from the possibility of assuming a neutral position. It is not within the realm of (a detached) reflection *upon* another person. Rather it requires an 'awareness of living *with* others' (Vosman & Baart, 2009). Such an ethical attitude should precede any intervention.

Witnessing

Supplementary to recognition, in the context of suffering in the lives of older people, the concept of witnessing is also used (Gilleard, 2018; Vosman & Baart, 2009). Witnessing can be defined as 'to bear witness, to testify, to give evidence, to be a spectator or auditor of something, to be present as an observer, to see with one's own eyes'. Although the meanings of recognition and witnessing are closely related, the concept of 'witnessing' underscores more explicitly the movement from the pathic level to the ethical level (Oliver, 2015; Stumm, 2010; Vosman & Baart, 2009).

Following Ricoeur, ethically witnessing others should not be understood simply as a matter of testifying to truths about the lives of others, but rather as a matter of responding to them as people, and thus responding to their humanity and otherness. Rather than being just spectators or analysers of other people's lives, ethical witnessing is a responsive way of being with and for others (Stumm, 2010). Hence witnessing can be described as a 'process of addressing and responding, testifying and listening' (Oliver, 2015). As such, it first refers to a 'practice of seeing' which shapes one's response, and second, to a way of 'being present in a response-able relationship and dialogue' to whom is being witnessed (Stumm, 2010). Witnessing,

understood in this way, becomes a form of testimony that explicitly acquires a political-ethical connotation.

Being Witness to the Lives of the Oldest Old

According to Chris Gilleard (2018), serving as a witness of the suffering of deep old age can be seen as a foundation for an ethics of human dignity and a call upon social solidarity (Gilleard, 2018). If we want to counteract the social neglect and/or abjection of the oldest old, he argues, we should control the tendency to turn our backs to tragic (often unsolvable) sides of the ‘fourth age’ and instead pay full attention to struggles that people might experience, suppressing the impulse to immediately dissolve or intervene their pain. Likewise, Vosman and Baart (2009) used the concept of ‘being witness’ to the lives of the oldest old and connect it to the concept of recognition. With reference to the work of Housset and Ricoeur, they also conceive witnessing to be a form of remembering and publicly voicing:

Not only have we seen, heard, felt and smelled what has happened and have understood it in one way or another; we publicly express what can be dismissed to oblivion and what must be remembered, whether the people we have encountered can speak for themselves or not (2009:25).

Being witness to the lives and the suffering of the oldest old requires an attempt not only to understand and face the experiences, but also to name, to narrate, and to connect to their stories. Even when these stories might evoke feelings of disapproval, disgust, or vicarious shame (Gilleard & Higgs, 2011; Higgs & Gilleard, 2015). It is, after all, by means of narratives that people can come to terms with suffering. Carefully telling and retelling stories is a form of acknowledgement. As Hannah Arendt has put it in *The Human Condition*: ‘All sorrows can be borne if you put them into a story or tell a story about them’ (Arendt, 1998/1958). By telling stories, we can make things real. Telling and retelling stories about suffering can be a way to acknowledge the authenticity of the suffering. It can open up the possibility for a real encounter with the suffering-event, and a recognition of what the sufferer has undergone/is undergoing. As such stories are a form of consolation. Cornelis Verhoeven, a Dutch philosopher, has made it clear that, in essence, consolation is not about helping others to get their mind off things and set their sights on new horizons (1971). Rather, he has argued, real consolation requires from us to ‘dig up’ the suffering, to dwell with it, to undergo the story without downplaying or trivializing its gravity and/or unbearability (Verhoeven, 1971). Indeed, suffering necessitates an ability to be present in/despite the (full) awareness of being unable to do, solve or fix anything. It requires the willingness to recognise and accept the potential meaninglessness of suffering.

Witnessing All Stories?

As mentioned before, it depends on the person in question how the gravity of the suffering is experienced. Many of my research participants often intensely suffered

from a pile of different losses, leading to a form of despair. Although most people would suffer from similar conditions more or less, presumably a majority would treat it more lightly and not develop a wish to die. The same goes for fears: most participants were horrified by all kinds of anticipated fears regarding the future, including but not limited to (further) development of certain illnesses, unwanted side-effects of possible treatment options, total dependence on others, and forced relocation (van Wijngaarden et al., 2015; van Wijngaarden et al., 2016; Hartog et al., 2020). Most people in a somewhat similar situation will recognise the concerns, but supposedly not become paralysed by such concerns and rather find ways to cope with them. In fact, some fears may even sound (or perhaps be) exaggerated or unrealistic to those around (den Hartogh, 2017). But even if so, an important question is: should we try to 'educate' the people concerned, telling them that – for example – a good life may include being dependent on others, attempting to reframe their story? Or should we rather try to respect their ideas and values? By contrast, can we take other people seriously without being honest to them if we seriously doubt their perception?

Den Hartogh (2017: 420) actually defends that if a person has lived in 'an illusion' of self-sufficiency or independence all his life and believes that it is just humiliating to be dependent on the care of others, we had better acknowledge and respect that as a relevant fact about his identity as a person whether this belief is realistic or not. And I agree; a suffering-experience is first and foremost a mood that requires to be respected. It is determined by the way in which one experiences the world and by one's life values, disregarding whether others can conceive this experience as consonant with reality or not. This means that, when telling and retelling stories about suffering-experiences, bystanders should not start disputing a person's approach to the situation, but rather start from the primacy of witnessing.

Nevertheless, witnessing should not be understood as an end point as such. Through immediate presence and recognition, a bridge can be built and function as the starting point. A responsive, reciprocal relationship, though, requires not just an echo, but mutual exchange (Rosa, 2019). Those involved in the relationship should be open enough to be affected and reached by the other, but also be sufficiently self-consistent to (speak up in their own voice) (Rosa, 2019). Consequently, this does not rule out dispute, but rather emphasises the importance of postponing it until a right moment.

A Communicative Ethics of Suffering

In making a plea for an ethics of suffering, some pitfalls need to be avoided. Care ethicist Selma Sevenhuijsen (1998), for example, has criticised some ethics of suffering. Basically, she demands our attention to the fact that caring for those who suffer can stem from less noble motives, such as the urge to meddle or control others, which can lead to paternalism and undue protection, and become an element in power strategies (1998: 20). Although she does claim that an ethics of suffering requires the ability and willingness to place oneself in the perceptions and viewpoints of those who suffer, she argues that an (over)emphasis on attentiveness and empathy can lead to entrenched divisions of moral roles between those who suffer

and those who bear witness (e.g. the victims and the relievers) (Sevenhuijsen, 2003: 186). Sevenhuijsen also distrusts the Christian ideal of self-sacrificing love that, according to her, is characterised by ‘a peculiar mixture of dedication to suffering and normative self-assertation of the moral subject’. Following Michel Foucault, she warns for so-called ‘pastoral power’ that labels care for the other and ‘love motives’ as ‘one of the most insidious of the many shapes of domination’ that might blackmail its objects into obedience (Sevenhuijsen, 1998:18).

In Sevenhuijsen’s view, these adverse effects can be prevented when an ethics of suffering becomes a communicative ethics (Sevenhuijsen, 1998, 2003). Such an ethics emphasizes the recognition of plurality and particularity, advocating more inclusive speaking styles as a way to more efficiently enable persons to speak across difference as well to express the particularity of a social situation. It also calls for the demand for self-transcendence inherent in the communicative process. Grounding her argument in the work of the feminist philosopher Iris Marion Young, she suggests that the concept of ‘asymmetrical reciprocity’ is helpful here. This notion, she argues, implies the assertion that we can never completely see the world ‘through someone else’s eyes’, nor that it is possible to ‘stand in someone else’s shoes’. In fact, the other is someone whose mental life I will never truly know. In fact, it is this non-knowability that constitutes the alterity of the other. It follows that for Sevenhuijsen, ethical relations do not so much imply a norm of ‘role reversal’ but they paradoxically begin from respectfully taking distance from the other. An ethical relation requires the willingness to be open to everyone’s unique, embodied subjectivity as well as the idea that everyone is positioned differently and leads an existence which cannot be reduced to that of others (Sevenhuijsen, 2003: 186–187). Ethical relations (and ethical communication), she argues, are aided by the existence of ‘interpersonal space’. With these, she means ‘topographical and symbolic spaces in which people can distinguish themselves from one another and in which they can respect the differences among themselves: spaces in which they can be together in one place, rather than being given the moral assignment of ‘taking each other’s place’ (Sevenhuijsen, 2003: 187).

Applied to an ethics of suffering, this means that we should strive to aim for a *communicative* ethics that implies careful and respectful listening and responding to the voice of those who are suffering. Such communication – based on respect for plurality – can lead to more or less extensive forms of ‘mutual understandings’, and as such offer a form of consolation.

Concluding Remarks

In the writing of this paper, my endeavour was not to identify a set of resources for how we can overcome or restore experiences of meaninglessness and suffering. Rather my endeavour was to (reluctantly) think through how to face, and come to terms with suffering from life in old age, and establish some possible outlines for a communicative ethics of suffering, particularly from the perspective of bystanders. Certainly, I did not mean to trivialise our duty to do our best effort to minimise

and relieve suffering if such is possible. My aim was first and foremost to underline the *primacy* of witnessing as a form of care, preceding any intervention. Only after ethically witnessing the gravity and the meaning of the suffering for the sufferer, we might be able to figure out appropriate ways to help and support those who suffer and appropriately make a stand against solvable, unnecessary and/or unjust suffering.

Acknowledgements With particular gratitude, I acknowledge the older persons who participated in my research over the years. This article is mainly a reflection of the lessons learned from these encounters. I presented a former version of this article on the 2020 McDonald Centre Conference. I thank the delegates for their thought-provoking comments that helped my thinking forward. I am also indebted to the anonymous reviewers and my colleague Carlo Leget and Bernadette Roest for their constructive comments on earlier drafts of this article.

Declarations

Ethics Approval Not applicable.

Conflict of Interest The author has no relevant financial or non-financial interests to disclose.

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>.

References

- Ahlzen, R. (2020). Suffering, authenticity, and physician assisted suicide. *Medicine, Health Care and Philosophy*, 23(3), 353–359. <https://doi.org/10.1007/s11019-019-09929-z>.
- Arendt, H. (1998/1958). *The human condition*. University of Chicago Press.
- Barnow, S., & Linden, M. (1997). Suicidality and tiredness of life among very old persons: Results from the Berlin Aging Study (BASE). *Archives of Suicide Research*, 3(3), 171–182. <https://doi.org/10.1080/13811119708258269>.
- Bauman, Z. (1992). *Mortality, immortality and other life strategies*. Stanford University Press.
- Black, H. K. (2018). *Soul pain: The meaning of suffering in later life*. Routledge.
- Bohlmeijer, L. (2018). “Angst en onzekerheid geven betekenis aan het leven. Ga ze niet uit de weg”: interview met Damiaan Denys. *De Correspondent*. Retrieved from <https://decorrespondent.nl/9039/angst-en-onzekerheid-geven-betekenis-aan-het-leven-ga-ze-niet-uit-de-weg/637183985328-283b8250>.
- Cassell, E. J. (2004). *The nature of suffering and the goals of medicine* (2nd ed.). Oxford University Press.
- Cohen, S. (2011). The proto-ethical dimension of moods. In *Philosophy's moods: The affective grounds of thinking* (pp. 173–184): Springer.
- De Leo, D., & Spathonis, K. (2003). Suicide and euthanasia in late life. *Aging Clinical and Experimental Research*, 15(2), 99–110. <https://doi.org/10.1007/bf03324486>.
- de Wachter, D. (2019). *De kunst van het ongelukkig zijn*. Lannoo Campus.

- Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Vissers, K. C., & van Weel, C. (2011). 'Unbearable suffering': A qualitative study on the perspectives of patients who request assistance in dying. *Journal of Medical Ethics*, 37(12), 727–734. <https://doi.org/10.1136/jme.2011.045492>
- den Hartogh, G. (2017). Suffering and dying well: On the proper aim of palliative care. *Medicine, Health Care and Philosophy*, 20(3), 413–424. <https://doi.org/10.1007/s11019-017-9764-3>.
- Dennis, M., Baillon, S., Brugha, T., Lindesay, J., Stewart, R., & Meltzer, H. (2007). The spectrum of suicidal ideation in Great Britain: Comparisons across a 16–74 years age range. *Psychological Medicine*, 37(6), 795–805. <https://doi.org/10.1017/s0033291707000013>
- Dijkhuis, J. H., Markenstein, L. F., de Beaufort, I., van Berkestijn, T. M. G., van Delden, J. J. M., van Gool, A. R., ... Wigersma, L. (2004). *Op zoek naar normen voor het handelen van artsen bij vragen om hulp bij levensbeëindiging in geval van lijden aan het leven. [Searching for standards for physicians on dealing with requests for termination of life in case of "weary of life"] [in Dutch]*. Retrieved from
- Erikson, E. H., & Erikson, J. M. (1998). *The life cycle completed (extended version)*. WW Norton & Company.
- Frank, A. W. (1995/2013). *The wounded storyteller: Body, illness, and ethics* (2 ed.). The University of Chicago Press.
- Frankl, V. E. (2011). *Man's search for meaning*. Ebury Publishing, Rider Books.
- Freeman, M. (2000). When the story's over. In M. Andrews, D. S. Sclater, C. Squire, & A. Treacher (Eds.), *Lines of narrative. Psychosocial perspectives*. Routledge.
- Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.
- Galvin, K., & Todres, L. (2013). *Caring and well-being: A lifeworld approach*. Routledge.
- Gilleard, C. (2018). Suffering: The darker side of ageing. *Journal of Aging Studies*, 44, 28–33. <https://doi.org/10.1016/j.jaging.2017.12.001>.
- Gilleard, C. (2020). Finitude, choice and the right to die: Age and the completed life. *Ageing & Society*, 1–11. <https://doi.org/10.1017/s0144686x2000149x>.
- Gilleard, C., & Higgs, P. (2011). Ageing abjection and embodiment in the fourth age. *Journal of Aging Studies*, 25(2), 135–142. <https://doi.org/10.1016/j.jaging.2010.08.018>.
- Hartog, I., Zomers, M. L., van Thiel, G. J. M. W., Leget, C. J. W., Sachs, A. P. E., Uiterwaal, C. S. P., et al. (2020). Prevalence and characteristics of older adults with a persistent death wish without severe illness: a large cross-sectional survey. *BMC Geriatrics*, 20(342), 1–14. <https://doi.org/10.1186/s12877-020-01735-0>.
- Higgs, P., & Gilleard, C. (2015). *Rethinking old age: Theorising the fourth age*. Palgrave Macmillan.
- Illich, I. (1995). *Limits to medicine: Medical nemesis: The expropriation of health*. Marion Boyars.
- Illich, I. (2003). Medical nemesis. *Journal of Epidemiology and Community Health*, 57(12), 919–922. <https://doi.org/10.1136/jech.57.12.919>
- Kelly, B., Burnett, P., Pelusi, D., Badger, S., Varghese, F., & Robertson, M. (2002). Terminally ill cancer patients' wish to hasten death. *Palliative Medicine*, 16(4), 339–345. <https://doi.org/10.1191/0269216302pm538oa>.
- Kierkegaard, S. (1997). The joy of it: That one suffers only once but is victorious eternally (H. Hong & E. Hong, Trans.). In *Christian discourses: The crisis and a crisis in the life of an actress* (pp. 95–105). Princeton University Press.
- Kleinman, A. (1988/2020). *The illness narratives: Suffering, healing, and the human condition*. Basic Books.
- Kleinman, A., Das, V., & Lock, M. M. (Eds.). (1997). *Social suffering*. University of California Press.
- Lange, Fd. (2010). *Waardigheid: Voor wie oud wil worden*. SWP.
- Länge, A. (2001). Old age from an existential-analytical perspective. *Psychological reports*, 89(2), 211–215. <https://doi.org/10.2466/pr0.89.6.211-215>.
- McCue, R. E., & Balasubramaniam, M. (Eds.). (2017). *Rational suicide in the elderly: Clinical, ethical, and sociocultural aspects*. Springer International Publishing.
- Nussbaum, M. C. (2001). *The fragility of goodness: Luck and ethics in Greek tragedy and philosophy*. Cambridge University Press.
- Olafson, F. A. (1998). *Heidegger and the ground of ethics: A study of Mitsein*. Cambridge University Press.
- Oliver, K. (2015). Witnessing, recognition, and response ethics. *Philosophy & Rhetoric*, 48(4), 473–493. <https://doi.org/10.5325/phillrhet.48.4.0473>.
- Peters, M. (2010). *Completed life. What are we talking about?* NVVE.
- Prado, C. G. (1998). *The last choice: preemptive suicide in advanced age*. Greenwood Press.

- Priya, K. R. (2012). Social constructionist approach to suffering and healing: Juxtaposing Cassell, Gergen and Kleinman. *Psychological Studies*, 57(2), 211–223. <https://doi.org/10.1007/s12646-011-0143-5>.
- Richards, N. (2017). Old age rational suicide. *Sociology Compass*, 11(3), 1–14. <https://doi.org/10.1111/soc4.12456>
- Ricoeur, P. (1986). *Fallible man* (Vol. 1). Fordham University Press.
- Ricoeur, P. (1995). Intellectual Autobiography. In L. E. Hahn (Ed.), *The Philosophy of Paul Ricoeur* (pp. 1–53). Open Court.
- Rodríguez-Prat, A., Balaguer, A., Booth, A., & Monforte-Royo, C. (2017). Understanding patients' experiences of the wish to hasten death: An updated and expanded systematic review and meta-ethnography. *BMJ Open*, 7(9). <https://doi.org/10.1136/bmjopen-2017-016659>.
- Rosa, H. (2019). *Resonance: A sociology of our relationship to the world*. John Wiley & Sons.
- Ruddick, S. (2000). Virtues and age. In M. U. Walker (Ed.), *Mother time: Women, aging, and ethics* (pp. 45–60). Rowman & Littlefield.
- Sevenhuijsen, S. (1998). *Citizenship and the ethics of care: Feminist considerations on justice, morality, and politics*. Routledge.
- Sevenhuijsen, S. (2003). The place of care: The relevance of the feminist ethic of care for social policy. *Feminist theory*, 4(2), 179–197. <https://doi.org/10.1177/14647001030042006>.
- Slatman, J. (2014). *Our strange body: Philosophical reflections on identity and medical interventions*. Amsterdam University Press.
- Stumm, B. M. (2010). *Witnessing others: Ethical responsibility in relational life writing*. University of British Columbia.
- Svenaesus, F. (2014). The phenomenology of suffering in medicine and bioethics. *Theoretical Medicine and Bioethics*, 35(6), 407–420. <https://doi.org/10.1007/s11017-014-9315-3>.
- Svenaesus, F. (2018). *Phenomenological bioethics: Medical technologies, human suffering, and the meaning of being alive*. Routledge.
- Tippett, K., & Banhart, D. (2020). *When things fall apart*. Retrieved from <https://onbeing.org/programs/devendra-banhart-when-things-fall-apart/>.
- Todres, L., Galvin, K., & Dahlberg, K. (2007). Lifeworld-led healthcare: Revisiting a humanising philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy*, 10(1), 53–63. <https://doi.org/10.1007/s11019-006-9012-8>
- Toombs, S. K. (1993). *The meaning of illness: A phenomenological account of the different perspectives of physician and patient*. Kluwer Academic Publishers.
- van Campen, C. (2020). *Gelukkig ouder worden in een veranderende samenleving: een pleidooi voor zingeving en creativiteit*. SCP.
- van Campen, C., & Verbeek-Oudijk, D. (2017). *Gelukkig in een verpleeghuis? Ervaren kwaliteit van leven en zorg van ouderen in verpleeghuizen en verzorgingshuizen*. SCP.
- van den Berg, J. H. (1972/2013). *A different existence: Principles of phenomenological psychopathology*. Duquesne University Press.
- van den Berg, V., van Thiel, G., Zomers, M., Hartog, I., Leget, C., Sachs, A., Uiterwaal, C., van Wijngaarden, E. (2020). Euthanasia and physician-assisted suicide in patients with multiple geriatric syndromes. *JAMA Internal Medicine*. <https://doi.org/10.1001/jamainternmed.2020.6895>.
- Van Den Noortgate, N., & Van Humbeeck, L. (2020). Medical assistance in dying and older persons in Belgium: trends, emerging issues and challenges. *Age and Ageing*. <https://doi.org/10.1093/ageing/afaa116>.
- Van Hooft, S. (1998). The meanings of suffering. *Hastings Center Report*, 28(5), 13–19. <https://doi.org/10.2307/3528226>.
- Van Humbeeck, L., Dillen, L., Piers, R., & Van Den Noortgate, N. (2019). Tiredness of life in older persons: A qualitative study on nurses' experiences of being confronted with this growing phenomenon. *The Gerontologist*. <https://doi.org/10.1093/geront/gnzz088>.
- van Wijngaarden, E. J. (2016). *Ready to give up on life: A study into the lived experiences of older people who consider their lives to be completed and no longer worth living*. (PhD). University for Humanistic Studies, Utrecht.
- van Wijngaarden, E. J., Leget, C. J. W., & Goossensen, A. (2015a). Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. *Social Science & Medicine*, 138, 257–264. <https://doi.org/10.1016/j.socscimed.2015.05.015>.
- van Wijngaarden, E. J., Leget, C. J. W., & Goossensen, A. (2016). Caught between intending and doing: Older people ideating on a self-chosen death. *BMJ Open*, 6(1), 1–11. <https://doi.org/10.1136/bmjopen-2015-009895>.

- Veldman, I. (2019). “De mens functioneert het beste als hij voldoende lijdt”: interview met Damiaan Denys. *NieuwWij*. Retrieved from <https://www.nieuwwij.nl/interview/damiaan-denys-de-mens-functioneert-het-beste-als-hij-voldoende-lijdt/>.
- Verhoeven, C. (1971). *Het leedwezen: beschouwingen over troost en verdriet, leven en dood*. Ambo.
- Vosman, F. J. H. (2017). The moral relevance of lived experience in complex hospital practices. A phenomenological approach. In S. C. V. D. Heuvel, A. Roothaan, & P. Nullens (Eds.), *Theological ethics and moral value phenomena: The experience of values*. Routledge.
- Vosman, F. J. H., & Baart, A. J. (2009). Being witness tot the lives of the very old. *Journal of Social Intervention: Theory and Practice*, 17(3), 21–32. <https://doi.org/10.18352/jsi.75>.
- Wijngaarden, E. J. (2021). Choosing death in anticipation of older age-related suffering: Reflections based on a Dutch study. In S. Westwood (Ed.), *Death Rights*. Routledge.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.