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## Research Article

# Till Death Do Us Part: The Lived Experience of an Elderly Couple Who Chose to End Their Lives by Spousal Self-euthanasia

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#### **Abstract**

Purpose: This article provides the first qualitative account of spousal self-euthanasia in older people, a previously unexplored phenomenon. It investigates the lived experience of a Dutch elderly couple who strongly wished—and chose—to die together at a self-directed moment, despite not suffering from a life-threatening disease or severe depression. It describes their subjective experiences and considerations prior to their self-chosen death.

Methods: The case study focuses on the particular experience of one elderly couple (aged above 70) by presenting two personal accounts from an insider perspective. These were analyzed using a thematic existential phenomenological method.

Results: Spousal self-euthanasia—which in the literature is associated with self-deliverance, self-determination, and a reasonable wish to die—is presented here as related to alienation from one's body and identity, the growing emptiness of life due to loss of activities, and an inability to reconcile oneself with one's changed "being-in-the-world." Their decision to end life is largely based on the anticipatory fear of further deterioration, further losing control, and not being able to control time and manner of death in the future. The couple's agreement to end their lives together, however, held both in an impasse, as their concerns, sense of time and logic differed significantly. In this case, a close relation between having a death wish and severe depression is questioned.

Implications: This article concludes by outlining the practical implications for professionals working in gerontology and recommends further research on the relation between self-euthanasia and depression in elderly people.

Keywords: The Netherlands, Suicide pact, Death wish, End-of-life, Qualitative phenomenological study

In France, November 2013, Georgette and Bernard Caves, both aged 86 years, simultaneously ended their lives in a Parisian hotel suite. The next morning their bodies were found. They died hand in hand with a plastic bag over their head. After this self-directed death, their son confirmed to the press that both feared separation, dependency, and physical decline more than death. 'They wanted to abandon life in all serenity.' (Willsher, 2013, November 25)

In the Netherlands, February 2014, David Postma (86) and his wife Willemke Postma-Kloosterman (84) committed auto-euthanasia. They were 'on the threshold of a nursing home', but by no means wanted to give up their independence. Before they took a lethal dose of medicine, they played some favourite music and danced their last dance. 'A wonderful farewell.' In the midst of their children, they died at a self-appointed moment. A short poem by David was printed in the obituary: 'We leave this earthly life satisfied, it is our time, we're going.' (Meulen, 2014, February 4)

The two aforementioned news reports describe elderly couples involved in suicide pacts, also referred to as spousal suicide, joint suicide, or double suicide. A suicide pact is "a mutual agreement between two people who resolve to die at the same time and, nearly always, at the same place" (Cohen, 1961). Despite the fact that suicide pacts involving older people are rare, they attract extensive media attention, probably out of all proportion to their frequency (Brown, King, & Barraclough, 1995). They are often framed as an expression of romantic attachment: as the thought of being separated—by the relocation or death of one of the two—seems unbearable, the couple choose to end life the way they lived it; together as partners in life and death.

Vink (2013) terms these pacts "double self-euthanasia" (or double auto-euthanasia), to distinguish them from suicide or *folie-a-deux*, which are associated with depression or other psychiatric disorders, insanity and self-destruction. In contrast, "self-euthanasia" refers to a person's intentional act to end his or her life independently; based on a persistent wish to die; decided after careful consideration; implemented in a careful manner (Chabot & Goedhart, 2009; Vink, 2013); and associated with self-deliverance, self-determination, reasonability, rationality, and dispassion.

The first systematic study on suicide pacts was published in 1961 by Cohen, who described 65 double suicides. Cohen suggests most pacts are an expression of the "romantic idea that two people who die together are not parted but travel together to a destination beyond the grave where they will remain eternally united" (Cohen, 1961, p. 149). A number of case reports have appeared since Cohen's study, mostly from a clinical or psychiatric perspective. These give some insight into the characteristics of partners in suicide pacts. It appears that people who die in a suicide pact are more likely to be older, married, ill, and from a higher social class (Brown & Barraclough, 1997; Young, Rich, & Fowler, 1984). In most cases, the nature of the spousal relationship is characterized as "exceptionally close and devoted" and mutually dependent (Brown & Barraclough, 1997, 1999; Brown et al., 1995; Liem, 2008). Most couples seem to live an isolated life, "absorbed in their own small world" (Cohen, 1961), which inhibits them from discussing their ideas with others (Liem, 2008). In most pacts, the initiator seems to have been the man (Liem, 2008). Some studies associate pacts with coercion or pressure on the part of the initiator (Liem, 2008; Young et al., 1984). The study of Brown and Barraclough (1999), however, challenges this claim as they found no evidence for coercion.

Previous studies have revealed the main grounds for spousal suicide pacts, which include relief from mental or medical disorders and reasons related to mental disorders (Brown & Barraclough, 1999; Brown et al., 1995; Cohen, 1961). One should note, though, that participants in suicide pacts suffer less frequently from mental disorders than those who commit suicide alone (Liem, 2008). Other motives include the negative impact of ageing, ill health, and

constant mental suffering caused by grave illness. When an intimate bond is threatened, couples start balancing the pros and cons of a mutual suicide pact (Liem, 2008).

Most studies focus on examining characteristics and motives, based on data gathered from an outsider perspective, such as police files, coroners' records, medical reports, and interviews with friends and relatives. We found no research that addresses the experiences and motivations of participants to a suicide pact themselves, other than the suicide notes of the deceased (Cohen, 1961). Many scientific questions regarding this phenomenon thus remain unanswered, including: How do agreements to commit suicide develop? What is the background to and what are the considerations underlying a suicide pact? What about the degree of mutual influence? And to what extent are pacts based on voluntariness or coercion?

Taking an idiographic approach, this article aims to provide a unique, in-depth insight into this rare and complex social phenomenon—spousal self-euthanasia on the grounds that life is no longer worth living—through a detailed exploration of first-hand accounts of two members of an elderly couple who strongly desired, and chose, to die together at a self-directed moment, despite not suffering from a life-threatening disease or severe depression. This is the first study to investigate the process prior to a spousal self-euthanasia by describing the subjective, existential experiences and inner considerations of an elderly couple planning a spousal self-euthanasia. We show how spousal self-euthanasia became an option, and how the couple experienced their existence toward the end. As such, we offer an exploratory and tentative understanding of this complex phenomenon. In the literature, both the terms suicide pact and spousal self-euthanasia are used; however, for the aim of this phenomenological study, the term spousal selfeuthanasia is preferred, because this term best expresses the self-understanding of the elderly couple involved.

#### Methods

### An Existential Phenomenological Approach

Phenomenological methodology seeks to examine human experience as manifested in concrete situations, by asking: how is the phenomenon lived and experienced by people? For this case study, we focused on the particular experience of one elderly couple by presenting two personal accounts from an insider perspective. The two accounts were analyzed using an existential phenomenological method (Ashworth, 2003; Finlay, 2011). This methodology was employed to develop in-depth understanding of the subjects' lifeworld—understood as "the world that is subjectively lived", rather than objectively explained (Finlay, 2011)—by describing the meanings that arise from those accounts.

In phenomenological research, every effort is made to limit presuppositions and theoretical assumptions, so as to approach the phenomenon with a sense of openness and wonder (Van Manen, 2014). Phenomenologists acknowledge the impossibility of being truly open and

negating one's subjectivity. However, they agree on the crucial need for "a phenomenological attitude": maintaining as open as possible to enable "the process of entering into the experience itself" (Finlay & Molano-Fisher, 2008). Through a careful, iterative reflective process, the researcher seeks to become aware of certain preconceptions and assumptions, and then manage their impact on the research.

### Participants and Sampling

This case study formed part of a larger research project on the lived experience of older people who consider their lives as "completed" and no longer worth living, and who strongly wish to die while not being terminally or mentally ill. (Van Wijngaarden, Leget, & Goossensen, 2015). Participants for this overall study were recruited between April and September 2013. Recruitment advertisements were placed in several magazines and websites all targeting elderly people, describing the context and aim of the research project. Twenty-five people aged above 70 were selected by purposeful sampling. (For an in-depth account of the overall sample strategy, see Van Wijngaarden et al. 2015). The couple under research in this case study was part of our larger sample. We decided to analyze their case separately because of the uniqueness of their story. To obtain an indication of whether their wish to die was driven by severe depression, participants were asked to complete the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). With regard to this case, the husband scored "mild" on the screening items for depression (8) and "no indication" for anxiety (5). The wife scored "mild indications" on the screening items for both anxiety (10) and depression (9). These outcomes suggested no indication for further diagnostic testing and little chance of serious depression.

## **Data Collection**

In October 2013, the first author visited the couple twice in their home. On the first occasion, the wife was singly interviewed in the living room. On the second occasion, the husband was singly interviewed in his study on the first floor. Both interviews lasted 1.5 hr. Before and after the interviews, the author and the couple met together in the living room. In sum, the interviewer spent about 4.25 hr with the couple.

Following the phenomenological approach, open indepth interviews were conducted to explore the lived experience of this elderly couple who had jointly chosen to end their lives because they felt that life was no longer worth living. The guiding interview questions were: "Tell me your story about what it means to feel that life is over"; "Can you describe what it means to have a strong desire to die together?"; and "Tell me about the process of how your agreements developed." Further leading

questions were avoided, because it was intended that the direction of the interview be dictated by the interviewee. The interviewer tried to engage empathically with both participants and encouraged them to articulate their experiences in detail and offer concrete examples, posing questions such as: "Can you elaborate a bit more as concretely as possible?"; "What do you mean by...?"; and "What is it like...?" (see Supplementary Appendix 1 for the complete interview guide).

Both interviews were recorded and transcribed verbatim. To be able to understand the interview text in relation to its context, observational field notes were made during and immediately after the visits. They covered the contextual characteristics, the atmosphere, and relevant nonverbal expressions. All written correspondence was added to the data: before the interview, the husband e-mailed six times about their personal situation and the developments in his wife's rehabilitation. After the interviews, he e-mailed another four times. One of their children approached the first author by e-mail, which led to an additional interview lasting 1.5 hr. The interview confirmed and strengthened our understanding of the case and provided insight into the children's perspective. Shortly after they died, the children sent a notification of their deaths to the interviewer.

### **Ethical Considerations**

The research project was evaluated by an accredited ethical board, based on the following provided documents: a research protocol, the informative letter, a consent form, the interview guide, and the HADS. The ethical board confirmed that the Medical Research Involving Human Subject Act (WMO) did not apply, as persons were not subjected to treatment or required to follow a certain behavioral strategy as referred to in the WMO (art.1b). All participants (the couple and the child) received an informative letter outlining the aim, procedure, the right to withdraw at any moment, privacy, contact details, and aftercare if needed. They gave their written informed consent to participate in the study and for the use of their accounts in research and publications.

As this case contains a high degree of confidential information, the researcher asked the Central Committee on Research Involving Human Subjects for specific advice on how to strike a balance between protecting the privacy of both participants and providing sufficient detail to make this case study useful (McCurdy & Fitchett, 2011; Woodhouse, 2012). To ensure that the case study truly preserved confidentiality, nonessential information was disguised.

### Data Analysis

A thematic lifeworld analysis was performed by using eight existential lifeworld dimensions: self, embodiment, temporality, sociality, spatiality, project, discourse, and mood-as-atmosphere. These interrelated dimensions, which have been developed in philosophical phenomenology, together form the "essential features" of the lifeworld while "each one separately is helpful to emphasize particular nuances of the lived experience" (Todres, Galvin, & Dahlberg, 2007). They are applied to psychological and medical science by empirical phenomenologists, for instance Ashworth (2003) among others. By means of an evocative description of these essential dimensions, a particular empirical lifeworld can be disclosed in a thorough and phenomenological manner (Ashworth, 2003). The lifeworld dimensions are described in Box 1.

The analysis was performed in several stages. Every stage of the analysis was mutually discussed in the team. First, the researchers tried to engage deeply in the couple's lifeworld by thoroughly rereading the whole data set (transcripts, correspondence, observational, and reflective notes) and replaying the audiotapes. Keywords or key sentences were marked and notes were made. Based on this empathetic consideration, the first author wrote two narrative reports, supplemented with some initial, tentative conclusions regarding the lived experience of the elderly couple. Those were discussed in the team and then sent to the participants for a member check. Aside from some minor factual details, the couple could completely identify with the narratives and initial conclusions. Next, the first author used Atlas.ti 7.5.1 software to code all the data, to compare the themes that emerged and to relate them to the lifeworld dimensions. Outcomes were mutually discussed in the team in several rounds. During the whole process, the authors adopt an open, slowed down attitude toward the phenomenon and the process of understanding.

## **Brief Description of the Participants**

Peter and Suzan, both in their 70s, were married for over 40 years. They raised four children and both worked as university lecturers. In his spare time, Peter was an artist. They looked back on their lives "with satisfaction" and evaluate their marriage as "happy and intimate." In his 40s, Peter went into therapy because he suffered from a child-hood trauma and separation anxiety, which had quite an impact on their family life, as his problems caused mental suffering to their children as well. Things went "all right after all," but with one child personal contact remained rather difficult.

Short after retirement, both had to face physical problems. Suzan was diagnosed with severe, progressive arthritis, while Peter suffered from several transient ischemic attacks (TIAs), a sensory disorder and impotence. Because of decreased mobility, they had decided to move to a town nearby their children, but they were unable to take root in their new dwelling. The development of their wish to die was closely associated with deteriorated health and age-related losses. To their children, they spoke about

#### Box 1: Elucidation of the lifeworld dimensions

**Self**: What does the situation mean for (social) identity?

The self, considered a fraction of the lifeworld, includes the attributions of identity, such as "I am an artist," as well as one's experience of one's own presence, agency, and voice within a situation and how this is related to our interaction with others (Ashworth & Ashworth, 2003).

**Embodiment**: How does the situation relate to feelings about one's own body?

Embodiment is about how a person relate to one's own body, including their gender, disabilities, and emotions. A body is not a thing or a possession, but it is a being-in-the-world. In daily life, people tend not to be conscious of their bodies and take them for granted, but when serious bodily changes emerge, the body is no longer taken for granted and becomes an object, a thing-other-than-me. In phenomenological research this is called the distinction between "the subjective body" and "the objective body."

**Temporality**: How is the meaning of time intrinsic to the situation?

Everything has a time and duration, in a quantitative and qualitative sense. In lifeworld research, temporality refers to people's sense of time and the way they experience continuities and discontinuities. It is about temporal meanings. The past and the future influence the present day as interconnected spheres: the past that is significant in people's lifeworld is the past "as it appears now and the future is what comes, as it is coming towards us now" (Van den Berg, 1972/2013), not as an objective, factual event, but as meaning.

**Sociality**: How does the situation affect relations with others?

Sociality refers to the way people's lives are related to the surrounding social world. People do not just live on their own, but are part of an inter-subjective world. The way they relate to others—and others relate to them—may be central to understanding their sense of being. Thus, the individual lifeworld cannot be fully understood without exploring this interpersonal dimension.

**Spatiality**: How is the personal topography affected by the situation?

Spatiality refers to the meaning of the surrounding world, things, and the places in which one lives. What is the meaning of distance and closeness in the personal topography and how do changes in spatiality affect lived experience? In lifeworld research, the focus is not merely on physical space, but more on the social and existential meaning of space. It is about how meaning is altered when circumstances change.

**Project:** How does the situation relate to the persons ability to carry out the activities they are committed to and which they regard as central to their life?

Projects in lifeworld descriptions refer to what people "care" about, in the sense of having a personal concern for something. As it is through the body that people are able to perform activities, physical changes and especially physical disabilities have huge impact on how people relate to their projects/activities.

**Discourse**: What sorts of terms are employed to describe the situation and thus to live?

Discourse—in lifeworld research—is about the terms that people employ to describe their lived experience. In the words used, we can discover more deeply how people give meaning to their lives and how they modify and interpret their world, as language is the "house of being" (Ashworth, 2006).

**Mood-as-atmosphere**: How does the situation affect "the state of mind"?

The lived experience is colored by mood, as mood immerses all other dimensions of the lifeworld. It indicates the lived meaning of the situation, as Todres et al. (2007) point out: "Mood has organising power is a great motivator or de-motivator (...) and affect people's embodied, functional capacities."

Reference: This description of lifeworld dimensions is based on a combination of the work of Ashworth (2003); Ashworth (2006); Todres, Galvin, & Dahlberg, (2007) and Van den Berg, 1972/2013).

their strong aversion toward ending up in a nursing home and their intention to terminate life before losing their independency.

With regard to their death wish, no mental health therapies were sought, as Peter and Suzan did not perceive themselves as being mentally ill and having a pathological wish to die. They rather perceived themselves as "normal" citizens, with a "reasonable" wish to die, in search for what they call "a dignified death." For decades, they had been active members of two Dutch right-to-die organizations. Both organizations provide information on how to perform a self-chosen death. The couple planned to perform the self-euthanasia in their home, by taking lethal doses of medicine. Within a few months after member check, they died together at a self-directed moment. In Box 2, a short description of the Dutch context and some law-related issues is provided.

#### Results

What follows is an in-depth lifeworld description of the lived experience of Peter and Suzan, following the lifeworld approach described above. Due to space limitations, we focus on the following lifeworld dimensions, as they were most prominent in participants' stories (a) self and project; (b) embodiment; (c) temporality; and (d) sociality.

## Self and Project: Feeling Alienated From Oneself

Both Peter and Suzan strongly defined themselves in terms of their ability to engage in the activities they loved. Peter's work as a lecturer in fine arts meant everything to him: it was his identity. He hoped that his lectures had "inspired students, stimulated them to look with new eyes and sparked a passion for arts in their lives." He looked back on his working life with pride and satisfaction. When he had to retire, his world changed dramatically: "If your work is taken away from you, that's just awful."

His self-definition was based entirely on his past identity and was associated with former projects. In the first years of his retirement, he aimed to continue his former life through academic writing, painting, and visiting art exhibitions. But when his health problems increased and his wife's arthritis progressed, opportunities for "projects that animate life" dwindled. Due to several TIAs he gradually lost his coordination, which meant he was no longer able to paint or sculpt adequately anymore. He talked about "a lousy, inept watercolour of his grandson" and "a failed attempt to model a clay statue of his granddaughter." The thought of being unable to create what he had in his mind was appalling. He dissociated his sense of self from his actual self:

"Not being able to draw and paint is the worst. (...) It feels as though my identity has been taken away. What do I have left? (...) Look, my identity is entirely in art. If you can no longer be active, if you cannot express yourself, then something quite substantial has been taken away."

# Box 2. Dutch context and some law-related issues The Dutch law on Euthanasia

Since 2002, euthanasia and physician-assisted suicide are legalized under strict criteria laid down in the Dutch Termination of Life on Request and Assisted Suicide Act. The physician performing euthanasia is concerned immune from criminal prosecution only if the following criteria for due care are fully observed.

- The patient's request is voluntary and well considered.
- 2. The patient's suffering is unbearable and hopeless.
- The patient is informed about his situation and prospects.
- 4. There are no reasonable alternatives.
- Another independent physician should be consulted.
- The termination of life should be performed with due medical care and attention.

# Public debate about "elderly and self-chosen death"

Nowadays, the public opinion is shifting. An increasing number of Dutch people can imagine appreciating physician-assisted dying, even if they do not suffer unbearably from a serious medical disease. In 2010, the initiative group "Out of Free Will" started a campaign and placed the discussion about "elderly and a self-chosen death" on social and political agendas. The most important issue of this campaign was "making self-determination of life's end a reality." Elderly people may come to the conclusion that the quality and the meaning of their life has deteriorated to such an extent that they prefer death over life. Based on a "rational and well-considered choice," elderly people aged above 70 should have legal options for assisted dying as well, they plead. Under current legislation, most of the concerned elderly people are not in the position to have a legal right for euthanasia, as they do not meet the criteria specified in the law: they do not suffer unbearably without prospect of improvement from a medical perspective. This controversial debate-about whether the law should change or not-is still going on.

The participants of this case study were strongly engaged in this debate and favored change of policy and law. However, due to the fact that they were not considered eligible for physician-assisted suicide or euthanasia, they chose to perform self-euthanasia.

Suzan's identity was associated less with specific activities than with the possibility of "being useful to others": she regarded this as central to her life. "Life must make sense." When she retired, she committed herself to "other projects on voluntary basis" and her family. What mattered most was to continue making a valuable contribution to society. But after her health deteriorated rapidly, she felt limited to taking care of her own body. The fact that she could "not be productive" anymore and do the things that made sense of her life, strengthened her feelings of uselessness: "I'm no longer needed."

She felt hindered to attend art exhibitions, galleries, and museums, which was a great loss, because she lived for art: "an indispensable, enriching part of life" and "the most important thing in my relationship with Peter." As she put it, "Now I have to miss the indispensable things." Although she kept herself informed about new trends and expositions, this was not fulfilling, because she no longer felt fully engaged in the subject. Like Peter, she was an art-lover but she could not express her love anymore, something she experienced as a diminishing of her identity.

Despite the fact that Peter and Suzan went through different processes, they both felt distanced and estranged from their identities and were unable to reconcile themselves with their changed, actual selves. This caused deep existential uncertainty.

# Embodiment: Being Threatened by One's Own Body

Both Peter and Suzan felt threatened by their own bodies, as they no longer did what they expected them to do. Peter suffered from a sensory disorder. As he was fond of good food and cooking, he experienced diminishing smell and taste as a significant loss, spoiling his appetite. Life became utterly "tasteless":

"When I'm going to make preparations for dinner, I often make a cheese course with Camembert, Brie and a piece of blue cheese. Look, of course I still know how it tastes (...) and I feel the substance in my mouth and then I try to imagine what the taste is like, but there is nothing. So, well, it's not inspiring. Basically, it's not fun..."

As well as his drawing and painting, Peter was also struggling with feelings of incompetence relating to his scientific work, which he continued after retirement: "I am not sure whether my writings are still kosher". He had been an intellectual—capable of "sharp and lucid" thought—but now he had a growing sense of uncertainty about the quality of his research: "I can no longer fully assess whether my accounts are conclusive." Although he had previously taken his ability for granted, his thoughts were now clouded by "lingering doubts popping up all day." Peter went to hospital because he was worried about developing dementia. Despite the brain scans showing no evidence of this, he was not reassured. He "panicked" at the thought that some

day they would discover "plaque in his brains." He feared ending up as "an insane idiot," emphasizing: "You know, all my life I was in charge, able to write books and being addressed as a "highly learned and honourable gentleman." I simply want to maintain my status until my final breath."

His physical awareness was overshadowed by a sense of shame, exemplified by his struggle with impotence: "You lose something very important, especially in marriage. Sure, there's acceptance, it's just the way it is, though undeniably, it also causes severe embarrassment, because you're no longer potent while the other might like you to be. That's very difficult." His body became such an embarrassment that he stopped expressing himself—no longer painting, sculpting, or writing—to hide his dysfunctions. He judged his body to be incompetent and it greatly undermined his sense of dignity.

Suzan's embodied self was gravely threatened by pain and the increasing immobility caused by arthritis. Her body used to be her "being-useful-in-the-world," but now she felt locked in by her body and trapped in the house. She also hated the fact that she had become overweight. Bodily changes caused profoundly alienating feelings; her body became an "it." She dissociated herself from this "it," expressed in her words: "It is a strange body. It's not my body anymore, it doesn't belong to me." Every night, she said, she dreamed about her body functioning "normally" again: "Jumping and endlessly walking, caring for the kids." But in the same breath, she brushed her thoughts aside as "illusions" and said: "I hide my head in the sand. Of course, I know that things are no longer possible, but I just don't want to realize it. I simply cannot reconcile myself to reality." Despite her undeniable deterioration, she joined a physical rehabilitation program in an endeavor to make progress, hoping for physical recovery. However, she was simultaneously convinced that the physical change she desired would never happen, which even increased her feelings of estrangement: "You might call it ridiculous. And you're right. At best, it will only bring a brief halt to the on-going decline. (...) It's an idle hope, unreasonable, but still..."

#### Temporality: Reaching an Impasse

Lived temporality turned out to be a source of strong tension in the story of Peter and Suzan. Peter was obviously in a hurry, ideating on quitting life "sooner rather than later." He was no longer able to engage in the "here-and-now," as his existence was determined by fond memories of the past, as well as by his anxiety for the future facing him, appalling and inaccessible. He was seized by feelings of incompetence and fear of "that shameful humiliation" of further deterioration and loss of control: "It's the reason why I would rather take the short cut!" Shame drove him to seek a way to counter these threats, and the only possible way out seemed a self-directed death. He felt compelled to take "precautions" and organize his own death "before it is too late."

Peter's movements and way of communicating were endowed with a notable sense of urgency. This was strengthened not only by his bodily experiences, but also by negative memories of his parents living in a nursing home. Images of indignity, dependence, and a lack of privacy were etched on Peter and Suzan's minds and struck terror into their hearts. After Peter's parents had died, Peter and Suzan had firmly promised each other that they would end their lives before losing their independence, to avoid ending up in a nursing home.

Despite this promise, Suzan's death wish was not as urgent as Peter's. Like him, she had fond memories of her life before the physical problems, and she had no positive expectations of the future. Yet she was not as fearful of the near future as her husband seemed to be. Rather, she struggled with an on-going dilemma: on the one hand, she had a dormant wish to die and felt that she was no longer able to make a valuable contribution anymore. Moreover, she knew that her husband strongly wished to die and she certainly did not want to be left alone. Thus if he persisted in ending his life now, "it's the best solution to go together." On the other hand, she had a forlorn hope that she might be of some significance in the lives of their children and grandchildren, and might make some physical progress, as she reluctantly admitted: "There might be a possibility to still participate somehow... I still might be of some importance to others... who knows, a little physical recovery might be possible..."

While they found it difficult to discuss this dilemma together, they seemed to have reached an impasse: Peter felt ready to give up on life immediately, but he also felt obliged to postpone until Suzan also felt ready, as they had agreed to end their lives simultaneously. Suzan suffered from this pressure from her husband, who was emphatically waiting for her to decide. She still needed more time. During the interview, she cursed emotionally several times: "Damn, why can't he wait a little longer for me. (...) Damn it, give me another year!" At the same time, she realized that the longer she delayed, the longer he had to wait, while she knew that life had become an abomination to him. In a way, Suzan thought that she was being unreasonable by delaying the decision, that she was being unfaithful to their agreement: "Actually, we have not talked this through. It is just a bit difficult at the moment. I'm a little afraid that talking about it might unleash a torrent of arguments and emotions. (...) And of course, more than ten years ago, we captured our wishes in an advance directive. (...) So well, it is a bit unreasonable of me." She tried to push away her "need for more time" as a subordinate feeling, focusing on their agreement in the past.

In our contact prior to the interviews, their promise to end life together was presented as an expression of a close connection. During the interviews, however, considerable tension emerged: on one hand, their promise indeed reflected a strong bond, but on the other hand, their promise let to an impasse and held them in a hold, as their sense

of subjective time differed significantly and they were unable to really talk about it.

## Sociality: Living in an Empty World

Due to Suzan's physical problems and rapidly decreasing mobility, they "rationally decided" to move to have more contact with their children and grandchildren, but the move turned out to be a disappointment. The fact that they were housebound made it very difficult to build new contacts and explore their new environment: "Actually, you have nothing to do with this town. (...) You don't know the shops, it's a totally different world." Shortly after moving, their old friends still visited them, but that ended. "Our world has become much smaller, more empty." They both felt uprooted and lost their sense of belonging: "Nothing binds you here. (...) If we hadn't done it, we would probably have seen the kids much less, but for our own salvation it would have been better if we had stayed there. But going back is simply impossible."

In relation to her children and grandchildren, Suzan felt reluctant and emotionally unable to talk about her hopes of being of some significance in their lives, which she associated with "an accusation" her son had made after he went into therapy years ago. He accused her of "emotional neglect in childhood," which left her scarred. Although they had "formally made amends," she still talked about "feeling crushed." She "buried this sadness deep inside" and "tried to focus on other things." Despite her attempts "to push it away," these memories loomed large at certain moments and hindered her sense of being mother and grandma.

In a way, Suzan still felt responsible for her children and grandchildren, and did not feel ready to leave them: "I would like to see that things go well with the kids". Peter did not feel this sense of responsibility or connection anymore: "I simply don't have that feeling, because I think: my life is over". He informed his children about their plans:

"About half a year ago, we talked about it, more or less. (...) My oldest son understands, but doesn't like it. But then I think: there are many things in life that are not fun. Death is not fun. But you cannot run away from it. (...) And they will get over it soon, in a manner of speaking."

Their son reported how he had received the information about his parents' plans, and how it had evoked feelings of powerlessness and detachment:

"I feel powerless, because we never really talk about it. (...) OK, we did talk about it, actually quite often. (...) But always very rationally and very abstractly. (...) But we never talked about the emotional side of things. (...) It's just absurd, it's absurd that they apparently believe that their life is over. Though we, as children, totally disagree with this idea. They have grandchildren who love having a grandma and grandpa. And they have children

who love them (...) but apparently that plays no role in their decision. In my eyes, it's a detached decision. (...) Sure, I feel forsaken, but that's not new, that's an old theme, so in that sense, it's not strange."

#### **Discussion**

This article presents the first in-depth account of an elderly couple who jointly wished and chose to die together at a self-directed moment, because they felt life was completed and no longer worth living, even though neither of them suffered from a life-threatening disease or severe depression. We present two individual but highly intertwined narratives about struggling with ageing, alienation from one's body and identity, the growing emptiness of life due to loss of activities and contacts, an inability to reconcile oneself with one's changed "being-in-the-world," and the deep existential uncertainty associated with this. This corroborates previous research on elderly people who feel ready to give up on life (Kjølseth, Ekeberg, & Steihoug, 2010; Rurup et al., 2011; Van Wijngaarden, Leget, & Goossensen, 2014; Van Wijngaarden et al., 2015). Our study adds to former research by giving the first insider account of the subjective considerations and experiences of two members of an elderly couple planning spousal self-euthanasia.

For the husband, the performed self-euthanasia strongly appears as a way to "prevent" and "safeguard" himself. His wish to die was based largely on a deep sense of embarrassment caused by a loss of control and abilities. For him, life was completely over, as his self-identity was based on independence, status, and excellence. As his competences decreased, he lost his "self." The anticipatory fear of further deterioration and the fear of not being able to control time and manner of death in the future urged him "to take the short cut." The wife also felt greatly hindered and threatened by her body. Though, in contrast with her husband, she was caught in an appalling dilemma: on the one hand, she felt more and more disconnected from herself and from life, having a conscious wish to die, but simultaneously she had concerns about her children, which continued to connect her to life. While her husband's account is full of urge, her account is full of what she calls "idle hope" to still be of any significance for her kids. For her, intending to end their lives by spousal self-euthanasia brought her in a considerable tension.

Although the couple talked about their agreement for years, they found themselves unable to discuss the *emotional* impact with each other and their children. The agreement to end their lives together exercised a hold on them, as they had very different concerns, sense of time, and logic. It seemed difficult for each to keep pace with the other without a form of coercion, emotional, or otherwise. The case ends in a paradox: on one hand, they died together at a self-appointed moment *according to their mutual agreement*; but on the other hand, their story indicates that this might not have been entirely what the wife wanted *yet*. The case

thereby clearly reveals the ambiguity of people's volition, as choices can shift over time. It also highlights the difficulty of distinguishing between voluntary action and coercion in real life.

## Some Ethical Thoughts

An important ethical question raised by this study is whether the researcher did have any obligation to intervene with regard to possible exercised pressure or coercion. As a matter of course, the researcher took into account all appropriate ethical rules to ensure safety of our participants, such as providing comprehensive information on beforehand; gaining informed consent prior to the interview; providing full contact information; debriefing afterwards; offering the possibility of an extra conversation at their home or referral to professional care. However, do these measures appropriately cover the researcher's responsibility, when participants are preparing a spousal self-euthanasia? What about the duty to intervene? In this context, we believe there are several important considerations that must be taken into account:

Firstly, participants were not patients, but mentally competent citizens. They perceived themselves as normal, independent, autonomous, and self-determining citizens. This is not just their private opinion, as part of Dutch society confirms the legitimacy of such a wish to die (see Box 2). Secondly, both were fully aware of the emotional tensions. In the interviews, they told about each other's emotional discomforts and the difficulty to communicate about these emotions. Afterwards, we debriefed them by sending them two narrative reports in which we explicitly mentioned the struggles and tensions that we had recognized. In their reaction, both endorsed these reports, but did not seek help or therapy for this. Thirdly, intervention would not be in accordance with our research approach and the appointments made prior to participation, as we told participants that we would take a phenomenological approach: free from prefixed theories about being-ill or not-ill; engaging with participants as they perceived themselves from an insider, nonjudging, lifeworld perspective, giving them the opportunity to talk freely about their lived experience. Lastly, it is important to respect boundaries between research and therapy (Finlay, 2011). Prior to the interview, we explained that the researcher did not act according to the role of a counsellor but as a researcher.

Hence, being mentally competent, highly educated people, who were aware of the possibilities of therapy, consciously choosing not to seek (mental or relational) therapy, we felt intervening while not being asked was unjustified. Most likely, participants would have judged unasked intervention to be highly paternalistic. We did thus not try to change these people's minds and their life view, but rather intended to understand them. Taking all this into consideration, we are of the view that, if extra support had been desired (which was not the case), a referral to external counselling would have been the only appropriate way.

### Implications for Practice and Research

The case study provides insight into a rare, previously unexplored phenomenon. Although this case is a specific story, situated in a specific personal, social, and cultural context, and while we acknowledge that elderly people within different contexts might have different stories, there are ways to learn from it, as it tentatively expands our understanding of the phenomenon of spousal self-euthanasia. First, professionals engaged in caring for older people should note that the identity of active, independent people, who strongly define themselves in terms of their life-projects, is at risk when these people have to deal with significant age-related losses. These elderly people might try to reassert themselves and compensate for circumstances they cannot accept, but when they fail, they might feel alienated from their bodies. And perhaps they might perceive ending their lives at a selfappointed moment as a way of regaining control.

Second, it is noteworthy that this case questions the close relation between death wishes and depression, as depression is the most frequently studied factor in relation to death wishes in elderly people. These findings are consistent with other research that also indicates that suicidal ideation in old age often does not meet the criteria for clinical disorders such as depression or anxiety (Corna, Cairney, & Streiner, 2010) and suggest that depressive feelings might not be related to pathology but rather to normal aging (Ludvigsson, Milberg, Marcusson, & Wressle, 2014). Further research on this topic is thus recommended. To what extent is (spousal) self-euthanasia in elderly people related to depression? Should this phenomenon be primarily assessed from a psychopathological perspective or more from an existential perspective? For professionals, this highlights the significance of careful assessment as to whether depression is the (primary) cause of a wish to die. Lastly, our study illustrates the complexity of a joint decision by a couple to end their lives together. Moving toward this ultimate choice is an ambivalent and ambiguous process, which initially has a great impact on an individual's lifeworld. The situation becomes even tenser when it comes to a joint decision. For professionals, the difficult question is whether one should accept such an ultimate choice, rather than intervene. Probably, encouraging people to really talk about the emotional tensions about the different concerns and sense of time is most appropriate.

## Supplementary Material

Please visit the article online at http://gerontologist.oxford-journals.org/ to view supplementary material.

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#### References

- Ashworth, P. (2003). An approach to phenomenological psychology: The contingencies of the lifeworld. *Journal of Phenomenological Psychology*, 34, 145–156. doi:10.1163/156916203322847119
- Ashworth, P. D. (2006). Seeing oneself as a carer in the activity of caring: Attending to the lifeworld of a person with Alzheimer's disease. *International Journal of Qualitative Studies on Health and Well-Being*, 1, 212–225. doi:10.1080/17482620600967786
- Ashworth, A., & Ashworth, P. (2003). The lifeworld as phenomenon and as research heuristic, exemplified by a study of the lifeworld of a person suffering Alzheimer's disease. *Journal of Phenomenological Psychology*, 34, 179–206. doi:10.1163/156916203322847137
- Brown, M., & Barraclough, B. (1997). Epidemiology of suicide pacts in England and Wales, 1988–92. *BMJ*, 315, 286–287. doi:10.1136/bmj.315.7103.286
- Brown, M., & Barraclough, B. (1999). Partners in life and in death: The suicide pact in England and Wales 1988–1992. *Psychological Medicine*, **29**, 1299–1306. doi:10.1017/s0033291799001294
- Brown, M., King, E., & Barraclough, B. (1995). Nine suicide pacts: A clinical study of a consecutive series 1974–93. *The British Journal of Psychiatry*, **167**, 448–451. doi:10.1192/bjp.167.4.448
- Chabot, B. E., & Goedhart, A. (2009). A survey of self-directed dying attended by proxies in the Dutch population. *Social Science & Medicine*, 68, 1745–1751. doi:10.1016/j.socscimed.2009.03.005
- Cohen, J. (1961). A study of suicide pacts. *Medico-Legal Journal*, 29, 144–151. doi:10.1177/002581726102900305
- Corna, L. M., Cairney, J., & Streiner, D. L. (2010). Suicide ideation in older adults: Relationship to mental health problems and service use. *The Gerontologist*, 50, 785–797. doi:10.1093/geront/ gnq048
- Finlay, L. (2011). *Phenomenology for therapists: Researching the lived world*. West Sussex, UK: Wiley-Blackwell.
- Finlay, L., & Molano-Fisher, P. (2008). 'Transforming' self and world: A phenomenological study of a changing lifeworld following a cochlear implant. *Medicine, Health care and Philosophy*, 11, 255–267. doi:10.1007/s11019-007-9116-9
- Kjølseth, I., Ekeberg, O., & Steihoug, S. (2010). Why suicide? Elderly people who committed suicide and their experience of life in the period before their death. *International Psychogeriatrics*, 22, 209–218. doi:10.1017/S1041610209990949

- Liem, M. (2008). Dader- en slachtofferschap in het suïcidepact. In A. A. Franken, M. De Langen, & M. Moerings (Eds.), Constante Waarden. Liber amicorum prof. mr. Constantijn Kelk. Den Haag: Boom Juridische Uitgevers.
- Ludvigsson, M., Milberg, A., Marcusson, J., & Wressle, E. (2014).
  Normal aging or depression? A qualitative study on the differences between subsyndromal depression and depression in very old people. *The Gerontologist*, doi:10.1093/geront/gnt162
- McCurdy, D. B., & Fitchett, G. (2011). Ethical issues in case study publication: Making our case(s) ethically. *Journal of Health Care Chaplaincy*, 17, 55–74. doi:10.1080/08854726.2011.559855
- Meulen, A. v. d. (2014, February 4). Bejaard stel koos eigen einde en ging dansend het leven uit. *Algemeen Dagblad*.
- Rurup, M. L., Pasman, H. R., Goedhart, J., Deeg, D. J., Kerkhof, A. J., & Onwuteaka-Philipsen, B. D. (2011). Understanding why older people develop a wish to die: A qualitative interview study. *Crisis: Journal of Crisis Intervention & Suicide*, 32, 204–216. doi:10.1027/0227-5910/a000078
- Todres, L., Galvin, K., & Dahlberg, K. (2007). Lifeworld-led health-care: Revisiting a humanising philosophy that integrates emerging trends. *Medicine, Health Care and Philosophy*, 10, 53–63. doi:10.1007/s11019-006-9012-8
- Van den Berg, J. H. (1972/2013). A different existence; principles of phenomenological psychopathology. Pittsburgh, PA: Duquesne University Press.
- Van Manen, M. (2014). Phenomenology of practice: Meaning-giving methods in phenomenological research and writing. Walnut Creek, CA: Left Coast Press.
- Van Wijngaarden, E. J., Leget, C. J. W., & Goossensen, A. (2014). Experiences and motivations underlying wishes to die in older people who are tired of living: A research area in its infancy. Omega Journal of Death and Dying, 69, 191–216. doi:10.2190/om.69.2.f
- Van Wijngaarden, E. J., Leget, C. J. W., & Goossensen, A. (2015).

  Ready to give up on life: The lived experience of elderly who feel life is accomplished and no longer worth living. *Social Science & Medicine*. doi:10.1016/j.socscimed.2015.05.015
- Vink, T. (2013). Zelfeuthanasie. Een zelfbezorgde goede dood onder eigen regie. Budel: Damon.
- Willsher, K. (2013, November 25). Suicide of elderly French couple stirs euthanasia debate. *The Guardian*.
- Woodhouse, S. S. (2012). Clinical writing: Additional ethical and practical issues. *Psychotherapy*, 49, 22–25. doi:10.1037/a0026965
- Young, D., Rich, C. L., & Fowler, R. C. (1984). Double suicides: Four modal cases. *Journal of Clinical Psychiatry*, 45, 470–472.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, **67**, 361–370. doi:10.1111/j.1600-0447.1983.tb09716.x