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# Ethical uneasiness and the need for open-ended reflexivity: the case of research into older people with a wish to die

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## ABSTRACT

This article focuses on research ethics in highly intimate research with possible impact on life and death. In order to stimulate an open-ended dialogue about research ethics, we reflect on four ethical challenges that came up during our research into older people with a wish to die. Drawing on our experiences, we discuss (1) the possibly confirming influence of our research on the death wish (moral experience of whether or not to disregard responsibility); (2) the suggested duty to intervene (moral experience of whether or not to compromise the person's autonomy); (3) the researcher's authority and power over the data (moral experience of threatening a person's self-narrative) and (4) the dilemma of intimacy (moral experience of encountering the tragic). For guidance in addressing these challenges, we draw upon work on research ethics from phenomenological and care ethics scholars, as well as from those writing about relational ethics in health research. We suggest that being open about ethical uneasiness is important, because in most cases of a grey area, there are only open-ended answers needing an enquiring mind, rather than clear and fixed guidelines. Acknowledgement of ethical uneasiness and open-ended reflexivity are indispensable to constitute a morally good research practice.

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## 1. Many ethically uneasy moments

During our phenomenological research project on relatively healthy older citizens with a wish to die, we found ourselves pondering many times over ethically uneasy moments. We conducted highly intimate research with a possible impact on life and death, talking with people about their struggle with life and their wish to die. The interviewer [EW] entered participants' homes and they opened up their very intimate, private lives. They told their personal stories and then the interviewer left them. Despite the fact that all of the older people participated on their own initiative, gave their informed consent, knew the procedure and often explicitly expressed their relief to have the possibility of sharing their stories, in many cases the interviewer still felt more or less uncomfortable leaving them. The fact that we knew that some of them were actively ideating on a self-directed death strengthened these feelings. We wondered about our moral duty to intervene in order to prevent suicide, knowing that participants, without exception, did not want any intervention. Participants perceived themselves as

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‘normal’, independent, autonomous and self-determining citizens with a ‘reasonable’ wish to die, and truly did not perceive themselves as being mentally ill. Should we have compromised their autonomy, freedom and self-determination by insisting on treatment options, while they considered themselves as fully capable of handling their own lives?

These urgent questions, among many others, came up during the meetings in our ethics of care research group. They were also noted in the review reports we received after we had submitted our papers for publication in peer-reviewed journals. To quote two anonymous reviewers:

I have a concern about the ethical nature of the research (which may reflect my experiences in conducting research with vulnerable populations). I strongly believe that people who are vulnerable have a right to participate in research, if protected. However, I am not convinced that they were appropriately protected. This type of research requires extra caution, not just referrals to health care professionals.

It appears that no formal ethical breach is evident in that proper human subjects protections and approvals were in place, however [I still have an ethical concern]: Did you have any obligation to intervene?

The reviewers’ concerns about the safety of the participants who disclosed a wish to die resembled our own reflections during our research meetings. Once again, we [all three authors who formed the research team] became keenly aware that conducting research into a highly intimate topic goes far beyond procedural research ethics. Conducting methodologically rigorous and procedurally sound research is not necessarily an equivalent of morally good research. Given that the exchanges with several reviewers were very fruitful, we felt encouraged to publish this paper about our experiences.

The central thesis of this paper is that morally good research involves the importance of being honest and open about ethical uneasiness, doubts and uncertainties. In cases of a grey area, there are only balanced and open-ended answers needing an enquiring mind, rather than clear and fixed ideas and solutions. We think researchers should more frequently share these vulnerable reflections with other colleagues in order to contribute to an ongoing and learning dialogue about research ethics.

In this paper, we proceed as follows: first, we provide some context by briefly describing our specific research project. Next, we concisely outline the academic debate about ethical research practices. Thereafter, we come to the central part of our paper and discuss some of the most complex and ambivalent issues that came up during our research project. We recap on how these issues were addressed during our research process and which open-ended questions remained. We conclude by posing that conscious awareness and acknowledgement of ethical uneasiness and open-ended reflexivity are indispensable to constitute morally good research practice. Besides, we suggest that – just like methodological reflections on strengths and limitations – such ethical reflections should be included in research articles.

## 2. Context: research into the wish to die in old age

To take the reader on our reflective journey, we will first provide some context information about our research project. In the Netherlands, euthanasia and physician-assisted suicide can be performed under strict criteria laid down in the Euthanasia Law. Currently, the end-of-life debate is progressing. A growing group of Dutch citizens is now in favour of further relaxation of the law. They ask for the possibility of having a physician to assist them in the dying process, not only in cases where there is suffering from a serious disease, but also when they suffer from being old and dependent (Beekman, 2011). There is a growing level of support for the availability of a so called ‘last-will-pill’ to enable older people who are tired of living to organize their own deaths (Buiting et al., 2012).

Notably, though, the issue of tiredness of life in older people is a research area in its early infancy. Only a small number of empirical studies have examined this phenomenon, and even fewer have analyzed it in the absence of a mental disorder or a life-threatening condition (van der Heide, Onwuteaka-Philipsen, & van Thiel, 2014; van Wijngaarden, Leget, & Goossensen, 2014). We think that in order to develop careful and responsible policy on this issue, it is a prerequisite to first gain a deep and robust understanding of this phenomenon and find out what is really at stake in the lives of these older people. Therefore,

the aim of our empirical research project was to provide in-depth insight into what it means to feel that 'life is completed and no longer worth living' as lived and experienced by older people themselves (van Wijngaarden, Leget, & Goossensen, 2015a), so that policy development could be aligned with the needs and the concerns of the people at stake. We used a phenomenological approach adopting an open and non-judging attitude (Dahlberg, Dahlberg, & Nyström, 2008), not taking a stance in advance.

After placing research advertisements in various magazines, we purposefully selected 25 people aged 70+ to participate in our study. All of them considered their lives to be 'completed' and strongly wished to die, while not being terminally or mentally ill. Nor were there indications that any of the respondents suffered from a psychiatric disorder or clinical depression. Most participants lived independently, only two lived in a care home. We performed in-depth phenomenological interviews (Dahlberg et al., 2008; Englander, 2012) in participants' home environments, aiming to gather rich, experiential descriptions of daily situations (see Appendix 1 for the original interview guide).

Our empirical study has shown that participants essentially felt disconnected from their actual lives: daily experiences seemed incompatible with their expectations of life and their ideas of whom they were, which strengthened a strong desire to end life at a self-directed moment. This experience of disconnectedness was further explicated in the following themes: (1) a sense of aching loneliness; (2) the pain of not mattering; (3) the (growing) inability to express oneself; (4) a multidimensional tiredness; and (5) a sense of aversion towards (feared) dependence (van Wijngaarden et al., 2015a).

The in-depth interviews that were conducted were very intense and emotional. People shared their sadness, fears and shame. They talked about feeling unneeded, redundant, lonely and undignified. And for most of them, the only way to escape from these uncomfortable feelings seemed to be a self-directed death. While most had a strong preference for a physician-assisted suicide, this would often have been illegal because they did not meet the current criteria laid down in the Dutch Euthanasia Law. That was the reason why most of them were ideating on how to end their lives by themselves.

Before discussing the ethical challenges that we have faced during this research project, we will first position our paper in the academic debate about research ethics.

### 3. Beyond the borders of procedural research ethics

There are several principles and procedures for research ethics which all emphasize important principles for the ethical conduct of research, such as the principle of informed consent, the right to withdraw at any moment, confidentiality, the absence of coercion, protection from harm and beneficence towards participants. The Nuremberg Code (1947) has served as an ethical foundation for human research since its publication. This code was developed in response to the terrors of human experiments undertaken by Nazi physicians and researchers. It describes the human rights of research subjects and the obligations of physician-researchers towards research subjects. The Declaration of Helsinki (1964) restated similar principles and both codes still function as international reference points for research ethics. Based on these codes, most countries have now established national (and regional) committees for research involving human subjects who protect subjects taking part in (medical) research by reviewing and approving research proposals on the basis of their statutory provisions, codes and guidelines.

The main aims of these ethical committees are to maximize ethical and responsible conduct of research involving humans by taking into account their interests, and to protect them from possible harm and methodologically poor research. In practice, though, most research encounters bring up ethical uncertainties that go beyond the formal procedures. There are no definite rules or universal principles about (i.e.):

- possible power imbalances and instrumental and exploitative tendencies in research (Abma, 2000; Abma, Baur, Molewijk, & Widdershoven, 2010; Finch, 1984; Finlay, 2011; Head, 2009; Schipper et al., 2010).
- doing compassionated research and forming intimate and emotionally expressive relationships with participants (Ellis, 2017; Ellis & Patti, 2014).

- doing research into the lives of intimate others like family, students or clients (Ellis, 2007; Etherington, 2007).
- confidentiality in cases where one is confronted with very intimate disclosures about family secrets, abuse or traumas (Guillemin & Gillam, 2004).
- talking about a difficult and probably traumatic experience that might cause distress or even re-traumatize participants (Buckle, Dwyer, & Jackson, 2010; Finlay, 2011; Guillemin & Gillam, 2004; Labott, Johnson, Fendrich, & Feeny, 2013; Usher & Holmes, 1997).

In all these grey area cases, among others, there is a moral tension that has already been acknowledged by many qualitative researchers. A lot has been written about how researchers can reflect and act in these grey areas. Guillemin and Gillam (2004) have made a distinction between what they call 'big-issue' ethics and acknowledgement of 'ethically important moments' (p. 265). Although they stress the importance of procedural ethics as 'a valuable function in forcing us to consider and reflect on fundamental guiding principles that govern research integrity' (p. 277), they also draw on the notion of reflexivity as an essential way of dealing with what they call 'ethically important moments' that come up during every research project (Guillemin & Gillam, 2004). Being reflexive at these often subtle, unpredictable and difficult moments means that a researcher (1) acknowledges the ethical dimension of everyday research practice; (2) is sensitive towards specific ethically important moments; and (3) is able to show a means of addressing these ethical concerns (Guillemin & Gillam, 2004). In this paper, we want to elaborate upon this three-step approach and particularly highlight the need for honesty and openness about ethical uneasiness, doubts and uncertainties.

#### 4. Uneasy moral experiences

During the research process, we encountered a number of uneasy moral experiences. In this paper, we want to reflect on the most striking ones and explicate to what specific ethical questions they lead. These are:

- (1) *The moral experience of whether or not to disregard responsibility*: Could it be that the interview unintentionally confirmed the participants' wishes to die? Could it be that joining this research project unintentionally strengthened their intentions to end their lives at a self-directed moment? Did we take sufficient caring responsibility or could it be that we are (partly) responsible for confirming their plans?
- (2) *The moral experience of whether or not to compromise the person's autonomy*: Should we have compromised the autonomy, freedom and self-determination of the respondents and insisted on treatment, while they considered themselves fully capable to handle their lives by themselves? Did we have a duty to intervene knowing that participants were seriously ideating on a self-directed death?
- (3) *The moral experience of threatening a person's self-narrative*: How should we relate to the fact that participants' stories, in many cases, turned out to show them as much 'more ambivalent and vulnerable' than they would have liked to described themselves? Is it justifiable that the researcher has the final authority and power over the data or can this be seen as a threat of a participant's self-narrative?
- (4) *The moral experience of encountering the tragic*: How to deal in a morally good way with the dilemma of intimacy? Is it justifiable to have a very intimate (and quite rare) conversation about the experiences of ideating on a self-directed death and then 'leave' a participant alone again? Obviously, it is inherent to a research relationship that it has to come to an end. But how should we relate to the existential human experience of 'encountering the tragic' that goes beyond the researcher's role?

#### 4.1. *The uneasy moral experience of whether-or-not to disregard responsibility*

We took all procedural precautions we could think of to ensure the (emotional) safety of participants. In the Dutch context, our research project was in full compliance with the law and the respected way of performing research on sensitive topics. Our study was evaluated by the Medical Ethics Review Committee UMC Utrecht (MERC), based on the following documents provided: a research protocol, a participant information letter, a consent form and the interview guide. The MERC confirmed that the Dutch Medical Research Involving Human Subjects Act (WMO) did not apply, as our potential participants were not patients but mentally competent citizens, and participants were not subjected to treatment or required to follow a certain behavioural strategy as referred to in the WMO (art.1b). Subsequently, official approval of this study by the MERC was not required (protocol: 13-176/C). However, despite the fact that our research was not under the scope of the WMO, we applied all rights and obligations pertaining to a study under the scope of the WMO to our own research project (see Box 1).

**Box 1.** Rights and obligations pertaining to a study under the scope of the WMO.

- providing comprehensive information beforehand;
- gaining informed consent prior to the interview;
- communicating about the right to withdraw at any moment;
- respecting and protecting privacy and confidentiality rights;
- providing contact details of all researchers and full personal contact information of the interviewer (who is available for contact during the full term of the study);
- debriefing afterwards (narrative report and contact);
- protecting the safety of participants by communicating about the possibility of a follow-up conversation at their home or referral to a counsellor if appropriate.

After every interview, a narrative report was written and sent to the participants, not primarily for participant validation but mainly for ethical reasons (Finlay, 2011; Patton, 2002). Rather than validating the correctness of our findings, it was about ‘empowering participants to share in the meaning-making process’ (Finlay, 2011, p. 224). After they had received the narrative report, there was a final phone call or correspondence to share ideas and evaluate the interview. The responses were very positive with no exception. The majority of the participants explicitly said they considered it a great honour to have the opportunity to contribute to the scientific research and more indirectly to the public debate. They also explicitly underlined that participating had been a positive experience, because the interview had helped them to express their thoughts and feelings in a non-judging environment, which gave them a sense of relief and recognition. Several participants expressed themselves in words like these: ‘This really is my story. I’m very grateful for it. I hope my family wants to read it’. Although emotional relief and insight are not the primary purpose of an interview, it nevertheless can be a positive side effect (Dahlberg et al., 2008). Our experiences confirm the suggestion of Buckle and colleagues (2010) that a research interview which explores complex, personal issues may be seen as beneficial to participants, rather than harmful.

However, we continuously asked ourselves the question: What benefits and (even more importantly) what possible damage could be expected during and after the interviews? What were reasonably foreseeable risks and discomforts to participate? We always gave an interviewee explicit permission to withhold thoughts and details whenever they preferred. And, in line with Dahlberg et al. (2008), we think this is highly important, as this is ‘an acknowledgement of their sovereignty as human beings’ (p. 205). We felt the responsibility to provide support as long as needed, until the participants had



‘recovered composure’ (p. 205) before the interviewer left (Dahlberg et al., 2008). In practice, this meant that in a few cases, the interviewer stayed for another hour. Additionally, participants were informed that they could always contact the interviewer to ask for an additional visit or a referral to a counsellor.

Despite the fact that we made all efforts to ensure protection from possible harm, some uncertainty remained about whether or not the interview could possibly have confirmed participants’ wishes to die. An uneasy comment of a research colleague went as follows:

You should realize that, in an inconspicuous manner, an interference may take place under the influence of an in-depth interview. All precautions you took do not preclude what I mean. In my view, in-depth communication and its elusive influences have many layers and are very complex.

Of course, one can jump to conclusions by presenting all sorts of reasonable arguments to rebut that the interview did *not* further confirm the wish to die, for example by raising the fact that participants had been thinking about a self-directed death for years (which was very often the case); or by stating that the interviewer remained as non-judging as possible and never confirmed their plans; or that it is generally held that talking about suicidal thoughts and plans does not increase suicidal intent or hopelessness (Dumon & Portzky, 2013). However, research has provided empirical evidence that qualitative research interviews do indeed impact participants’ views of their situations (Britten, Borgen, & Wiggins, 2012; Butterfield, Borgen, & Amundson, 2009). During our project, we did ask for participants’ feedback after the interviews. They were very positive without exception: they felt recognized, relieved and understood. Possibly, the research encounter even strengthened their sense of dignity. But if an interview can empower participants in the meaning-making process (Finlay, 2011; Schipper et al., 2010), it is not inconceivable that it has (indirectly) empowered them in their plans to end life. Indeed, giving participants the chance to articulate their wishes, in what they regard as a secure environment, may result in them becoming clearer about their wishes and commitment to pursue them. The question is, should a researcher be concerned about this? And did we exercise sufficient responsibility?

Ellis (2007) has stated that ‘relational ethics requires researchers to act from their heart and their mind, and to fully acknowledge their interpersonal bonds to others’ (p. 4) and take responsibility for actions and their consequences, but what does this kind of responsibility actually mean in concrete terms for research practice? What exactly can we be held responsible for, and to what extent? In our view, morally good research requires full responsibility for *foreseeable* consequences of the research. However, to hold researchers responsible for so-called ‘inconspicuous influences’ that go beyond words might lead to a ‘hypertrophy of the responsibility’ (ten Have & Welie, 2005). This means that the attribution of responsibility to the researcher is not only confined to the foreseeable consequences of the research, but the researcher is also responsible for (and thus complicit with) the choices, lifestyle and life of the participant. We think that this would be inappropriate and goes too far in attributing responsibility.

Nevertheless, this is not a conclusive answer eliminating the need for reflection. Some uneasiness remains. We think it is highly important that researchers endure this uneasy uncertainty, and dedicate themselves to ongoing and open-ended reflexivity, instead of hiding themselves behind ‘safe’ procedures or argumentations. We believe that enduring this uneasy uncertainty means that researchers remain aware of risks and are more careful in conducting their research.

#### **4.2. The moral experience of whether or not to compromise the person’s autonomy**

During our research, participants expressed their wishes to die and sometimes spoke about the preparations they had already made to perform a self-directed death. Several times, we asked ourselves whether we had a responsibility to encourage participants to find treatment. Indeed, as mentioned before, some reviewers even suggested that we might have had a duty to intervene. The sense of uneasiness was strengthened when we undertook a case study with an elderly couple who strongly wished – and a few months after the interview actually chose – to die together at a self-directed

moment (van Wijngaarden, Leget, & Goossensen, 2015b). This couple told us that for years they had talked about their agreement to end their lives when they would have reached the moment at which they considered life to be no longer worth living. However, this pact seemed to hold both of them in an impasse, because they differed in their assessments of life and the timing of their deaths. The case study clearly shows a paradox: on the one hand, the couple died together *according to their mutual agreement*; but on the other hand, it gives an indication that it might have been a premature decision for the wife, not reflecting what she wanted *yet*. Precisely because of the impression of a form of coercion, one reviewer remarked:

I was wondering why you did not encourage the wife to seek resources to support her in having a discussion with her husband about the timing of the planned deaths, because she was suffering from the impasse with her husband. I did not expect you to try and change their minds about dying. But with the hindsight you now have, would you recommend other researchers to ask the wife directly if she would like to get support?

This is an intriguing question. We have chosen not to actively emphasize treatment options. But was that the right thing to do? There were other situations in which participants' wishes to die would seem premature. Perhaps it would have been possible to counsel some of these older people to give up their plans. However, participants themselves were often very explicit in that they definitely did not want any intervention. Some participants did go to a hospital or to physical rehabilitation therapy for physical treatment, but deliberately *no psychological* health therapies were sought. During the research process, we asked ourselves: Should we have compromised their autonomy and integrity by insisting on treatment fuelled by a desire to safeguard them, even though they did not want it? What is a humane and ethical approach in such situations? Did we have a duty to intervene knowing that participants were seriously ideating on a self-directed death? And would we have lost their trust if we had decided to insist on them having support without their consent?

The fact that our participants did not want psychological treatment might be partly explainable by the Dutch cultural context. In 2010, the Right-to-Die-NL started the campaign 'Of Free Will' and put the discussion about 'older people and a self-directed death' on the social and political agendas. The most important issue of this continuing public debate is 'making self-determination of life's end a reality'. Based on a 'rational and well-considered choice' older people should have legal options for assisted dying, they argue. This presupposes the idea that ending one's life can be considered as a 'rational and autonomous' choice. This idea is supported by a considerable part of the Dutch general public. In the light of this cultural context, one might understand that the older people involved truly did not perceive themselves as being mentally ill and having a pathological wish to die. They perceived themselves as 'normal', independent, autonomous and self-determining citizens, with a 'reasonable' wish to die. They were not searching for help or treatment (while being aware of the possibilities), but rather in search of what they call 'a dignified death'. In many cases, they had been active members of a Dutch right-to-die organization for decades. These organizations confirmed the legitimacy of their wish to die and provided information on how to perform a self-directed death. Most likely, participants would have found further protection to be highly paternalistic and would probably have withdrawn from this study if we, for example, would have proposed treatment. So from a cultural perspective, one could argue that this wish to die – at least in a considerable part of Dutch society – is seen as acceptable and reasonable, not in need of intervention. We think we should take into account these contextual givens, but is this a decisive argument for not intervening?

There was an additional methodological argument that strengthened our decision to not intervene. Our research project aimed to give insight in the lived experiences of people from an insider perspective, not from an outsider, normative perspective. Therefore, we chose to engage with these people as they perceived themselves. A phenomenological approach, free from prefixed theories or frameworks about illness or no illness, seemed to be the best option to achieve this. Prior to the interview, we explained this open, non-judging and non-committal interview approach to our participants. We assumed that this approach – lacking a medical, psychological paradigm – gave room for people to tell their story freely. We indeed sensed that people did not feel objectified and the fact that their wish to



die was not medicalized or psychologically ‘understood’ strengthened trust (van Wijngaarden, Leget, & Goossens, 2016b). Participants were very grateful to be able to openly share their experiences and struggles. In daily life, many of them experienced that most people (i.e. their family, friends or their GP) found it extremely difficult to listen without judgement when it came to disclosing a death wish. Several interviewees said they experienced the openness during our encounter as ‘a gift’. Should we then have made concessions to our own promises about an open, non-judging and non-committal research approach? Or would that have been an act of untrustworthiness? We attached great importance to staying within the terms of our agreements.

We also believe that using our phenomenological approach made it possible to get as close as we came to the lived experiences of the people involved and obtain unique data full of lived ambivalences, ambiguities, complexities and polarities. This might not have been the case, if we had been ‘protective’ in a way that participants themselves did not choose or prefer. But still the question remains: Do these arguments justify the fact that we did not intervene while people were ideating on a self-directed death?

In mainstream bio-ethics, this question would point to a conflict between the principle of non-maleficence and the principle of autonomy. The principle of autonomy entails respect for people’s self-determination. Patients may freely choose values, loyalties or systems of belief according to which they make far-reaching decisions. The principle of nonmaleficence requires that we avoid harm and refrain from doing anything that damages the patient’s interest, taking all reasonable precautions to protect them from harm and promote well-being (Beauchamp & Childress, 2009). Yet an important thing to bear in mind is that our participants were not patients but mentally competent citizens who perceived their wish to die as being in consonance with their life view and values. In their view, their wish to die was a result of an autonomous and realistic assessment of their life when the negative aspects had accumulated to such an extent that they preferred death over life.

We are of the opinion that intervention could have led to transgressing the boundaries between research and therapy (Finlay, 2011). Unbidden and unwanted interference with the choices, lifestyle and life of the participant might also have resulted in what we earlier touched upon as a ‘hypertrophy of the responsibility’ (ten Have & Welie, 2005). This is especially the case because of the fact that participants considered themselves sane, healthy citizens, capable of running their own affairs, living in a society where their wish to die is considered to be legitimate by at least a (large) part of the population. So wouldn’t it be presumptuous of researchers to think they have the right to interfere? We are of the view that prudently offering a free possibility of referral to external counselling was the only appropriate way to protect these people, without compromising their autonomy and freedom as citizens.

After scrutinizing our motivations and considerations, we felt that the most ethical approach was to respect the choices of our interviewees. But, for us as researchers, some uneasiness remains, fuelled by a felt moral responsibility to nurture concern for participants’ well-being. Our uneasiness was enhanced by the fact that within the period of one year after the interviews, we received death notices of eight out of the twenty-five participants (two of which were from the couple). Surely, competent people have a right to make their own choices, whether or not others may have preferred them to act differently. Besides, our participants may very well argue that their well-being was served by being able to end their lives at a time of their choosing. But what if someone had been crying for help and we did not notice?

Although it might increase feelings of uncertainty and vulnerability, the maintenance of ongoing, open-ended reflection about these complex questions is needed to stay sensitive towards the moral aspects of research. We fully agree with Etherington (2007), who wrote that ‘researchers should come from behind their protective barriers of objectivity’ (p. 615) and impeccability, inviting others to join them in the learning process as this is the only way to build and sustain a transparent and ethical research practice.

### 4.3. *The uneasy moral experience of threatening a person's self-narrative*

In qualitative research – just as in everyday life – it is fairly common that there turns out to be a gap between what participants think about themselves and how they present themselves in telling their experiences (Goffman, 1959/1990). In our research project, this was clearly the case. On the one hand, participants thought of themselves as independent, autonomous and self-determining ‘agents’. Based on an individual and ‘rational’ evaluation, they assessed their lives to be ‘no longer worth living’. They were in favour of further relaxation of the euthanasia law and several participants also expressed the hope that our research project might accelerate this process. On the other hand, they presented themselves as highly dependent on others when it came to their well-being. Their stories were full of anxiety, sadness and loneliness and a strong human desire to be visible, recognized, wanted, needed, valued, depended upon or attended to by others (van Wijngaarden et al., 2015a). Besides, it turned out that the wish to die was not at all clear, coherent and unambiguous; rather it was characterized by ambivalent feelings of being torn, expressed in words like: ‘dilemma’, ‘doubt’, ‘a difficult balancing act’ and ‘a split position’ (van Wijngaarden, Leget, & Goossens, 2016a). Thus, after a putatively rational decision had been made (that life was considered to be over), all kinds of ambivalences and ambiguities remained present (van Wijngaarden et al., 2016a).

The power of phenomenological research is precisely to illuminate such ambivalences and ambiguities, as it does not focus on perceptions and opinions, but focuses on *contextualized* lived experiences (Slatman, 2014). Therefore, the interviewer asks to elaborate on actions, situations, habits and events, for example: *At what specific moments do you experience that your life is completed? Can you tell me what exactly happened, what you felt? Who else was involved and in what way? When do you feel confronted with these feelings?*

Our way of interviewing thus invited participants to go beyond their cognitive considerations and reflect on their *lived* experiences. In most cases, a significant incoherence between participants’ cognitive-rational considerations and their much more ambiguous experiences came to the fore. Probably unconsciously, participants exposed themselves as dependent and wavering people, the opposite of how most preferably positioned themselves: as independent, self-sufficient people. As mentioned above, it is common that there is a gap between ‘what people think about themselves’ and ‘how they present themselves’ in relating to their experiences. Indeed, such incoherence is part of being human. However, the issue here is that the older people at stake seemed to struggle with the exposure of this inner incoherence and their ambiguous and multivoiced narratives.

Let me illustrate this by describing two reactions of two participants: one lady wrote me a lengthy letter after having received the narrative report. She completely agreed with the ‘careful and beautiful narrative’, which fully corresponded to her experiences. Simultaneously, though, she regretted that she had presented ‘such a one-sided, vulnerable picture of herself’ and argued that she was much stronger and more opinionated than she had portrayed herself. Following this, she sent me a detailed political argument about her views and position regarding the self-chosen life in older people and urged me to include this in the data-set to make her story ‘less vulnerable’. Another interviewee sent me an email about a year after the interview. She had read a news item about the outcomes of our research and she was disappointed. She wrote:

I have such fond memories of the interview and the narrative report had been so recognizable, but this characterization in the newspaper is so vulnerable. Maybe this concerns the other twenty-four people you have interviewed. But when I read it, it feels like we are in need of help and I don't like that at all.

What do these reactions of both ladies illustrate? Apparently, they made an attempt to guide and control the impressions they made on the researcher (Goffman, 1959/1990). Perhaps, they wanted to conceal some (what they call ‘vulnerable’) aspects of their narrative selves, which is again most human. Conceivably, the inability and the unwillingness to relate to the increasing dependency, deterioration and losses – which turned out to be the essence of the lived experience of these older people (van Wijngaarden et al., 2015a) – might also play a role here; they might have intended to present their

‘opinionated’ selves. However, it is likely that, during a confidential interview about matters of life and death, emotional reservations are to surface, at least from time to time. At hindsight, this exposure could be experienced as a relief *and* as an unpleasant experience at the same time.

Finlay (2011) describes that there are all kinds of complex conscious and unconscious dimensions that resonate in the participant validation. Participants see their experiences from their own perspective: they will never be able to see the research in the same way as the researcher does (and of course the same applies vice versa). She quotes Giorgi by posing that ‘participants are experts in what they have experienced, they are less clear and categorical about the *meanings* of their experiences’ (Finlay, 2011, p. 96). Participants have their own motives, ethos, needs and interests, she argues. ‘It may be in their interest to protect their socially presented selves’ (Finlay, 2011, p. 223).

While the aim of phenomenological research is to go beyond the social presented selves, the fact remains that this relates to the principle of power. The researcher has the authority over the outcomes and decides what picture is presented. Ellis (2007) quotes Josselson who argued: ‘Language can never contain a whole person, so every act of writing a person’s life is inevitably a violation’. And she asks herself: ‘If this is true, how do we research and write ethically?’ (Ellis, 2007, p. 6). How can we expose people in a true and ethical way, especially when there is a considerable incoherence between participants’ lived experiences and their cognitive considerations? How to highlight their ‘ambiguous and multi-voiced selves’ if this might be experienced (more for some than others) as a threat to their self-narratives? How should a researcher relate to the interests of participants?

Driven by the outcomes of our research (and not by prefixed ideological ideas), we tend to favour restraint and qualify the public debate: the results have given insight into the shortcomings in the prevailing conception of people as independent, autonomous and self-determining agents; the need for due consideration of all ambiguities present in the wish to die; and the inadequacy of considering this wish to die to be an individual problem (van Wijngaarden et al., 2016a). Besides, we have suggested that addressing the social and positional aspects of the wish to die might be a more appropriate response to the concerns of these people than offering them a legal opportunity to die (van Wijngaarden et al., 2015a). Most participants, though, hoped for quite the opposite: they were in favour of a more liberal euthanasia policy. Even though we have always been very open and clear about our position (not having adopted a political position in advance, being neither opponents nor proponents of a further relaxation of the euthanasia law) and research aim, some participants might still experience our conclusions as a disappointment or even as a threat to their self-narratives. We presume that this disappointment, or sense of misrepresentation, is not caused by a lack of truthfulness or a wrong interpretation. Indeed, it seems much more a matter of unwanted revealed incoherence in participants’ lives. However, this still can cause an uneasy feeling for the researcher. Enduring the uneasy feeling once again makes us, as researchers, aware of our position of power. It not only urges truthfulness to the data, but also to the participants’ sense of self and identity. In our case, I contacted both ladies and tried again to be as transparent as possible about our choices and approach. This has restored the mutual understanding for now, but naturally there is no guaranteed outcome.

#### **4.4. The uneasy moral experience of encountering the tragic**

The relational approach of our phenomenological research (Dahlberg et al., 2008; Finlay, 2009, 2011) implies that we aimed for an open, embodied and empathic presence to participants. We hold the opinion that in-depth research requires an embodied encounter – in which both the participant *and* the researcher are actively involved, touched and impacted (Ellis, 2017; Ellis & Patti, 2014; Finlay, 2009). During the research encounter, an intersubjective space arises between the researcher and participant. Acknowledging these intersubjective dynamics helps the researcher to better understand the lifeworld of the other (Abma, 2000; Finlay, 2009, 2011). Finlay makes a comparison with Martin Buber’s I-Thou relationship: it is a relationship of mutual regard, free from judgement, demand, possessiveness and objectification (Finlay, 2009). The other is seen as a subject, not as an object. This, of course, is not an

easily achievable task, yet these are the ‘underpinning foundations and the spirit of what we aim for’ in a phenomenological research approach (Finlay, 2009).

We have conducted our research by following this relational approach. The interviewer tried to be bodily and emotionally present, engaging as fully as possible with the participants. This approach required not only ‘a true willingness to listen to the other’ (Dahlberg et al., 2008, p. 98), but also an awareness of her own bodily reactions and ‘a vulnerable engagement’ (Finlay, 2009, p. 5). It will be recognizable to qualitative researchers that this way of doing research means that the interviewer is often deeply touched by participants’ life stories. The embodied approach enables researchers to better constitute the lived experiences of participants, but can also be accompanied with heaviness of heart (Ellis, 2017; Ellis & Patti, 2014).

In our research project, this heaviness of heart became very noticeable during the sampling process. Due to the sensitive nature of this research project, this process involved much more than simply deciding sample numbers, characteristics and inclusion criteria. We placed research advertisements in magazines targeting older people. We mentioned that we might not be able to interview every respondent; that we might have to select people. However, the number of responses we received was far beyond our expectations. We received 144 responses, all giving a short description of people’s personal situations, which were sometimes quite intimate. While we conducted a very clear and transparent sample procedure and kept every respondent informed about this procedure, we still felt encumbered by not selecting people, because all of them seemed quite willing to participate and tell their stories. A few people mentioned that they had never talked explicitly about their own death wish before because they feared rejection. Regarding the safety of all those people who disclosed a death wish: it is important to underline that excluded respondents were offered the possibility of contacting the first author for referral to professional help at any time. From a procedural perspective, our approach was fair and clear, but still a dormant sense of uneasiness remained. In a way, all those people deserved to be visited by us.

During the interviews, participants’ disclosures were impacting on the researcher on an emotional and bodily level, which provided deep insight. Sometimes, the sense of aching loneliness became almost tangible. For the researcher, this opened up the ability to empathize with feelings of not mattering and disconnectedness. But this approach also had an uneasy side effect, which we will illustrate by an example: one participant cried almost constantly while he was telling his story. After two hours, he asked the interviewer to stay a little bit longer. And so she did. Later on, when the intense interview came to an end, he wanted to hug the interviewer out of gratitude. He was extremely grateful for the opportunity to share his feelings, which he not only expressed during and after the interview, but also the other morning. He sent her an email with some beautiful pictures of nature to say ‘thanks again.’ After this research encounter she felt deeply touched, but also uncomfortable because his loneliness became so obvious. Despite the fact that he had some social contacts and lived in an apartment where he could join a daily communal meal, he did not feel heard by the people among whom he lived.

Several other times, something similar occurred. Once, the interviewer was invited to stay for a while and go out for dinner. Several people asked her whether they could help her with my research, by typing the transcripts, recruiting other participants or joining her at conferences, because they wanted to do something meaningful. To stay true to the role as a researcher (Finlay, 2011), and to the agreements we had made on beforehand, but also to protect herself from getting too much involved, we felt she had to draw a line. But it made us ask ourselves the uneasy question: How to feel about entering a life, trying to create an open, dialogical and reciprocal encounter for the time of the interview, and then ‘leaving’ these people again? Once more, we could quickly push away the felt discomfort and pose that the interviewer had had additional contact after the narrative report was sent. Besides, participants had the opportunity to get in contact at any time and ask for an additional visit or a referral to a counsellor if preferred. But in some cases, it still felt a bit like emotional abandonment.

Inevitably, every research relationship has to come to an end. However, if you find yourself intensely confronted with (e.g.) the loneliness of another human being resulting in a wish to die, it is one thing

to realize that it is inextricably linked to your role as researcher to end this relation and manage this in a morally acceptable way. But it is another thing to be deeply touched by this tragic as a fellow human being, sensing a deep longing for contact and not being able to answer it: a human experience of ‘encountering the tragic’ that goes beyond the researcher’s role. Although this is not an unusual experience in qualitative research, in our view, it is very important to explicitly and openly acknowledge these uneasy feelings as it keeps researchers on their toes when it comes to their responsibilities. It makes them more alert and careful, and in search of the most sensitive attitude achievable.

## 5. Uneasiness as a constituent of a morally good research practice

In this article, we have presented some self-disclosures about ethically uneasy moments that we have faced during our research with older people who have a wish to die. Scrutinizing these ethical challenges made us realize once again that conducting methodologically rigorous and procedurally sound research is no assurance of morally good research. In practice, ethics goes far beyond procedures and needs constant open-minded *and* open-ended reflection. Earlier on in this article, we referred to the three-step approach of Guillemin and Gillam (2004), who describe that practicing ethical reflexivity requires the acknowledgement of the ethical dimension and the ability to address these ethical concerns. We have elaborated on this idea by explicitly qualifying that addressing an ethical concern is not the same as ‘solving’ ethical challenges and concerns. We particularly highlight the need for open-ended reflection by emphasizing the complexity and diversity of the ethical possibilities in borderline cases of great responsibility. Indeed, we argue that ethical uneasiness can be seen as an important research tool in these situations. An open-ended reflective stance – with room for complexity and plural understandings – rather elucidates moral complexities and enlarges moral sensitivity than ‘solves’ problems.

Therefore, we would encourage researchers to explicitly reflect on their efforts to enhance morally good research practice. Just like methodological reflections on strengths and limitations, we argue that detailed ethical reflections should be a basic part of research articles. By discussing ethical issues and thoroughly recapping on how these issues were addressed (rather than solved), researchers contribute to the course of research ethics. Sharing these reflections with other researchers is helpful in that it might: (1) increase the researcher’s awareness of risks and cautions during the whole process; (2) build a learning dialogue between researchers, providing guidance for other colleagues in dealing with complex ethical issues; and (3) contribute to the ongoing, collective task of rethinking the research practice to nurture an ethical research climate which is committed to trust and accountability.

To conclude, when practicing open-ended reflexivity, researchers might become ‘vulnerable researchers’ as Etherington (2007) has stated, but only by means of transparency can we invite others to join us in our ongoing learning process of becoming ethically competent researchers (Etherington, 2007). To become thoughtful and thoroughly reflective researchers, Hansen (2011, 2015) has noted, we have to put ourselves ‘at risk’ and acknowledge the unknown and uncertain. Only by ‘living the questions’ can we get into a true relation with the world (Hansen, 2011, 2015). Room for lasting ethical uneasiness and open-ended reflexivity seems indispensable to constitute accountable and morally good research practice.

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## Appendix 1. The interview guide

*Researching the lived experience of older people who feel life is completed and no longer worth living*

### Introduction of the interview

- Acknowledgements for time and participation
- Information about the research project and the procedure
- Information about the character of the in-depth interview (open structure and the focus on the thorough exploration of the lived experience)
- Possibility for questions about the project and the interview

## The interview

### Introductory question

- Can you tell me in what way our call to participate in this study did appeal to you?

### Sequence 1: about completed life

- Can you describe what it means to experience that life is completed<sup>1</sup>?
- Can you focus on a particular example of this experience? Can you describe a specific event or particular experience when you (first) experienced that life is completed?
- Can you describe as fully as possible how this experience influences your daily life?

<sup>1</sup>Note: if a participant used another word, such as ‘life is over’, ‘ready to give up on life’, ‘tired of life’, the interviewer used this way of saying in her questions to stay as close as possible to the participant’s experience.

**Sequence 2: about the wish to die**

- Can you describe what it means to have a strong desire to die?
- Can you describe as fully as possible how the wish to die influences your daily life?
- Can you describe a moment when the desire for death was very strong?
- Can you describe a moment when it was less pronounced, more at the background?
- What kind of things influence your wish to die?

**Sequence 3: about a self-directed death (if suitable)**

- Tell me about your preference of a self-directed death. Can you explain why it is important to you?
- Tell me about the process of how your decisions / ideas developed.
- What is to like to live in this in-between period: living on while ideating on a self-directed death?

**Elaborating questions**

In order to encourage participants to articulate their experiences in detail, during the interview, the interviewer keeps on posing questions such as:

- Can you describe the experience as much as possible as you live(d) through it?
- Please, try to describe the experience from an insider perspective, as it were almost like a state of mind. Tell me about the feelings, the mood and the emotions.
- Can you elaborate a bit more on that as concretely as possible?
- What do you mean by ...?
- What is it like ...?
- In what way?

**After the interview**

- *Closing words and summarization*
- *Voluntary administration of the HADS*
- *Ask for the completed personal information form*
- *Acknowledgements*
- *Appointments about member check and privacy*
- *Appointments about reciprocal possibility to contact for any additional info*
- *Appointments about possibility aftercare*