Anticipating Doing a Study With Dying Patients: An Autoethnography on Researcher Well-Being

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Abstract
It is a well known problem that qualitative researchers in the social health sciences are potentially at risk of experiencing emotional burden when confronted with sensitive topics, such as death and dying. A number of research papers and reviews suggest that self-reflection could be helpful in dealing with the associated emotional burden. These publications however typically mention strategies that deal with the problem when emotional burden is already present. In this article I explored if a proactive self-reflective approach could be useful to prevent emotional problems when dealing with dying patients and their relatives during my research project. For this paper I used an autoethnographic approach to describe the self-reflective process I undertook before the start of my research project to identify, reconstruct and analyze a number of critical personal experiences that were likely to cause emotional problems. Five themes emerged: seeing people suffer or die, dealing with bereaved family members, difficulties regarding interdisciplinary research, unresolved personal issues from the past, and unwillingness to take part in my research study. From a methodological point of view, a proactive self-reflective approach deserves consideration as a tool to help better prepare researchers in the social health sciences to conduct research into delicate topics. Not only does it enhance researcher wellbeing, it also increases the quality of the researcher-as-instrument. This article is a worked example of how to engage in such proactive self-reflection and illustrates the added value of including this step at the start of a research project looking into sensitive topics.

Keywords
death, emotion work, reflexivity, emotional burden, autoethnography

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Introduction

To imply that challenging encounters such as the ones recounted in this paper do not happen is to ensure that novice researchers are not prepared or equipped to face them; it keeps some of the more emotionally and intellectually demanding components of the social research process firmly in the closet. (Woodthorpe, 2011, p. 107)

It is a very well known problem that early career nurses, doctors, researchers and medical students are particularly vulnerable to the loss of patients (Ko & Kiser-Larson, 2016; Smith-Han et al., 2016; Woodby et al., 2011). Several studies have also shown that facing death can be a stressful experience for nursing students, who experience stress and anxiety related to death and dying (Hopkinson et al., 2005; Kent et al., 2012; Kurz & Hayes, 2006; Mok et al., 2002). For social scientists, who are typically even less familiar with death and dying than nursing or medical scientists, this may be even more the case (Menzfeld, 2018; Woodthorpe, 2011).

As an early career researcher in the social health sciences, being enrolled on a PhD on the topic of how to improve assessment of pain and discomfort in palliatively sedated patients during the last days of their life, I was especially aware of this. A few years ago, a department colleague had suffered from serious emotional distress when doing qualitative research with...
cancer patients and had to take a leave of absence for 6 months because of ensuing mental health problems. As a result of this, she started to explore the dynamics that drove her toward these mental health problems and wrote an autoethnography about the emotional risks she experienced during sensitive research (Benoot & Bilsen, 2016). She described three types of emotional burden during her research: emotional burden linked with suppression of emotions, emotional burden linked with distal traumatization (vicarious victimization that happens when there is no longer any direct contact with the distressing event), and emotional burden linked with overidentification with the participant (Benoot & Bilsen, 2016; K. R. Gilbert, 2001). She concluded that writing down the experiences of doing qualitative research in a reflexive way can protect the researcher and enhance the quality of research (Benoot & Bilsen, 2016). Although her article—as an example of embodied reflexivity—was written only after completion of the research process and after a period of emotional distress and could thus not serve as “evidence” of the prevention of researcher distress, it makes sense to investigate whether engaging in reflexive practice beforehand would be helpful in preventing emotional distress.

Self-reflection and reflexive practice are increasingly considered as essential attributes of competent professionals’ functioning (Kanthan & Senger, 2011). Considering that the researcher is the embodiment of the instrument for qualitative data collection, unique researcher attributes have the potential to influence the collection of empirical materials (Pezzalla et al., 2012). It is therefore of great importance that the qualitative researcher is not experiencing emotional distress when researching a sensitive topic, as this could not only potentially lead to one of the aforementioned types of emotional burden, but also from a methodological point of view the quality of the data collection may suffer. Using self-reflection to mitigate the effects of emotional distress has been suggested as a tool in ongoing emotionally disturbing situations (e.g., doing sensitive research, or working in a challenging healthcare setting), the positive effects of which have been reported (Dorffman et al., 2019). In a sensitive research context, the aim is to become aware of (anticipated) emotionally burdensome issues and reflect on these beforehand so that these would only minimally impact researchers’ wellbeing and the research itself. A number of studies have called for more awareness for the effects that undertaking qualitative research on sensitive topics may have on researchers’ emotional wellbeing and suggested that they need to be proactive about self-care; going through a proactive self-reflexive process as described in this article can be one of the tools contributing toward achieving this goal (Dickson-Swift et al., 2008, 2009; Fenge et al., 2019; Hanna, 2018).

**Aims, Objectives and Significance of the Current Study**

The present autoethnography describes how I have used a reflexive approach to prevent emotional problems when confronted with my own feelings and possible distress in dealing with dying patients and their bereaved relatives. It outlines the different strategies that I developed based on previous experiences, literature and critical self-reflection, by presenting my personal story as data. It presents a metacognitive dualistic process, grounded in my own real-life situation, with the aim to show how the very act of engaging in proactive self-reflection when dealing with a sensitive or confronting research topic, can enhance researcher wellbeing and consequently improve the quality of the researcher-as-instrument.

**Understanding the Sensitivity and Ethics Involved**

A large part of this autoethnography describes how I developed and applied a stepwise proactive self-reflective approach to deal with a number of problems, specifically related to the topic I was about to study. Before I elaborate on that however, it is important to realize that this topic itself (the use of monitoring devices to make assessments of patient comfort during continuous sedation until death) has multiple aspects that are culturally and ethically sensitive, and as such there are multiple dynamics involved, against which my own story needs to be situated and that are necessary to understand how this autoethnography can be legitimized as critical social research.

In what has become known as the Belgian model of integral end-of-life care, euthanasia is an available (and legal) option, even at the end of a palliative care pathway. This approach became the majority view among the wider Belgian public and palliative care workers. It is argued that this synergistic development was made possible by public confidence in the healthcare system and widespread progressive social attitudes that gave rise to a high level of community support for both palliative care and euthanasia (Bernheim et al., 2014). However, this historical narrative, where the promotion of the legalization of euthanasia and the advocacy of the development of palliative care in Belgium were synergistic, rather than antagonistic, has also been challenged. The main criticisms were that legal safeguards against potential abuse were insufficiently enforced, while others offered arguments based on fundamental ideological grounds to demonstrate the incompatibility of palliation and assisted dying (Cohen-Almagor, 2013; Materstvedt, 2013). These arguments are strongly linked to religious versus secular worldviews, and to this day strongly influence the public debate. However, the majority of health care institutions have links with the Christian religious tradition that considers palliative sedation as a preferable alternative to euthanasia, although here too there are major differences of opinion between institutions. The theme of end-of-life care is highly ideologically and politically colored and continuous sedation until death, and the choice of whether or not to do so, is very sensitive to many people because it also embodies an ideological preference by extension. This ideological influence concerns as much the patient, his family as the caregivers. This underlying tension also plays a role in the background for my narrative, since the university where I work is notoriously secular and free-thinking, and I feared that this would possibly affect finding participants for my study (it would later turn out that my fears were unfounded).
Another important cultural influence can be observed in the conception of the idea of palliative care itself. One of the tenets of palliative care is to alleviate suffering but not to shorten life. This means that the administration of medication (analgesics and sedatives) should be proportional to the severity of the symptoms (Cherny et al., 2009). However, there is a problem with regard to making assessments of patient comfort during continuous sedation until death (which was also the conceptual starting point of the study I was about to do). Patient comfort during continuous sedation until death (CSD) is usually assessed by observing the patient for any behavior-based signs that could indicate consciousness or pain (e.g., moaning, grimacing, reaction to a stimulus, etc.). However, the problem here is that the medication used to induce CSD interferes with motor responsiveness. Hence, traditional approaches to assess level of consciousness and pain based on behavior-based observable signs could be unreliable and patient suffering may remain undetected or underappreciated. Decisions about adjustments to the medication regime, based on the subjective interpretation of these observations, may be misinformed and thus lead to under- or oversedation of a patient (Six, Bilsen, et al., 2020). The main research study I was about to do, would look into the correctness of these subjective observational assessments when compared with objective neurophysiological indicators of level of consciousness and pain. Whatever the outcome of this study, a lot was going to be at stake for all people involved. If the assessments would confirm each other, this could be seen as a validation of the current clinical assessment practices; in the other case, this aspect of palliative care would need to be improved substantially. Another important tenet of palliative care is to recreate a home-like environment for the critically ill and dying person and to avoid the use of technology. The mere fact of conducting a study during the last days of a person’s life was already very challenging; but on top of that the study would use monitoring devices and visible electrodes, which are generally thought of as having no place in a palliative care setting. In addition, caregivers and family members would be unable to see the output of the monitors and would also be asked to make subjective assessments of the patient or beloved family member respectively. After the death of the patient, the caregivers and family members would be interviewed about how they thought the patient’s last days had transpired (Six et al., 2020).

All of this would be superimposed upon the already very hard to accept decision that a curative treatment was no longer possible and had been replaced by a palliative treatment. Upon the very grave news that a father or mother, brother or sister, son or daughter, . . . would soon no longer be there . . . (Glajchen & Goehring, 2017) And to make sure that this transition to death would be as comfortable as humanly possible, he/she would be sedated until that moment of death, because their suffering had become so unbearable that the only thing left to do was to bring him/her into a deep sleep so the pain would no longer be experienced . . . And in this context, a caregiver would ask the patient or his/her substitute decision maker if it would be acceptable, at such a difficult and emotionally burdensome moment, that a researcher would come to inform them about a study he was doing in patients undergoing CSD.

In addition to the areas of tension already mentioned, we must also not lose sight of the unease in our culture when dealing with death. Speaking about death and dying is a taboo for many and when it is spoken about it often turns out to be very difficult to find the right words (Rawlings et al., 2017). A silent witness to this is the emergence of initiatives such as the so-called death cafes to make dying a more discussable topic (Hammer et al., 2019; Nyatanga, 2017). In general, however, we can state that in our societies, too little attention is paid to how to deal with or talk about dying and, in particular, there are few initiatives or tools available to provide guidance to early career researchers in such a topic, especially when they have not had any medical prior education (although medical professionals also indicate that they have not received sufficient training in this area; Dhaliwal et al., 2017). A number of studies call for more attention to be paid to these aspects, but few concrete suggestions are made. This wider cultural unease with regard to talking about death, not being able to find the right words, drawing attention to the subject, but not being able to put it into concrete terms—all these things have led me, as a researcher, to think about how best to prepare myself to deal with the aforementioned complexities that my research would involve.

With such a sensitive subject, it is of the utmost importance to think carefully about the ethical implications. Failure to do so means that the quality of research could suffer. Trying to prepare yourself as well as possible, to carry out the study in the best possible way in a culturally very complex situation, with serenity and respect for the patient’s dignity, is the best possible way to live up to the commitment and trust placed in you by the participants in such a delicate study (Martins Pereira et al., 2018). This is the ethical duty of a researcher when he/she has received permission and trust to be part of something as valuable as the last moments of a person’s life.

**Understanding the Nature of Coping With Patient Death**

A recent systematic review and qualitative meta-analysis of how nurses cope with patient death showed that a wide range of coping strategies exist and a number of intrinsic and extrinsic resources could be identified (Zheng et al., 2017). Intrinsic resources mentioned were: setting boundaries, reflection, crying, beliefs about death, life and work experience, and daily routines and activity. Extrinsic resources found were: talking and being listened to, spiritual practices, education and programs, and debriefing. While this review offers an interesting overview of the different included strategies, it is noteworthy that the focus is mainly on how to deal with one’s emotions after the patient has died and—with the exception of distancing yourself emotionally from the patient—no strategies are offered to proactively prepare for the expected loss of a patient. The need for such strategies has nonetheless been highlighted in a number of studies, in particular within an educational
because researchers have direct access to intimate information. These personal topics fit autoethnographic enquiries well, topics, sometimes including those conventionally kept private. (Farrell et al., 2015). Autoethnographic studies frequently cover emotive cal research in medical education are available (Farrell et al., 2015). Researchers should consider autoethnography as an important methodology to help advance our understanding of the culture and practices of medical education” (Farrell et al., 2015, p. 974). Autoethnography as a method should be ethnographical in its methodological orientation, cultural in its interpretive orientation and autobiographical in its content orientation (H. Chang, 2008). The data consists of the memories of lived experiences of the author (N = 1), which are reconstructed through a personal narrative and assembled into a coherent structure that allows the author to make sense of the experiences under scrutiny. The very act of reconstructing memories also implies co-creation and interpretation. This dyadic shift between an insider and outsider perspective enables an in-depth analysis of subtleties that might otherwise have remained unnoticed.

Personal narratives, as an approach to autoethnography, propose to understand a self or some aspect of a life as it intersects with a cultural context, connect to other participants as co-researchers, and invite readers to enter the author’s world and to use what they learn to reflect on, understand, and cope with their own lives (Ellis, 2004). This type of research does not allow generalization to a larger population but instead gives an in-depth view of several nuances involved in overcoming certain personal obstacles that may interfere with one’s role as a researcher, which is rarely seen in the scientific literature, at least not from a proactive viewpoint (Flyvbjerg, 2012). From a (socio-medical) educational perspective it may serve as a worked example to others of objectifying the researcher as a human being, proactively taking measures to prevent emotional burden and, through self-reflection, mediate its potential to induce researcher biases.

Summary of “My Story”

Since an autoethnography is oriented toward autobiographical content, I will first introduce myself and provide some basic information about the study I was preparing for. I am a 42-year-old man, with a master’s degree in anthropology, and started my academic career 4 years ago by becoming a researcher in the field of social health sciences. The topic of my research project is how to assess whether people who are receiving continuous sedation until death are really free of pain or discomfort. My academic advisor had warned me beforehand that this topic would be particularly challenging, not only because of working with dying people and their family members who are left behind, but also because there would be numerous methodological challenges associated with trying to assess pain and discomfort in a non-communicative group of patients and because of the transdisciplinary mixed method design. I soon realized that I would not be the first person to be confronted with emotional distress when researching such a
delicate and difficult topic and not cope in the best possible way. I knew what happened to the department colleague mentioned in the introduction and, after reading the paper she wrote about her experiences, I realized it would be best to try proactively to minimize the chance of falling victim to this “vicarious suffering syndrome”. I decided to do this in a systematic way, using a stepwise strategy which I will describe in the next pages.

**Step 1: Identifying Potential Problems**

It would make a lot of sense to take the time to think about which events might be distressing and to think about why this might be the case. The first step in trying to negotiate potential difficulties is obviously becoming aware of them. In my case, I identified the following potentially stressful situations:

1. seeing people die or suffer,
2. talking with bereaved family members,
3. difficulties regarding the research study, such as methodological problems and problems associated with interdisciplinary research (lack of knowledge or expertise),
4. unresolved issues from the past (regarding deceased family members), and
5. difficulties in recruiting participants for my study.

Next, I started to reflect upon these potential stressors more deeply to find out why and how exactly these could cause emotional distress. For me, seeing people die or seeing intense suffering was something I had seen only on a few rare occasions, so being relatively unfamiliar with these major life events, it certainly made sense to assume these would impact me emotionally. Furthermore, being confronted with a dying person receiving continuous sedation until death might cause feelings of unease because it would likely lead me to ruminate about that person’s intense suffering and quality of life and lead to thoughts about what I would do if I or a significant other were in such a situation. It would be reasonable to assume that I would be at risk of over-identifying with the patient.

Talking with bereaved family members would most likely be emotionally burdensome as well, because of my tendencies to empathize and over-identify. However, it would be only fair to say that I had some prior professional experience in talking with bereaved family members and conducting difficult and sensitive interviews in general. Nevertheless, these interviews would probably be very demanding in terms of interviewing and interpersonal skills. Another challenging aspect of my study would be its transdisciplinary orientation, meaning that researchers from several disciplines were involved in the design of the study, each of them a specialist in their own discipline (i.e., anthropology, neurology, anesthesiology and psychology), and of course their own idea of what makes for good science. I was hoping I would be up to the task of making sense of these different views and was also very much aware of my lack of knowledge or experience in some aspects of my study (such as how to use specific monitoring devices, how to combine different types of data, how to interpret certain observations, what software to use, etc.).

Another likely source of emotional distress would be the memory of departed family members, such as my grandfather, grandmother and more recently my stepfather. I was particularly concerned that I might relive some painful memories when seeing dying patients and might be emotionally distracted and not objective enough to conduct the research study. And finally, I was unsure whether I would be able to convince medical staff and patient family members to take part in such a sensitive and ethically delicate study and also questioned my ability to handle their possible rejections well. If the latter occurred a lot, it would definitely lead me to doubt that my PhD project could be completed successfully.

**Step 2: Introspection**

The second step in my journey was far more demanding than merely identifying and reflecting upon potential issues; in this step I delved deeper into my own fears, trying to find out what caused them in the first place. This meant revisiting some very specific memories of events that occurred in my life with the idea of finding out how and why these memories influenced my present view of things. In my case, I could do this alone because there was no reason to assume I would not be able to deal with the associated emotional content; however, for some people it might be a good idea to seek professional help with this step, particularly when there is a history of mental health problems or a suspicion these might occur during the process. In this step I will present two brief descriptions of reconstructed memories I revisited during introspection, while also reflecting on them to unveil the role they played in certain fears and thoughts I had when preparing for my PhD project.

I remember standing at my grandfather’s hospital bed when he had been diagnosed with lung cancer. He looked very pale and frail—I remember that the thought crossed my mind at the time that he had lost a great amount of weight due to his illness and was little more than skin and bones. Seeing him like that made me feel very uncomfortable. It was clear he would not live much longer. After a number of attempts at speaking he made me promise him I would finish my university studies. After that he lost consciousness again. I left the room feeling very sad and decided not to visit him again; I wanted to keep a certain image of him in my mind when he was still healthy. A few days later he passed away.

The illness and subsequent passing of my grandfather obviously made an impact on the 19-year-old young man I was at the time. It confronted me more closely with mortality, by actually seeing a family member go through a lot of suffering and pain and undergoing several treatments that did not deliver the much-desired alleviation of symptoms. In the end I remember thinking that the fact that he died at least meant that his intolerable suffering had stopped, and I know some other family members at the time had similar thoughts. But this feeling is very double-edged and looking back now at how everything unfolded, the question rises as to whether some treatments might better have been forgone in favor of palliative treatment.
which I am sure would have provided more comfort both to my
grandfather and to all who were left behind. And it is exactly
this sentiment which tied into the mixture of unprocessed emo-
tions I was experiencing myself when thinking about the study
I was about to conduct. The main problem was clearly that
I was afraid that these memories would surface again and make
me relive all the negative emotional content I experienced as a
young man who decided at some point not to visit his dying
grandfather again.

Many years later, and about 1 year before I would be appointed as a
PhD researcher, my stepfather became seriously ill and died in a
short time at the rather young age of 63. He never made it to
a palliative ward and passed away in the ICU. By that time, I had
seen some more people passing away, but never such a close rela-
tive. Again, a whole load of memories and feelings came up that
needed to be worked through and although I was older now, things
were not any easier.

The problems I struggled with were similar to when I was a
19-year-old. Apparently, age did not matter much and although
I had better coping skills, clearly they still did not suffice and my
fears regarding the upcoming PhD project would be fueled even more by what had happened to my stepfather just 1 year
before it started.

**Step 3: Executing an Action Plan to Negotiate the
Anticipated Adverse Effects**

After thinking about this for some time, I found some ideas on
how to deal with these potential issues. An important insight I
developed is that to do something about it, I should not only
recognize that there might be a problem: it would be a good
idea to share some of my concerns with others who were
involved in my project as well. And, as such, have an open
attitude about it, letting go of the stereotype of show-no-
weakness, and instead proceeding to a dynamic ongoing state
of reflexivity, where I would be aware of what was going on
and its impact on me. This type of meta-cognition, where one
describes the situation and the feelings it evokes with an inner
voice, would be helpful in exerting some control over my own
emotional experience.

To deal with my own uncertainties regarding my lack of
knowledge about palliative sedation and the use of monitoring
devices, I started reading specialized works, but I also went to
see several experts and talked with them about my concerns.
This proved to be especially useful, because my PhD project
would be a transdisciplinary study, and as is typical for
researchers in those type of studies, I lacked some basic back-
ground knowledge about the other sciences involved, which
these experts were able to convey to me in the shortest possible
time, with a focus on what I needed to know and in a way
I would understand. This proved very helpful in making me
feel more up to the task. Additionally, I took specialized one-
on-one training to learn how to operate one of the devices I
would need for my study. Next, I did a trial run with a colleague
to test the equipment and the study protocol itself. This
revealed some practical flaws of the kind that are easily missed
during the design of the study. After correcting for these, we
contacted a palliative team in a hospital who agreed to do a
pilot study.

While mentioning my concerns of never having worked
with dying people before, the palliative care physician
promptly suggested that I go on a patient round with her to see
how things usually worked on a palliative ward. This enabled
me to explore the scene and to try out my insight about meta-
cognitive reflexivity. That afternoon I saw several very ill peo-
ple who did remind me of my deceased family members but,
much to my own surprise, I went home feeling empowered and
confident. I should emphasize that the emotional burden was
still there, but I did manage not to let it overpower me or throw
me off guard. As a next step in my action plan, I decided to do
something about this emotional burden itself and wrote a short
poem about the death of my stepfather, which I then submitted
to a palliative care journal (Six, 2017).

To deal with the methodological complexities of doing a
transdisciplinary mixed method study using neurophysiologi-
data, my academic advisor involved me in writing a paper
about the intricacies of this type of study design, which helped
me gain a better understanding of the methodological back-
ground (Deschepper et al., 2017). We further agreed that if for
any reason I felt the urge to talk about something that bothered
me, he would lend a sympathetic ear. Later on, when the first
patient who took part in my study died, I did indeed take him up
on his offer.

A final problem that I looked into before effectively starting
my study was how to engage the caregivers and motivate them
to be the ambassadors of my study. It would be vital to gain
their trust and support for my study, otherwise recruitment
would be nearly impossible. In my experience, based on my
pre-academic professional career as a branch manager, people
tend to cooperate best if they get the chance to participate in the
design phase of a project and have the feeling that their con-
cerns are being heard and taken into consideration. In my PhD
project we therefore included people actively working in the
field, that is, palliative care nurses and physicians, from the
very beginning.

This meant that they became engaged with the project and
made several good suggestions about how to proceed, varying
from practical tips on how to approach patient family members
to which kind of monitoring device to use based on their expe-
rience. For example, I originally wanted to use a sensor that
could be put onto a finger to measure heart rate variability, my
idea being that this would be minimally invasive, but the nurses
anticipated that this would likely lead to erratic readings
because blood circulation in the extremities is often proble-
matic in dying patients. Hence, we chose another type of sensor
which could be put on the chest instead. This type of practical
information is very valuable and resulted from the consecutive
meetings we had to discuss the project leading to the construc-
tive engagement of all parties involved. We thus ensured the
feasibility and acceptability of the pilot study.
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When the first patient enrolled in the study passed away after several days, we had another meeting to discuss the protocol, to see if changes needed to be made. As it turned out, it was acceptable in its current form, also for the family members of the deceased patient, whom I interviewed about their experiences. For me this way of working also seemed feasible as I was able to show empathy to the family and at the same time keep a firm grip on my own emotional sensitivities. Looking back to it now that the project is near completion, this state of dynamic equilibrium proved helpful throughout the entire duration of my study. The self-reflective proactive approach I adopted had indeed prepared me better to deal with such a sensitive topic.

From an educational point of view, even though the self-reflective process described in this paper is based only on the experience of the author, a more abstract formulation could be useful. Transferability is after all one of the core concepts of education (Cambon et al., 2012). Based on the autoethnographic narrative I have described, the self-reflective process I undertook can be summarized as follows: 1) identifying potential problems, 2) introspection; revisiting recreated memories and elaborating on them to find out the underlying causes of emotional distress, 3) executing an action plan to negotiate the anticipated adverse effects.

Discussion

Using Theory and Research Literature to Interpret My Story

In this autoethnographic account I identified a number of themes which in general can be attributed to two categories; problems revolving around the topic of death and problems more generally associated with being an early career researcher. I will discuss both in relation to the relevant research literature, followed by a discussion of the self-reflective process I undertook to better navigate the cultural and ethical sensitivities involved. Lastly, I will discuss the legitimacy of this autoethnography as critical social research.

Problems revolving around the topic of death. Researchers engaging in topics such as death or dying are at particular risk of vicarious trauma (Taylor et al., 2016). Anticipating seeing people suffer or die felt quite unusual for me as a social scientist, who had no prior training in dealing with these types of situation. Having the opportunity to walk a consultation round with a palliative care physician during the exploration phase of my research project who was understanding of my unfamiliarity, talking with nurses about what life is like on a palliative ward and having some practical exposure to this very special setting, where suffering, dying and everything related to it can be made the subject of conversation, was very helpful in alleviating anticipative stress. Ek et al. (2014) found in first-year nursing students, who were involved in the care for cancer patients, that the thought of patient death is more frightening than the actual experience, and that such events lead to a confrontation with one's own feelings (Ek et al., 2014). Both the former and the latter are echoed in my story. They concluded that nursing students require continuous support and opportunity to reflect and discuss their experiences about caring for dying patients and confronting death throughout the entirety of their education.

In addition, teachers and clinical supervisors need to give support using reflective practice to help students to develop confidence in their capacity for caring for dying patients. Another study with second- and third-year student nurses showed how they found it difficult to handle their emotions when caring for patients with cancer (King-Okoye & Arber, 2014). A number of students described the whole experience as emotionally distressing and draining and where avoiding contact with these patients by using distancing and avoidance strategies. Using reflective practice and good mentoring to enable students to feel supported were suggested here as well to address this problem. My own story fits well with the conclusions of Ek et al. (2014) and King-Okoye and Arber (2014) and clearly shows that reflective practice is to be considered as a tool to improve researcher wellbeing.

Being mindful of potential emotional risks for the researcher working on a sensitive research topic is important. During the proactive self-reflective process I undertook, I identified and (briefly) described two reconstructed memories of family members who had died. I expected these memories could lead to emotional distress during the data collection phase of my research. Becoming aware of this and reflecting on this in a self-distanced way (e.g., by writing a short narrative or by sharing with a colleague or mentor) allowed for better “management” of emotions during the research itself (as was demonstrated in my story when I walked a consultation round with a palliative care physician during the pilot phase). The realization that I would be carrying an amount of personal “baggage” when conducting sensitive research was instrumental to allow for this better management of emotions, which can involve allowing, acknowledging, and even integrating them into research (Holland, 2007). Before the start of my research project I feared that the focus on patients, who underwent continuous sedation until death, would unearth emotions and reflections on personal experiences to an uncomfortable and unhealthy extent. By proactively acknowledging this however these feelings passed and I was able to reframe my personal memories so that they would provide context rather than be intrusive (Mitchell & Irvine, 2008).

Talking with bereaved family members proved to be one of the more difficult aspects of the study I undertook and as such I experienced it to be more difficult and demanding than the actual fact of seeing their relative die (although this passing away also had a major emotional impact). As Howard et al. (2018) observed witnessing the impact of death on relatives is one of the major factors associated with emotional disruption in physicians (Howard et al., 2018). They reported bearing witness to the pain and distress of the surviving family and friends as more distressing than being involved in the death of a patient, a finding which is also confirmed by my story. Looking

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back now that the data collection phase of my research project is finished, a large part of my time in the field was invested in talking to family members present at their dying relatives’ bed and trying to be as supportive to them as humanely possible. Beyond the family, the greatest emotional strain is on people who work directly with the patient and family (Allie et al., 2018). This proved indeed to be emotionally very demanding and I dealt with it by, immediately after the conversation took place, talking about it with the nurses and volunteers. They suggested this to me because they regularly talked with each other in such a way if they felt the need was present; this kind of mentoring by peers proved very useful to manage the emotional stress of having a difficult conversation. In a study about how social support affects the ability of clinical nursing personnel to cope with death the author concluded that sufficient support from colleagues can be an important source of comfort for them to manage their preparation for and overall strategies to cope with the death of patients (W. P. Chang, 2018). This is also confirmed in a review by Zheng et al. (2017) that shows that the need to communicate with others and being heard was identified as important in dealing with patient death (Zheng et al., 2017).

Problems associated with being an early career researcher. As Hacket and Rhoten (2009) argued, early stage researchers are those most explicitly confronted with potentially conflicting ideas about what counts as “good science” in an interdisciplinary context (Hackett & Rhoten, 2009). In my autoethnographic account I mentioned that as an early career researcher I originally felt uncertain how to deal with these different views, which led me to worry about methodological issues and my own lack of knowledge or expertise. This finding is also confirmed in a publication by Sverdlik et al. (2018) who reviewed the factors that influenced doctoral students’ completion, achievement and wellbeing. They found that negative emotions (e.g., frustration, confusion) were dominant in the doctoral writing experience and that self-worth fluctuated during the PhD process as a result of external evaluations, progress and self-assessment (Sverdlik et al., 2018). They also found that collaborative writing is associated with more optimal self-regulation, higher motivation, more positive emotions, and better writing quality, which is also confirmed by my experience of co-writing a methodological paper with my academic supervisor.

A review by Schmidt and Hansson (2018) further shows that doctoral students face multiple challenges and that there is a need for increased awareness of the basic nature of research as a highly challenging endeavor whose progress is unpredictable and nonlinear—as is how doctoral student’s emotions and abilities impact their well-being and PhD work process (Juniper et al., 2012; Schmidt & Hansson, 2018). Receiving help and getting support from field experts who conveyed their knowledge to me in an understandable format, or in other words mentoring, was instrumental in negotiating these challenges, which is consistent with literature findings (Schmidt & Hansson, 2018; Sverdlik et al., 2018).

Meaning of self-reflection before and during the research process. As I noted earlier I had studied anthropology before, and as such I was aware that during fieldwork there exists a risk of losing objectivity by becoming too involved or emotionally compromised. The role of researchers’ emotional responses and the self-care strategies that, in some circumstances, are appropriate for the researcher and other research support personnel have not received the attention they deserve in qualitative research literature (Rager, 2005; Tierney, 2018). Strategies such as counseling, peer debriefing, and journal writing have been mentioned as means of dealing with the potential for “compassion stress” as experienced by the researcher (Rager, 2005, p. 423).

Additionally in the nursing sciences, reflection as an educational strategy is now considered a critical component of professional practice (Miraglia & Asselin, 2015). These strategies however typically only deal with a problem after it poses itself, and do not really allow one to prepare for anticipated emotional problems. The only suggested strategy from a proactive viewpoint that has been mentioned in the literature is distancing oneself from or avoiding patient death (Zheng et al., 2017). This however has been shown to be problematic and ignores the risk of bereavement overload and vicarious trauma (Allie et al., 2018; Taylor et al., 2016). The self-reflective strategy I described in my autoethnographic narrative consists of three steps; 1) identifying potential problems, 2) introspection; revisiting recreated memories and elaborating on them to find out the underlying causes of emotional distress, 3) executing an action plan to negotiate the anticipated adverse effects.

The first step—identifying potential problems—refers to the self-conscious act of objectifying one’s inner world to help understand one’s feelings. It is a descriptive and explorative phase, where by means of dialectic phrasing the object of our attention gets defined. This means that the researcher asks himself questions from an etic perspective and provides answers from an emic perspective. For example: an etic question could be “Why do you think research about palliative sedation is going to be difficult for you?” and the emic answer would be “Because it reminds me of the death of certain family members and I fear I might relive some of the emotional burden associated with that.” This first step implies a form of self-awareness and self-distancing to enable self-reflection (Ayduk & Kross, 2010).

The second step—revisiting recreated memories during introspection and elaborating on them—focuses on confronting negative experiences with the aim to facilitate adaptive coping and psychological adjustment. Research has shown that interventions that direct individuals to construct narratives about upsetting events lead to a variety of physical and mental health benefits presumably by leading people to assign meaning, coherence, and structure to their emotions (Ayduk & Kross, 2010; Wilson & Gilbert, 2008). Whereas some research finds that self-reflection of negative experiences is adaptive, facilitating long-term resolution of distress, other studies suggest that self-reflection is maladaptive, leading to rumination and the escalation of negative affect (Ayduk & Kross, 2010).
Rumination can prevent the creation of new meanings, while the emotional arousal exacerbates the negative states, making people feel overwhelmed (Nolen-Hoeksema et al., 2008). In contrast, distancing facilitates reconstruction of experience, and analyses have shown that distancing helps people to make meaning out of problematic experiences and to gain a sense of closure, improving the emotional well-being (Ayduk & Kross, 2010; Barbosa et al., 2018).

Immersion and distancing play a fundamental role in facilitating adaptive coping, and rather than considering one to be superior over the other, a number of studies have shown that the timely coordination of both is essential to arrive at a positive outcome (Ayduk & Kross, 2010; Barbosa et al., 2018). It has been shown that less recounting (i.e., describing the specific chain of events and emotions one experienced during these events) and more reconstructing (i.e., describing new realizations about or changes in the way one understands the causes underlying one’s feelings) leads people to feel less upset after analyzing their feelings (Kross & Ayduk, 2017). This finding is also confirmed by my own narrative; during the self-reflective process I referred to this as adopting an emic or an etic perspective, which in this case can be compared with a self-immersed or a self-distanced perspective, respectively.

The third step—executing an action plan to negotiate the anticipated adverse effects—involves shifting one’s perspective from the present self to a distant future self. Most of the research on self-distancing had focused on how people can reflect adaptively on negative experiences by self-distancing using visual imagery (i.e., adopting a fly on the wall perspective) or linguistic (i.e., engaging in non-first-person self-talk) techniques (Kross & Ayduk, 2017). Only recently an alternative mechanism has been explored, namely whether people can self-distance by focusing on their future selves. Kross and Ayduk (2017) mention that their motivation to pursue this research question stemmed from the recognition that both common wisdom and research suggest that the passage of time improves the way people feel about negative experiences (D. T. Gilbert et al., 1998). They wondered if the healing power of time can be harnessed through mental time travel to imagine a future self without having to wait for actual time to pass (Kross & Ayduk, 2017). I refer to the literature list for their detailed and interesting discussion of this topic and will only mention their conclusion: shifting one’s perspective from the present self to a distant future self, enhances people’s ability to control their feelings surrounding negative experiences. Acting to negotiate anticipated negative effects can be considered a proactive conative expression of mental time travel and as my narrative clearly demonstrates, it allowed for a much better emotional control and general researcher wellbeing.

Dealing with underlying cultural areas of tension. Being allowed, as a researcher, to be part of a uniquely intimate moment such as the last moments of a person’s life, brings the ethical responsibility with it not to disturb the social reality that has unfolded between the family members of the patient and the caregivers. At those moments, the patient is no longer consciously present, but is obviously the focus point of attention. As the patient can no longer communicate, the family usually looks very closely for any visible sign of discomfort. Looking back, now that the study has completed, I was very aware of the impact anything I would say could have on the family members. In a few cases in particular, where objective neurophysiological monitoring indicated that although the patient seemingly looked serene, in actual fact there was discomfort, it was very hard for me to deal with questions from family members. As the original study was meant to find out if this type of neurophysiological monitoring should be preferred over traditional clinical assessments, family members and caregivers were blinded to the results. As mentioned before, family members were interviewed some weeks after the death of the patient, and they were all eager to know how the quality of the last days of their loved one had been. In some cases, this could detract from the serene image the family members had of the death of their loved one and would also thwart the efforts of caregivers who had tried their best to create such an image. This created an internal ethical conflict between choosing for the mental well-being of the family members or telling them the objective truth. However, prior pro-active self-reflection proved to be important here as well, since I had previously reflected on possible ethical conflicts at the start of the study and had therefore already determined (in consultation with the stakeholders when designing the pilot study) that the best ethical choice in this scenario would be to support the family members in starting their grieving process. This made it a lot easier to navigate these difficult situations.

The area of tension relating to the secular-religious ideological divide regarding end-of-life care manifested itself mostly in the individual conversations I had with family members and caregivers, and to my surprise did not really impact the recruitment process as such. I was able to relatively easy include the two major Belgian palliative care professional organizations, who were each a representative of this ideological divide. Eventually it transpired that the underlying ideological tension would manifest itself in a different way, and I had to make sure that my research would not be claimed by any of these organizations to serve as a sign of their outspoken support for this type of innovative research. It was good that I had thought beforehand about the underlying ideological tensions and paid attention to them, otherwise I would probably have realized too late that they, whether intentional or not, wanted to present my research in such a way that it seemed as if the initiative came from them, whereas in fact I have always chosen to remain neutral in this debate. The latter is important because otherwise the societal valorization of my research results might not be supported by society at large.

The unease of dealing with death and talking about death, was permeating throughout my entire study, with an obvious exception for the caregivers involved who, particularly in the palliative care wards, tried very hard to make death a discussable topic (Reigada et al., 2020). From the idea that serenity is important and from the commitment to support the family as much as possible in such a difficult circumstance, I briefly
visited the patient twice a day. On the one hand to check whether everything was technically still in order with the monitors and to make a number of observations as part of my research, but on the other hand I always tried to visit at times that I knew the family would be present, so that they could ask questions if they so wished. I always initiated an approachable conversation during these short visits in such a way that they had the opportunity to put into words what they were struggling with emotionally, something they told me afterward during the interviews that they really appreciated (Six, 2020). Although it was not the objective of the study I undertook, I also observed that some caregivers had emotional difficulties, and on more than one occasion they felt they could share this with me. My position as an external researcher surely will have facilitated this; but this is an aspect of my study I had not anticipated. In Belgium there is still some taboo associated with the caregiver needing emotional support, although things are slowly improving. However, being spontaneously placed in the position of sounding board came as a bit of a surprise. Although it is known that it sometimes happens that a researcher of a sensitive subject is spontaneously pushed into this role, because developing a trusting and positive relationship is the key to facilitating discussion on sensitive topics and this invites further sharing of experienced difficulties, I would not have expected this from palliative care professionals who often have to play that role themselves (Dempsey et al., 2016). Caregivers of all levels and responsibilities felt the urge to share all kinds of concerns with me, mostly related to the topic of my study, but also relating to how the department was run, what emotional difficulties they were struggling with regarding certain aspects of care, etc. This also illustrates how much room there still is for improvement in the (palliative) health care sector and shows the clear need for more “care for the caregiver” initiatives (Sinclair et al., 2017).

Legitimizing this autoethnography as critical social research. In this autoethnography I have described my story about how I prepared myself to carry out sensitive research in a culturally very delicate environment. By switching lenses between subjective and objective, I have alternated the emic and etic perspectives in such a way that the reader gets a sense of the cultural dynamics against which this story takes place. According to Starr the legitimacy of autoethnographic research in the social sciences is contingent on the application of the following requirements: fairness, ontological authenticity, catalytic authenticity, educative authenticity, tactical authenticity, methodological rigor and aesthetic rigor (Hughes & Pennington, 2016; Starr, 2010).

Fairness has been addressed by describing the underlying conflicting social constructions regarding the Belgian model of integrative end-of-life care, and the multiple cultural and ethical sensitive aspects related to the topic of CSD. Ontological authenticity—examining the space between critical self-reflection and action—can be observed throughout the entire proactive self-reflective process and evolution I made from trying to make sense of anticipated emotional distress, to achieving a state of dynamic meta-cognitive equilibrium that allowed for a continued presence and interaction in a very sensitive setting.

Catalytic authenticity refers to the transformative value of going through a process of self-evaluation that will inspire some form of action; the description of the proactive self-reflection is an illustration of this, but also how I as a consequence navigated the concrete intersection of cultural realities in the field.

Educative authenticity is illustrated by the honest self-reflexive analysis leading to an improved understanding of how I could bolster my resilience and consequently improve my functioning as researcher of a sensitive topic. The process is clearly described so that the readers can design a similar trajectory adapted to their specific needs. Tactical authenticity is illustrated by the very writing of this autoethnography: as a result of this self-reflective process, I took the step to encourage others to embark on a similar process. A worked example such as this, will hopefully clarify the added value of self-reflection at the start of a study and break the taboo on poor well-being among researchers of sensitive topics. Methodological rigor was maintained by making every aspect of the process explicit and comparing emic and etic perspectives critically. Finally, to uphold aesthetic rigor I combined evocative and analytical writing, representing a credible representation of the complex realities I have navigated.

Implications for Practice

This paper clearly shows the need for strategies to prepare researchers in the social sciences for dealing with participant death. This need has also been formulated for professional caregivers who experience patient death (Gerow et al., 2010; Khalaf et al., 2018). Due to a lack of formal training and education in the social sciences however in dealing with participant death, the call for such strategies when researching death or dying sounds even louder. Supervisors can take up a mentoring role by listening to the problems the early career researcher working on a sensitive topic is experiencing, and by proactively stimulating a self-reflective process.

Strengths and Limitations of the Study

One difference between ethnography and autoethnography at the initial stage is that autoethnographers enter the research field with a familiar topic (self) whereas ethnographers begin their investigation with an unfamiliar topic (others; H. Chang, 2008). A major strength of this study is that it allows an in-depth look at some of the more emotionally and intellectually demanding components of the social research process. Furthermore, it presents a worked example of a proactive self-reflective approach, to deal preventively with a problem that social researchers working on death or dying are likely to encounter. Although this study only had one participant, the self-reflective process proved very useful; it led to a concrete enhancement in researcher wellbeing and the proposed process,
although new, is in line with and extends the existing literature. Because of its specific and individual nature, the spontaneous emergence of the problem, it’s different aspects and their interconnectedness, and the lived experience of co-creating and applying the solution, ecological validity is very high.

Some limitations of this study are, as is often the case with qualitative research in general, low generalizability and reliability. These limitations are acknowledged: considering the individual nature of the discussed phenomena however, it is clear that within an interpretative framework the analytical discourse is mainly grounded in the specifics of the authors’ reflections. The autoethnographic researcher informs on (an aspect of) his culture by using reflexivity to describe their own experiences and interrelationships among, for example, learners, colleagues and themselves (Farrell et al., 2015). Through reflexivity, autoethnography enables the researcher to look inward, studying himself or herself to create a reflexive dialogue with the readers of the piece (Hayler, 2011). According to Ellis et al. reliability should be assessed differently for autoethnographic studies; in this context the narrator’s credibility is essential as juxtaposed with available “factual evidence” (Ellis et al., 2011). Reliability could also be judged in terms of whether the story helps readers to communicate with others and/or whether the story offers a way of improving the lives of participants, readers and/or the author(s) (Ellis, 2004; Ellis et al., 2011).

Conclusion

In this autoethnography I have shown that taking a proactive self-reflective approach to prepare for a study with dying patients has proved very useful. This helped me to better deal with a number of potentially distressing situations that arose during my research; as such it had a preventive and protective effect and enhanced the quality of my research. The proposed proactive approach is likely to be transferable to other research topics where researchers have to deal with sensitive issues that may cause emotional distress. From an educational point of view, a proactive self-reflective approach deserves consideration as a tool to help better prepare PhD students in the health sciences to conduct research into delicate topics. This paper is a worked example of how to do exactly this.

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