“Could You Help Me Die?”: On the Ethics of Researcher-Participant Relationship and the Limitations of Qualitative Research

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Abstract
Qualitative research is beneficial for researchers and society, and even for the participants themselves. Yet, end-of-life qualitative research also entails unique challenges given the sensitive topic and questions relayed to the participants, and the participants’ requests of the researchers. This paper was written following ethical issues that arose while conducting in-depth interviews with Israeli members of the Swiss Dignitas Organization in 2019. The interviews enabled participants to air their thoughts on assisted suicide and gather information about related plans that were not available to the public due to various issues. Yet, during these interviews, I also found myself dealing with significant ethical dilemmas that I had not previously encountered, such as participants asking me to lie for them, or accompany them to Switzerland to fulfill their wishes. While the interviews served as a safe environment in which the participants could air their thoughts on the topic, they led me to reexamine the ethical limitations of qualitative research and the researcher-participant relationship (within and outside the research context). By analyzing three of these interviews, I attempted to answer the following research question: What do the ethics of qualitative research entail with regards to researcher-participant boundaries, as established in sensitive situations and that involve vulnerable populations in end-of-life situations? The analysis was conducted in line with the ethical mindfulness framework and combined theoretical analysis of the literature. My analysis indicates that while qualitative research encourages the establishing of a researcher-participant relationship through trust and rapport – especially on sensitive topics that involve vulnerable populations – the researcher must also ensure both participant and researcher safety, by establishing and maintaining boundaries, even post-research. Introspective ethical inquiry, triggered by participants, requires the researcher to be vulnerable, potentially resulting in emotional discomfort. It also mandates re-engaging with the participants on ethical meanings that stem from this process.

Keywords
qualitative research, in-depth interviews, ethics, researcher-participant relationship, researcher-participant boundaries, reflection, ethical inquiry

In general, qualitative research seeks to explore, examine, and describe people and human phenomena from the participants’ points-of-view, usually in everyday settings and environments. Because of its dynamics and interaction-based features, qualitative research is characterized by an ongoing and emerging nature that frequently entails unforeseeable directions (Gibson et al., 2013). In-depth interviews, including videoconferencing-mediated interviews, provide a rich medium and enhanced personal interface for exchanging verbal and non-verbal data, and expressing emotions and meanings – through the rapport that is established between the researcher and participants (Gray et al., 2020; Oliffe et al., 2021; Sedgwick & Spiers, 2009). Typically, conducting qualitative research is beneficial not only for the researcher and society, but also for the participants themselves. As such, qualitative

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interviews can serve as a means for achieving catharsis, self-acknowledgement, self-awareness, a sense of purpose, empowerment, and healing, while providing a voice for marginalized or vulnerable participants (Alexander et al., 2018; Hutchinson et al., 1994).

It should be noted, that while interviews regarding end-of-life issues are a beneficial and meaningful tool for providing insights and further understandings of this phenomenon, it is not without its disadvantages, as will be expanded on later in this paper. In addition to conducting interviews with dying people and their caregivers serving as a moral imperative (Seymour & Ingleton, 1999), they also provide participants with a meaningful opportunity to be heard, and as such, may also have a therapeutic benefit (Allmark et al., 2009). In addition, these interviews meet the participants’ needs for human interaction, can assist others in similar situations, and even contribute to science and to society as a whole (Bloomer et al., 2018). Qualitative research interviews may also help end-of-life participants make sense of various situations and better understand certain events (Coombes et al., 2016; Emanuel et al., 2004). They also support calls from the literature whereby people at the end-of-life should not be excluded from research solely because of their perceived vulnerability (Bloomer et al., 2018). Denying this population the right to participate in research studies can be equated to denying their autonomy and respect as human beings (Wohleber et al., 2012).

In addition to their benefits, however, qualitative interviews in end-of-life research may also have some disadvantages. As argued by Allan Kellehear (1996), “The interview is the creation of an unnatural social situation, introduced by a researcher, for the purpose of polite interrogation” (p. 48). These interviews may, therefore, cause unnecessary fatigue, and may be experienced as intrusive or distressing by the participants. Moreover, conducting such interview is especially difficult when the participants’ verbal capabilities are limited because of the illness or if they are heavily sedated. When interviews are conducted virtually (e.g., by Zoom, Teams or Skype), they may be disrupted due to poor or unstable internet connections, external noise, and other interruptions, which may be affecting the participant’s experience (Trail et al., 2021). In addition, such interviews may be regarded as inappropriate, given the sensitive topics and questions addressed in the interviews, and at a time when the participants are dealing with serious emotional experiences (Goodman et al., 2012).

While research indicates that discomfort and pain, that stem from dealing with sensitive questions, do not lead to psychological harm (Sikweyiya & Jewkes, 2013), these outcomes and others may have ethical implications on the research plan, and as such, must be addressed and managed. Since interviews are usually conducted face-to-face, researchers often have a powerful connection with the participants. In fact, it is inevitable that some distressing issues will arise during these interactions.

Social research encompasses a range of interactional characteristics; the topics explored through such research – especially in the context of end-of-life issues – are sensitive, controversial, and difficult (Batchelor & Briggs, 1994). Hence, it is of no surprise that the benefits of interviews for the participants, and their potential disadvantages, can be understood within the context of the researcher-participant relationships and power, which are embedded in qualitative research (Brinkmann & Kvale, 2005; Orb et al., 2001).

Balancing between the benefits and possible disadvantages or even harm caused by conducting qualitative research interviews among end-of-life participants has ethical implications which have not been sufficiently addressed in the literature (Coombes et al., 2016). This article aims to fill this void.

Method
This study shares and analyzes certain ethical issues that have accompanied me for a while, as I research the sensitive topic of end-of-life matters. In general, ethical concerns relate to any situation or issue that involves a partial or complete compromise of a certain value or values, yet that is considered legitimate and even desirable in the given case (Beauchemin et al., 2021). Specifically, the ethical concerns analyzed in this article are related to a qualitative research study that I conducted in 2019, where I interviewed members of the Swiss Dignitas Organization who were planning to travel from Israel to Switzerland to receive aid-in-dying services (Sperling, 2022). The research examines and presents the stories, needs, difficulties, desires, and accomplishments encountered by these individuals. The study began with a sociological perspective of the phenomenon of suicide tourism guided by an attitude of openness and inquiry to ensure that concepts are constantly emerging. Interpretation of the data was based on a phenomenological-interpretive approach that focuses on the participants’ claims, explanatory logic, biographical contexts, and cultural frames of knowledge (Age, 2011).

As a seasoned researcher in the field of ethics relating to end-of-life care, exploring matters relating to death and dying was not a new experience. Yet encountering participants who were at their most vulnerable, and in the context of an act which is considered criminal in Israel (i.e., providing aid-in-dying), was especially challenging. During that research study, I talked with a range of people, old and young, some of whom were terminally ill and seriously suffering. My major concerns rose in light of three specific in-depth interviews, which will be described in brief using pseudonyms. Next, I provide a more theoretical analysis as a means for exploring these concerns and resolving the tension that stems from them.

Paying special consideration to ethical concerns in qualitative research upholds the notion of “ethical mindfulness” (Guillemin & Gillam, 2004, 2008, 2015), a term that refers to a group of abilities that assist researchers in recognizing and addressing “ethically important moments” in research. This
The notion has guided the method used for this study. It involves five features: (1) acknowledging such moments in everyday practice of research, rather than regarding them as insignificant or unimportant; (2) being prepared to accept feelings of discomfort in a given situation; (3) articulating what is ethically important in academic research; (4) acting courageously by opening yourself up to new ways of thinking about research ethics, while critically challenging established research practices, questioning your beliefs and attitudes about the way you conduct research, and confronting difficult situations through ethically preferable responses, even if they could potentially hurt the participant (Guillemin & Heggen, 2009).

In addition to the notion of ethical mindfulness, this study also combines theoretical analysis of the literature. The conceptual framework applied to this analysis is the “ethics-as-process” framework (Cutcliffe & Ramcharan, 2002; Gibson et al., 2013; Ramcharan & Cutcliffe, 2001). Based on this framework and deriving from the emergent nature of qualitative research and hindrances to project approvals at Research Ethics Committees (RECs) (Taquette et al., 2022), ethical issues (both anticipated and evolving) should be noticed and addressed throughout the research process, rather than viewed as a one-time discrete event that is dealt with before or at the onset of the research. Doing so reflects the notion that research ethics is standardized and applied regardless of the specific context (Mattingly, 2005). This view differentiates between “ethics in practice” or “particularistic ethics”, which involve unpredictable, subtle, and important ethical issues that develop throughout the research, and the more formal and procedural ethical decisions that are usually made prior to and in anticipation of the research (Guillemin & Gillam, 2004; Johansen & Frederiksen, 2021; Warin, 2011).

Moreover, the “ethics-as-process framework” challenges the position of REC and their rationale (Sperling, 2021), as well as common ethical principles, most notably informed consent. The philosophical justification for such an approach stems from determining the ethical as a process in the making, not subject to an a priori ruling or judgement regarding research ethics (Johansen & Frederiksen, 2021). In addition, this framework also rests on the “ethics of care framework” (Held, 2006), which focuses on caring relations, thereby taking into consideration how researchers care for their participants, their responsibility for the implications of their relationship with participants (Iphofen & Tolich, 2018; Shafi, 2020), and the way their own moral values impact such caring relations (Thoft et al., 2021).

As such, research entails a contract between the researcher and the participants that is and could be guided by universal and context-free norms. The purpose of this contract is to maximize benefits and minimize risk, so that if strictly applied and followed, it will or is presumed to ensure the researcher’s ethical behavior (Mattingly, 2005). Ongoing monitoring of risks and benefits of the research should be conducted, as new and potential ethical issues and concerns are balanced or weighed against other considerations and benefits. Therefore, qualitative researchers must be attentive to their ethical awareness, while continuously developing their moral understanding of such issues.

Prior to conducting the project interviews, including those three interviews that were presented in this research paper, the participants were informed about the research process, objectives, expected benefits, and possible risks entailed in their participation. Following this information, each participant decided to either consent or decline to participate. Moreover, when signing the informed consent form, the participants were able to add specific requests regarding their agreement, such as requesting to review their transcripts, be informed of the research findings, or be notified about the article publication.

The full research program was pre-approved by the Ethics Committee of the Max Stern Academic College of Emek Yezreel (Approval # 2018-41, dated 15 March 2018).

The Interviews

This section describes the three interviews which provoked the ethical inquiry and concerns that are the object of this study. The choice of the three interviews selected to be presented in this paper was based on the ethics-as-a-process approach. The researcher-participant interactions and the researcher’s ethical compassion and responsibility towards the participants were assessed during each of the project interviews, and were later re-confirmed after discussing them with colleagues as those interviews that provoked the highest, more intense ethical reactions (Awenat et al., 2018).

Vicky

I met with Vicky in a friend’s house in their extremely small hometown in the very north of Israel. At the time of the interview, Vicky was a 35-old-woman who suffered from depression, schizophrenia, and other mental conditions. She had a history of hospitalizations in psychiatric hospitals and had tried to die by suicide on three different occasions. Vicky was extremely lonely and isolated, both physically, living in a house (which was not even hers) in a remote region, and personally. During the interview, she spoke of her nuclear family with whom she had no relationships whatsoever. Vicky shared with disappointment in therapists’ mistreatment of patients in general, and their “mechanical, cold, and disinterested” interaction with her in particular. She also emphasized the negative effect of her failed attempts to commit suicide on her caregivers’ stigmatizing of her.

Vicky was very verbal, intelligently articulating her perspectives. Unlike most other participants, she refused for the meeting to be recorded because of legal uncertainty and fear of social implications. She was, however, fluent and confident in expressing her wish to die. She conveyed that she had had
enough, enough of this life, enough of the false and unfruitful interactions with others, enough of the futile attempts to cure her damaged soul. She showed no interest in continuing to live. She even regarded her living as a waste of global resources that are scarce enough as is.

Her experience with Dignitas was also very disappointing: Since she was not terminally ill and did not suffer from a severe physical condition, she faced tremendous difficulties in proving her case. She argued against the poor situation in which she now found herself. In addition to having to deal with her struggles in life, she now also had to convince the organization of her voluntary and justified wish to die. Her desire to finally free herself from everything in the world was harshly accompanied by complete dependence on people who did not even introduce themselves using their real names. She felt that this situation was extremely ironic.

During her interview, Vicky asked me to help her with the administrative issues concerning her request for aid-in-dying, and to later join her on her final trip to Switzerland. She also asked if she could contact me if she wanted to have a talk. She explained that she did not have anyone to rely on, and needed help communicating with the organization in Switzerland, and especially finding medical doctors in Israel who would support her request. Vicky also wanted to hire my legal services (as a certified lawyer) to help draft her will, and also to represent her in an unrelated criminal case that she claimed to be erroneously and unjustly involved in.

Dolores

The interview with Dolores, an 81-years-old woman, took place in her apartment, located in a prestigious residential building in a large city in the center of Israel. A retired healthcare professional, Dolores suffered from heart failure and had undergone a pacemaker transplant a year before the interview. Obese and unable to walk, she was fully dependent on her caregiver who lived with her. Dolores had no partner or children. She spent all day in bed, gazing out at the magnificent view of the city, which she could clearly see from her bedroom window. She described her situation as inside a “pressure cooker”, boiling from within and ready to go. She felt that she had lived her life to the full, with no regrets or misgivings concerning her Swiss plan. Dolores was, however, greatly distressed by the fact that in order to accomplish her plan, she needed to be physically able to travel to Switzerland – something she did not believe she was capable of achieving.

Dolores was not well informed about the procedure that was required for executing her plan. She did not know anyone who had accompanied their loved ones to Switzerland, or who had considered traveling there for aid-in-dying. She therefore asked me numerous informative questions about this process. She also asked if I could put her in touch with other Israelis in her situation. Although she had received some legal assistance from a family member, she also asked if I could assist her with the relevant legal and administrative procedures associated with the Dignitas application. Given her immobility and her skepticism regarding her ability to actually travel to Switzerland, she asked if I knew of any Israeli doctors who could help her end her life in Israel, without having to travel to Switzerland. When our interview ended, she wanted to pay me for my time and information, thereby reflecting that our encounter was as useful and informative for Dolores as it was for me, if not even more so.

Jacob

The interview with Jacob, a 73 years-old, took place in a café in a large city in the center of Israel. Jacob had been diagnosed with a rare group of bone marrow failure disorders known as myelodysplastic syndromes (MDS). He had already undergone bone marrow transplant surgery. Jacob’s symptoms included a sensitive digestive process, equilibrium issues, hoarseness, and constantly dry eyes that led to what he referred to as “feelings of sand in my eyes”. Jacob had to always stay out of the sun and make sure to cover himself to protect his body from sunrays.

The moment we met, Jacob asked me not to disclose the real reason for our meeting if his wife should appear. He asked that I lie instead, stating a different topic for my research. He confessed that he had not told his wife about his plans to travel to Switzerland, as he felt that she would not go along with his plan. For that same reason, Jacob also asked if I could help him make plans to travel to Switzerland, and even accompany him on his final journey. Jacob added that as he had not shared his plans with anyone, it is difficult for him to make progress with the process. He felt that there was no point in continuing to deteriorate while being severely limited in the quality of his life. He was extremely worried about finding support for conducting such a difficult physical journey. Indeed, about forty minutes into our interview, Jacob’s wife joined us at the café. He introduced me as a scientist who is conducting research on MDS. Our meeting ended shortly after.

The three interviews described above were based on mutual respect and trust, and on our inter-personal relationship which was constantly shaped and re-examined as each interview proceeded. They reflected the participants’ range of expectations of me as a researcher and as a professional, yet they mostly presented the interviewees’ expectations of me as a person, who they perceived as having values that were of the utmost importance to these participants.

At the time of the interviews, I reacted and responded intuitively. Although I tried to provide to Dolores with more information about the formal process with Dignitas, I told her I did not know of any physicians in Israel who would help her die without having to travel to Switzerland. Moreover, I did not charge or accept any offer of payment for my “visit”, nor did I put them in touch with other people in a similar situation. I informed them that I would not be able to accompany them to Switzerland, if they are approved for the process. I did, however, put Vicky in touch with another participant, who,
during our interview had said that she would be willing to help others in her situation, including travelling with them to Switzerland. I did not follow up on this and do not know if they are in touch.

I also declined Vicky’s request to draft her will or legally represent her in court. I referred her to an Israeli right-to-die organization to help her with her will and advance directive, and provided names of a number of criminal lawyers who might be a source of help. Since her case was extremely touching, and, perhaps due to her young age and solitude, I did keep in touch with her after our interview: We have spoken on the phone a few times, but have never met again in person.

Finally, in my interview with Jacob, I did not say anything when he introduced me to his wife in a different context. I did not have much time to reflect on the situation he had put me in, and as such, silently collaborated with him lying to his wife.

These three interviews served as safe environment in which the participants could examine their plans and try to expand them into other related areas and contexts. However, they also call upon need to examine the limits of qualitative research and researcher ethics in building and maintaining relationship with participants within and outside the research context. Such an examination is provided in this study.

The Problem

In all three encounters, the research participants challenged my position as a researcher. It is clear that the interviews served as safe environment for the participants to air their thoughts on assisted dying, try out their ideas, and seek support for their future plans. Such benefits for participants occur in most interviews, yet in this specific case, they are more complex – given the legality (or illegality) of the action at stake or parts of it. While assisted suicide is legal in Switzerland, it is illegal to offer any kind of aid-in-dying whatsoever in Israel. This may include providing information or offering assistance when preparing to travel to Switzerland, putting people in touch with physicians regarding their application to Dignitas, and making arrangements to accompany an Israeli resident who is travelling to Switzerland for aid-in-dying.

In all three interviews, I was asked to take upon myself unexpected roles, thereby blurring my identity as a researcher. The participants identified me as an advocate for assisted suicide and suicide tourism, and even requested that I facilitate and enable their participation in the phenomenon that I was researching. This was the result of their physical limitations and official barriers on the one hand, combined with my knowledge of the topic on the other hand. For these interviewees, meeting with me was invaluable, since they were unable to speak about their meaningful wish with their friends and families in a manner that would truly promote their own interests.

In addition, and building on their trust in me and the inter-dependent relationship with me, some of the interviewees leveraged their meeting with me as a researcher and referred to my professional expertise, asking me to help them with legal issues in relation to their end-of-life care planning and their overall wellbeing, which had less to do with the directly researched topic. I was also asked to perform unethical behaviors, such as deceiving or lying to their relatives, based on the assumption that I will comply with such requests not only because of my desire to conduct the given research (for which their participation was necessary), but also because I “owe” them, as without their participation, I would be unable to conduct the study. Given this complex situation and the nature of my interactions with the participants, I found it to be of the utmost importance to self-engage in introspection, including my ability to question my various roles and recognize my own limits.

More profoundly, and beyond the scope of my original research, such situations challenge the researcher-participant dyad, and fundamentally call for the examination of the limits of the qualitative research and the researchers’ ethics in building and maintaining their relationships with the participants, within and outside the research context.

The literature presents two conflicting approaches that may shed light on this subject. The first regards research participants as informants, namely they have the capacity and importance to provide information on the issues and questions that drive the research (Jonkman et al., 2020). With this view, research interviews are the best means for obtaining information that is relevant to the research, and as such, the participants should be selected based on their capacity to provide such information.

With the second approach, on the other hand, research interviews may be regarded as an interaction in which the researcher-participant encounter is viewed as a conversation, not as a means for one-sidedly providing the researcher with information. Their discussion is jointly constructed by the participants and the researcher. It is shaped by the context of the research, the interviews, and their interpersonal albeit short-term relationships that are based on mutual trust and expectations. Moreover, such discourse is and is mutually constituted, inter alia by their presence and the interface of their physical bodies (McClelland, 2017). Seen in its broad social context, such talks serve as a site of interactions and inter-subjective encounters between the researcher and the participants, in which social possibilities and constrains are played out and negotiated. The researcher-participant relationship is thus characterized and explained through phenomenological concepts such as being-with, attunement, and emphatic dwelling (Boden et al., 2016). As such, the researchers are part of the social context that they are studying, and they are also situated within the research process (Taylor, 2014). The complex issues presented in this research paper, and the various requests presented by the participants, support this latter approach.

Moreover, conducting qualitative research about sensitive and private issues (such as a person’s plan to end their life and to self-engage or engage others in an unlawful action),
especially those that involve vulnerable populations, is in line
with the concept whereby establishing a positive and trust-
worthy researcher-participant relationship is of paramount
importance (Guillemin & Heggen, 2009; Morrison et al.,
2012).

The concerns raised by participants’ request challenge the
ethical obligations that I hold and contest the suggested
boundaries of the researcher-participants relationship. To act
ethically in this situation should not be seen as a matter of rule
or compliance, but as negotiation of the researchers’ actions
regarding ethical concerns in a justified or excusable manner
(Hammersley, 2014; Liamputtong, 2007). Theoretically, such
a process should first and foremost take place within the
researchers themselves, as well as between the researchers and
the participants, within the research ethics committee, and
among colleagues. Yet how should researchers maintain their
relationship with the participants while continuing to act
ethically in such situations?

**Ethical Concerns**

In this section, I argue that there are four major ethical
principles or concerns that come into play in such situations,
including (1) securing participants’ safety and wellbeing; (2)
establishing researcher-participant boundaries; (3) forming
friendships with the participants; and (4) protecting the re-
searcher’s safety and wellbeing (Morrison et al., 2012).

**Securing participants’ safety and wellbeing** is an im-
portant concern for researchers, derived from the general idea
whereby not only do researchers hold a duty of beneficence to
participants (Orb, 2001), but they must also ensure that no
harm comes to the participants as a consequence of their
participating in the study, while taking proactive steps to
promote the participants’ wellbeing (Dickson-Swift et al., 2006).

Establishing researcher-participant boundaries, in-
cluding the distinction between personal, professional, and
researcher’s roles, is the second ethical concern. Regarding the
concept of “boundary”, I follow Dickson-Swift et al.’s (2006)
meaning of determining some type of limit or distance be-
tween persons. At first glance, qualitative research gives a
central and significant role to the researchers, in their assessing
and understanding the personal experiences of their partici-
pants, and in their contributing to the data collection and
analysis processes (Harvey, 2017). Drawing from psych-
analytic psychotherapy, Clare Harvey highlights, for example,
how inter-subjectivity is central to the researcher-participant
relationship in qualitative research, as through their interac-
tions, each party affects the other on multiple levels.

On the other hand, researchers are expected to refrain from
influencing or interfering in the participants’ choices, ex-
pressions, or beliefs. The researchers’ distancing from their
participants may prevent them from being emotionally
overwhelmed, while enhancing their perceptions of being
“professional” (Dickson-Swift et al., 2006). Forming
research-participant boundaries is especially challenging
when both the participant and the researcher share particular
identities and value-perceptions. Therefore, researchers
should always strive to make a balance between the dangers
and benefits of being “too far in or too far out of the lives of the
researched” (Gilbert, 2001, p. 12).

During the original research project, I frequently en-
countered interviewee attempts to re-negotiate our researcher-
participant boundaries and create a revised equilibrium. As a
result, I became even more aware – and confident – about
preserving blurred boundaries with them, and it is these at-
tempts and boundaries that I am now able to discuss and
review. On the one hand, some of the requests that I received
did not greatly impact the equilibrium of the original research-
participant boundaries, such as the participants’ airing their
thoughts and emotions beyond the scope of my interview
questions, or their seeking information about aid-in-dying (in
Israel and/or in Switzerland). On the other hand, participants’
requests for me to put them in touch with a physician who
would be willing to help them die in Israel, or to accompany
them to Switzerland, significantly challenged and disrupted
the original or intended researcher-participant boundaries.

**Forming friendships with the participants** is a third
concern that represents an extreme case of merging boundaries
between the researcher and participants. At one end of the
spectrum is a rapport and trust building process, through
which the researchers apply their self-examination, sharing,
and self-disclosure – usually showing an affiliation or solidarity with the participants, as well as being empathic and offering empathic responses to the participants’ emotional state or condition (Prior, 2018). The process of establishing a researcher-participant rapport is important for generating rich data and for ensuring the respect of the participants (Guillemin & Heggen, 2009). It involves a commitment to establish emotive involvement, personal relations, and connections with the participants based on trust and mutual consent, reflecting the idea that the research is conducted with the participants rather than about them. This is done, first and foremost, to facilitate participant disclosure or to let the participants know that the researcher really does understand their experience or story, and may even identify with them (Dickson-Swift et al., 2006). Today, such close acquaintances are also enhanced by modern digital technologies, that extend the research setting to also include more personalized interactions, such as through Facebook friends’ requests and LinkedIn invitations (Miller, 2017).

At the other end of the spectrum, however, the researcher becomes too involved in the researcher-participant friendship-like relationship. This process assumes that in general, the resonance of mutual feelings and emotionality is essential for achieving shared meanings and sincerity of narratives (Boden et al., 2016). This is especially reported towards the end of the research process, when researchers find it difficult to terminate their relationships with the participants. For some researchers, becoming friends with the participants may seem natural to them, following the participants’ frank and meaningful sharing of information, especially regarding sensitive and private issues (Dickson-Swift et al., 2006). In my case, this could have been the case had I agreed to the participants’ requests to be available for future phone calls and chats, that I accompany them to Switzerland, or even just put them in touch with a physician who will support their application to Dignitas. Such actions and gestures could have promoted a greater friendship between us, compared for example, to the participant’s request to lie to wife by disguising the nature of my research.

The fourth and final ethical concern involves the protecting the researcher’s safety and wellbeing. In addition to evidence suggesting that undertaking sensitive research can be a distressing experience for the researcher (Dickson-Swift et al., 2006; Howard & Hammond, 2019; McClelland, 2017; Rowling, 1999), the ethical literature places an emphasis on issues relating to researchers’ physical and mental health, as well as their physical and emotional safety. The literature also addresses the psychological, reputational, and general risks that researchers should be concerned with (Hughes, 2004; Mitchell & Irvine, 2008). Hence, it is advised in the literature, for example, that researchers refrain from disclosing personal details (such as their home address and other contact details), ensure the interviews are conducted in public places, carefully monitor the interviews to assess the emotional impact on the participants, discuss the research process with a supervisor or colleague, etc. (Fahie, 2014).

In this case, my active involvement in the participants’ applications, facilitation, and most notably, accompanying them to Switzerland – may pose a legal risk for myself and even a source of sacrificing my own personal safety. Lying to a participant’s wife about the nature of my research comes at the cost of preserving my ethical integrity and constitutes a reputational risk. On the other hand, it could be argued that drafting a participant’s will or representing them in a legal case, especially for a few, may positively contribute to my wellbeing and professional expertise.

Balancing the Ethical Concerns

It was only some months later that I was able to distance myself from the material, the participants, and the interviews, to reflect on whether my responses to participants’ requests were correct and ethically justified, and think about possible alternative responses to each given scenario. Given the complex issues at stake, I realized that what I had experienced and how I responded did not really raise questions of ethical concern. Instead, since all ethical matters are important and significant to my involvement in the research and to my maintaining a positive and respectful relationship with the participants, I realized that the real question is how each ethical concern that arose should be weighed in relation to one another.

To examine and answer this question, I applied a previously developed graphical approach to this ethical conflict (Field & Caplan, 2008; Rus & Groselj, 2021) arising from the nine requests presented by participants (see Figure 1). This approach promotes forming a balance between competing values on a focused and objectively visible debate and in a less emotional dialogue. It provides a graphical means to identify and observe all the relevant ethical issues and values following introspection and a process of ethical mindfulness. Doing so offers a graphical means for identifying and observing all relevant ethical issues and values following introspection and a process of ethical mindfulness. While this tool is based on the subjective estimated weight that are ascribed to each of these issues and values by the researcher, it nonetheless allows them to take a step back and translate such weight into an allegedly objective total evaluation of the sensitive issues, thereby taking the most ethically justified course of action in each of the disputed situations. Moreover, analogous to the method of bracketing, it seeks to mitigate the potentially malign effect of subjective and personal experiences with the research process, including the researcher-participant interactions, by separating between these and the more general picture that is being built throughout the research itself (Tufford & Newman, 2012).

The proposed tool is built and organized in the following way each ethical concern is represented by a colored tab,
follows the ranking of a numerical scale from 1 (too little weight) to 10 (very high weight). This refers to the proportional estimated weight that each ethical concern received according to the specific participant request from the researcher, and following reflective negotiation. For example, on this 1-10 scale, helping the participant with administrative issues relating to their application to Dignitas is ranked 7 in relation to the principle of securing participant safety and wellbeing for facilitating the participant’s plan, as this does also entail some risk to their safety. However, the same concern is ranked 6 with regards to the principle of maintaining relationship boundaries (since such actions are more remote than the researcher-participant work relationship), and is ranked 8 with regards to the principle of forming a friendship with participants (since such expected aid is a gesture that is more common among friends). Finally, it is ranked 6 with regards to the principle of protecting researcher safety and wellbeing, given the legal risk to the researcher that stems from providing such assistance without monetary compensation.

This graphical approach is advantageous, as not only does it signify the total estimated “score” ascribed to each participant request and as such reflects its ethical weight, but it also allows us to compare between various requests according to different ethical concepts or principles, and their relative contribution to the researcher’s final decision.

The following figure represents the proportional weight of the application of the ethical concerns in each of the nine requests asked by the participants following this framework.

Applying the graphical approach to my case shows that contrary to my initial and intuitive beliefs, providing legal representation to a research participant in an issue outside the scope of my research (such as providing legal representation in a criminal case or drafting a will) may in fact be justified ethically. On the other hand, accompanying participants to Switzerland and/or putting them in touch with physicians who could help them fulfil their goals in Israel without having to travel to Switzerland – are less ethically justified according to this framework, and as such, I was correcting in refusing to provide such assistance. More generally, this graphical approach demonstrates that the ethics of the participants’ requests vary when examining them according to concerns or principles that differ from maintaining relationship boundaries. Moreover, placing an emphasis on a certain ethical principle over could result in different justifications.

Focusing on the colored tabs also allows us to exclusively concentrate on a specific ethical concern, and ask questions about its absolute weight in a given situation or in light of a given request posed by a participant. If for one researcher forming a friendship with participants is of the utmost importance, then as we can see from the grey tab, agreeing to be available for chats or calls or to accompany them to Switzerland would constitute actions that would most likely promote such ethical principles. On the other hand, if the principle of securing participants’ safety and wellbeing matters the most to the researcher, then, as demonstrated by the blue tab, the researcher may prefer to accept requests to provide them with legal aid in a criminal case or draft their will. Given the varied researcher-participants interactions and the complexity of the requests posed by the participants during the research, the combination of focusing on the grey tabs with the more general application of the graphical approach (that refer to all major ethical principles at stake) provides a rich and comprehensive reflection and analysis of the given situation.

Epilogue

Applying the graphical approach to this research paper enabled me to perform a retrospective ethical analysis. Immediately after conducting these interviews, especially the interview with Vicky, I shared my thoughts and concerns with the former Chair of the Research Ethics Committees at my affiliated academic institution. I found this debriefing with a peer, who specializes
in qualitative research and is an expert in research ethics, to be very useful. Moreover, the analysis conducted in this research paper complements his intuitive feedback.

I believe that my training and experience as a researcher in the field of bioethics in general, and ethics of end-of-life care in particular, combined with my involvement in research ethics, made me more aware of the ethical problems and challenges which evolved from these interviews, while also rendering me more forgiving or lenient in my responses and negotiations with the participants on these matters. Above all, they allowed me to acknowledge the concept of vulnerable listening, and enabled me to continue to be vulnerable in my research, while reflecting upon how I chose to deal with this vulnerability (McClelland, 2017).

One important message that stems from this analysis relates to the constant introspective engagement and reflection of researchers in qualitative research – especially in relation to researchers’ responses and attitudes towards participants, their intersubjective experiences with their participants, and the researcher-participant power dynamics (Beger, 2015). Hence, this introspective ethical inquiry, that was triggered by the participants’ requests during their interviews and the researcher-participant interactions, led me to re-engage with the participants with regards to ethical aspects and meanings that stemmed from this process.

This type of re-engagement with participants is often reflected in complex situations that arise during qualitative research, such as conducting a member-check, whereby researchers share their qualitative research findings with the participants as a means for enhancing involvement and credibility (Goldblatt et al., 2011). For it is only through researcher-participant reflection and dialogue that ethical implications of research can be discussed and understood (Skovdal & Abebe, 2012). Implementing such a tool that involve the researchers provides an important opportunity for examining and conveying their values and beliefs in a transparent, conscious, and comprehensible manner, and in turn achieving ethical mindfulness (Etherington, 2007; Guillemin & Heggen, 2009).

Moreover, reporting on the ethical steps and reflections that are at stake provides the readers of the final research paper with a more comprehensive understanding of the research context and of how the researchers managed their research (Berkovich & Grinshtain, 2021). It also provides better means for perceiving the realities that are comprised of ethical issues and concerns, and that arise through qualitative research (Beauchemin et al., 2021). Specifically, in the context of sensitive and private issues where the data collection may be emotionally charged for both researchers and participants, applying this tool requires the researchers to reflect on processes that have occurred within and outside themselves and the researcher-participant relationship. In order to conduct practical reasoning and ethical analysis, researchers’ self-awareness and empathy are of the utmost importance, as are their willingness to be vulnerable while examining and negotiating their attitudes towards the emotional and intercorporeal experiences that stem from the research (Boden et al., 2016; McClelland, 2017; Nussbaum, 2003).

For this purpose, researchers should be trained and prepared to recognize and manage their boundary issues with their research participants (Dickson-Swift et al., 2006), while emotionally engaging with the study by caring about their participants, caring about that part that will become the research project, and taking care of themselves (Campbell, 2002). Other than working on the individual development of self-care in the context of emotionally demanding research, institutional initiatives should also address management strategies applied by researchers, such as mandatory self-care guidelines issued by Research Ethics Committees, support provided by dedicated research committees or peer support, researcher mentoring programs, and free access to counselling services (Dickson-Swift et al., 2007; Kumar & Cavallaro, 2018). Finally, researchers much allocate adequate time and space for stepping out of the role of researcher for the sake of understanding their concerns and emotional engagement in the study, thereby re-examining their attitudes towards qualitative research in general and the specific research project in particular.

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