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The Good, the Bad, and the Ugly: The Journey of an Architect-Researcher in Palliative Environments

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Abstract. As an architect, I felt a strong moral urge to engage in research aimed at creating more human-centred healthcare environments, particularly in the context of palliative care. Being relatively new to this field 4 years ago, my primary goal then was to develop a deep understanding of these unique contexts, with a special focus on the people involved. To achieve this, I embarked on an immersive ethnographic study over the last few years, involving participant observations in three distinct palliative environments (i.e., day-care centre, hospice, and palliative care unit) and interviews with residents, family members, caregivers, volunteers, and maintenance staff. While preparing to present this study to an ethics panel, I believed I had covered all possible questions until I was unexpectedly asked, "How will you consider your own emotional well-being?" At that moment (in the 1st year of my PhD trajectory), I was unsure how to respond, but today (in the 4th year of my PhD), I would say that my approach was to verbally and visually document the entirety of the experience, including the positive, negative, and challenging aspects. Throughout my journey, I maintained a journal not only to express my thoughts and feelings but also to capture the methodological and ethical insights I had gained while conducting interdisciplinary research on the spatial experiences of individuals within palliative environments. This article serves as a comprehensive overview of all significant events preceding, during, and following the study. The insights were organised according to 'the good, the bad, and the ugly' to shed light on the complexities and nuances of conducting research in this unique and sensitive domain. In doing so, the aim of my contribution is to inspire novice researchers to embark on such research studies and offer them guidance along this undoubtedly beautiful yet occasionally challenging journey.

Keywords. Palliative care environments, ethnographic study, research journal, fieldwork, interdisciplinary research

1. Introduction

'Not knowing how things would unfold, trying to anticipate as much as possible' is what my PhD's first year in 2020 looked like. This was largely due to the COVID-19 pandemic and my entering as a novice researcher in an uncharted territory, namely palliative environments. This reflective article documents my personal experiences and insights before, during and after an ethnographic study involving interviews (with residents, family members, caregivers, volunteers, and maintenance staff) and participatory observations in palliative environments. Embarking on this journey as an architect researcher, I brought empathy and intuition regarding the topic but lacked expertise or a background in (palliative) care. Beyond my personal experiences of saying farewell to my grandparents in diverse palliative environments, I found myself uncertain about what to expect and how to navigate through these sensitive realms. Of course, I had prepared extensively, read up on the subject, taken tours in the palliative case studies in advance, held discussions with my supervisors, doctoral committee and colleagues, and attended qualitative research training programmes before finally commencing this ethnographic study after a long period of uncertainty caused by the pandemic. I had been looking forward to this moment for a while. How would it be? Would I adapt well? And yes, what about my emotional well-being? This final question only surfaced after presenting this research proposal to an ethics panel in the 1st year of my PhD trajectory, after which I realised that perhaps I had not prepared myself thoroughly enough.

The protocol of this study only emphasised the well-being of the participants whom I would observe and interview, which was supported by a large body of literature investigating confidentiality and privacy [1-3], safety [4], (therapeutic) value [5-7], and emotional distress and discomfort [1, 3, 7-11] in qualitative studies. Despite an additional literature search pointing to an increasing acknowledgement that involvement in qualitative research can emotionally affect researchers [12, 13], several articles have suggested that the emotional impact and consequences of sensitive or challenging research on the researcher remain inadequately discussed [14-16]. However, I came across a few articles that studied the emotional impact of sensitive research on researchers when interviewing, transcribing [17-19] or coding [20] and even some articles discussing how researchers can arm themselves with self-care in emotionally demanding research [21, 22]. These last two articles suggest building an emotional support network with team members and friends to socialise, debrief and get guidance. Also, psychotherapy, relaxation therapies, spirituality, creativity, yoga, exercise, and seeking a good work-life balance are considered self-care by these articles. According to Barker, one should consider these recommendations as the oxygen mask on an aeroplane, where one is always instructed to secure their own mask first before helping others [23]. Furthermore, both articles recommend writing sessions [21] or keeping track of reflexive journals [22] as a self-care resource. Moreover, I raise the question of whether merely inquiring about researchers' well-being is sufficient or if, as indicated by some studies, ethics committees could take additional steps to safeguard researchers in these sensitive contexts (such as documenting potential risks, providing strategies, and maintaining open lines of communication) [24, 25]. Nevertheless, despite feeling overwhelmed by this valid question from the ethics panel, I chose not to worry immediately but rather to keep this concern in the back of my mind.

After an initial visit and guided tour of a hospice, a day-care centre for palliative care and a palliative care unit in a hospital, I had an overall impression of these (physical) environments, but not necessarily of the people, the organisation, the activities taking place, etc. To envision a picture of the people and the environment, a Google image search on ‘palliative care’ was carried out. However, this search culminated mainly in staged, romanticised photographs lacking diversity. Moreover, this search gave me the impression that palliative care mainly involved activities like 'holding hands'. However, on my first day of fieldwork in a day-care centre for palliative care in Belgium, we were all sipping our aperitifs before lunchtime for the simple reason of ‘celebrating life’. This incident made me realise that palliative care is not centred only on death, and bereavement is not just about tears; rather, it prioritises fostering connections, compassion, and dignity [26]. Later, a caregiver summed this up nicely in an interview: ‘We are not experts in dying; we are experts in living before dying’. I could immediately understand why caregivers and volunteers working or involved in palliative care find their (volunteering) work so rewarding and inspiring [26]. Yet, this starkly contrasts with the question I have been receiving for almost four years as I mention the topic of my PhD research: 'Is that not very depressing?' However, this question is often countered immediately when I bring up the aperitif story. Looking back at my first day of fieldwork in the day-care centre, I realised that my preconceived expectations might not always have been accurate. As a result, I immediately tried to put them aside and resolved to embark on this research with an open mindset.

While many articles on research in palliative environments primarily concentrate on the challenges [27-29], I also find it important to express the uplifting moments when conducting an ethnographic study in a palliative environment. Although the end-of-life has beautiful moments, ‘dying is not beautiful’. This last comment by a caregiver echoed through the hall at an international conference on palliative care in September 2022. He indicated that society often portrays this final stage as too beautiful, while in reality, dying is not always beautiful but rather dirty, often consisting of vomiting and defecation. He indicated that these intimate, rather dirty moments are often only experienced by people who care for the person in these final moments, which researchers are often not part of. This comment caused me to write this unpolished version of my research journey, which naturally encompasses more depth and nuance than the simple act of enjoying an aperitif before lunch. There seems to be a lack of transparency in the literature on challenges or hidden struggles with conducting fieldwork [30, 31]. That is why I have structured my journey according to the good, the bad, and the ugly. In doing so, I aim to paint a more truthful picture of undertaking an ethnographic study within various palliative environments.

Here, the good encompasses valuable methodological and ethical insights, meaningful interactions with participants, positive revelations during the research process, or any study aspects that yield valuable insights or positive outcomes. The bad covers challenges, obstacles, difficulties, or setbacks that I faced preceding, during and following this ethnographic study. It is about acknowledging and discussing the less favourable aspects of this study. Finally, the ugly involves personal, uncomfortable, difficult, unexpected and emotional situations or aspects. Ideally, as an ethnographer or participant-observer, you use yourself as a research tool or instrument through which information is collected, recorded and analysed [31, 32, p.13]. However, this position creates a unique paradoxical relationship between intense immersion and objective distance from research and participants, blurring the lines between personal and professional boundaries [14]. Hence, this article encompasses the experiences, emotions and feelings that this unique position has stirred in me as a researcher in palliative environments.

This article stems from the question: 'What advice would I give myself if I knew then what I know now?' Hopefully, it will provide novice researchers with some inspiration, guidance, and (self-care) tools to conduct research in sensitive and unique domains, such as palliative environments. Additionally, I see writing this article as a therapeutic process that gradually softens difficult feelings and thus contributes to my own emotional well-being.

2. The journey’s setting

This article discusses an ethnographic study on users' spatial experiences within diverse palliative environments. To tell the story like it is from the inside, I, as a researcher and also the author of this article, spent 23 days immersing myself in the daily activities of users across different settings: a palliative care unit (n=13 days), a hospice (n=6 days), and a day-care centre for palliative care (n=4 days) in Belgium. These days were spaced out over time, averaging two days per week in these environments. Throughout this span, I engaged in numerous informal conversations with residents, family members, caregivers, volunteers, and maintenance staff, establishing rapport and trust. I attended daily briefings and even took on volunteer tasks like meal preparation and assisting individuals with mobility or eating challenges. Simultaneously, I maintained transparency regarding my role as a researcher and the study's subject and objectives. Within the palliative care unit and hospice residents typically reside for an average of 16 to 17 days, while stays in the day-care centre vary from weeks to years. The palliative care unit has nine resident rooms, the hospice has eight, and the day-care centre accommodates an average of five individuals daily (with different residents each day). These environments are characterised by a centrally located open kitchen and living area connected to terraces. Beyond participatory observations, I conducted qualitative semistructured interviews with 31 participants: residents (n=10), family members (n=6), caregivers (n=7), volunteers (n=7), and maintenance staff (n=1).

3. The research journal

Acknowledging oneself as an instrument or tool in ethnography [31, 32, p.13] involves recognising the limitations in understanding the impact of the emotional, personal, and practical challenges during fieldwork on the research process and its outcomes [31]. The earlier traditional view is that openly discussing the emotional and personal struggles encountered by ethnographers during the fieldwork might be seen as irrelavant [33] and could undermine academic validity and credibility [31]. Nevertheless, it is crucial to recognise that fieldwork is inherently filled with emotions, and concealing these experiences is not realistic [33]. Therefore, revealing vulnerability as a researcher can provide valuable insights [31]. Additionally, it would be inconsistent to expect participants in a sensitive research study to disclose their experiences when we, as researchers, cannot be forthcoming in the literature about the challenges and hidden struggles while conducting this research.

A research journal could encourage a more systematic and analytical exploration of these emotional and personal challenges and their effects on the research [31]. Within ethnographic research, the research journal (or diary) is a common tool researchers use [30]. This journal can be seen as a valuable addition to the research protocol, ensuring more sincerity and rigour, as it allows researchers to 'reflect in action' on the issues that are not always included in the protocol [34]. Thus, to keep track of my journey as an architect-researcher in palliative environments, I decided to keep a research journal. Yet, addressing this journey encompasses more than just the 23 days spent in the field; it also includes the preparation, transcriptions, analyses, and writing processes that preceded, occurred during, and followed this ethnographic study. I purchased a small notebook and carried it everywhere, utilising it for three different purposes:

- For collecting fieldnotes: Field notes include records of occurrences in the field, often describing locations, events, people and activities [31]. These records encompass notes from observations, interviews, informal conversations;

analytical reflections on emerging ideas; considerations about themes, concepts, or research questions; and references to broader literature.

- For reflexivity: Reflexivity in qualitative research encompasses acknowledging and embracing the reciprocal influence between researchers and their research [35]. It is often seen as an overlooked aspect in qualitative analysis, commonly addressed after data collection or initiated during the writing phase [30, 34]. However, maintaining a research journal facilitates continuous reflection of the data collection process while still being actively involved in the fieldwork [34]. This constant reflection allows reflecting and acting on unexpected conditions, ethical dilemmas, methodological challenges, and exploring alternative approaches [34]. Moreover, this research journal also serves as a space to contemplate potential biases, the researcher's position, roles, assumptions, and considerations for future research endeavours [31, 34].
- As a cathartic tool or to place emotions: The research journal can assist the researcher in acknowledging and expressing emotions [34]. Specifically, when these emotions jeopardise the research progress, it aids in analysing and responding to them [34]. Hence, this journal documents the emotional highs and lows experienced throughout the research journey, encompassing fears, struggles, shortcomings, and intrinsic motivation.

In my research journey as an architect-researcher in palliative environments, I have experienced a recurrent exchange between various occurrences, reflective moments, and emotional responses. To encapsulate these, I decided to chronologically document them in a single notebook, aiming to capture the entirety of my journey. All extracts were thematically analysed.

4. Insights from my unpolished journey

For this article, various extracts from my research journal were chosen to explain the prominent recurring themes: bias and positionality reflexivity; finding a common language and equal value exchange; researcher's well-being, self-care and intrinsic motivation; flexible adaptation to sensitive settings; and ethical considerations and dilemmas. In addition, the 'good, bad, and ugly' aspects of each theme are listed in Table 1 to give a quick overview of my personal journey.

4.1. Bias and positionality reflexivity

It was my first day rotating in this palliative care unit at a hospital. A new group of caregivers had just arrived for the morning briefing at the nursing station. This space, mainly composed of glass, adjoins an open living-kitchen area, the heart of the unit. Alongside the volunteers, I was waiting in the kitchen for a briefing specifically for volunteers. Here, updates are provided about all the residents, their needs, and those of their families so volunteers know where they can be of help. Suddenly, a man stood next to us in the kitchen, looking distressed. The volunteer immediately interrupted our conversation and asked if the man wanted coffee and something to eat. While one volunteer prepared a loving breakfast, the other volunteer and I sat down with the man at the kitchen table. The man immediately began pouring his heart out about his wife's condition. He mentioned that his wife was in a lot of pain and that things were deteriorating very quickly. He also expressed concerns about their children at school, fearing they might not see their mother in time. While occasionally holding back my tears, I heard caregivers in the nursing station in the background, having fun, laughing out loud. The briefing was evidently over. The contrast was stark. It felt disrespectful. The architect in me immediately saw the solution: such future conflicts could easily be avoided by moving this nursing station. When the man returned to his wife, I recorded this experience and the feelings it evoked in my notebook. Two hours later, I heard that the man's wife had died. I revisited this event after conducting numerous participatory observations and interviews with residents, family members, caregivers, volunteers, and maintenance staff. Recognising my initial bias, I perceived this event from a new perspective. Substantiated by the data collected in the following weeks, I concluded that it was not disrespectful at all. Instead, I realised the essence of life and joy within palliative environments. In an interview, a resident and family member expressed that the palliative environment felt like home because of the presence of laughter. Volunteers also depicted a palliative environment as a place filled with laughter, and caregivers acknowledged that this 'laughter' serves as a distraction from the sometimes-heavy events. Therefore, it is crucial to integrate everyday life, including laughter, into these environments. Additionally, I recognised the significance of caregivers and volunteers being visibly present. Hence, the importance of the nursing station being centrally and visibly located in the palliative environment.

A few weeks later, I sat at the table with caregivers, volunteers, and residents at lunchtime. They discussed my research study and the significance of my gender in conducting it. Statements surfaced, claiming ‘a man could never conduct this research’ and ‘as a woman, you have much more tact to converse with people’. This conversation triggered my awareness of my positionality. Additionally, recognising my predominant role as a volunteer, I became aware not to view these palliative environments from a singular perspective narrowly. Furthermore, personal growth and evolving perspectives are part of reflexivity, emphasising the importance of revisiting your insights as they might have developed. Therefore, reviewing extracts from your research journal is crucial.

4.2. Finding a common language and equal value exchange

A colleague warned me that interviewing users of healthcare environments about their experiences with architecture is not straightforward. So, I opted to begin with participatory observations before gradually moving to conducting interviews. This approach allowed me to inform people about the research, build trust, and gain insights into how to shape these interviews best. Explaining the research within palliative environments quickly revealed that certain words or concepts were not as straightforward as initially thought. For instance, the term 'research' might be off-putting in a healthcare setting and could easily be mistaken for a clinical research study. Also, when I asked people if they were interested in an interview, I often received responses like 'but I don't know anything about architecture' or 'that's not for me'. Consequently, I avoided using the term 'architecture' and instead specified it as 'the building, layout, activities, environment, location, etc'.

I found a common language between interviewer and interviewee by utilising photoelicitation interviews. Displaying photographs of the building, inside and outside, alongside a clear floor plan of the palliative environment made the concept of 'architecture' more graspable and relatable to participants. I pre-tested the interview guide with individuals from varied backgrounds, some familiar with research, others not, some involved in these palliative environments, others not. Furthermore, providing participants with sample questions beforehand often helped reassure them and gauge their interest in such interviews. Additionally, I emphasised that there are no right or wrong answers and that every opinion matters.

For a while, I grappled with the discomfort of ‘bothering' people or taking up their time for interviews, especially in the sensitive context of palliative care where time holds great significance. Despite the vital role their insights play in shaping future palliative environments, I felt unable to sufficiently reciprocate this value, particularly to the residents who may have limited chances to see the study's benefits in practice. Indeed, some individuals failed to see the purpose of such interviews; however, other residents found it meaningful to still have a sense of significance as they approached the end of their lives. Yet, during the interviews, I realised I could give back therapeutic value to the participants by offering a listening ear, showing genuine interest, and providing companionship. For example, a participant was fascinated with butterflies, so we veered off the interview guide for half an hour to discuss this interest. This approach aligns with my aspiration to encompass a volunteer role alongside my researcher position to establish a better balance in value reciprocity.

4.3. Researcher’s well-being, self-care and intrinsic motivation

Due to the significant delay in the data collection process caused by the COVID-19 pandemic, I did not hesitate to dive straight into the field when this was back allowed in Belgium. I initially scheduled three consecutive days, but it quickly became apparent that this approach was overwhelming, and it was better for my own well-being to take some time to acclimate. Suddenly I realised why volunteers dedicate only half a day per week to assist. Moreover, intensively getting to know individuals in such a short span of time could intensify the impact when someone passes away. At the day-care centre, I got to know a resident with whom I had many conversations. A few weeks later, he moved to the hospice, where I conducted two interviews with him. Engaging in these extended conversations naturally fosters a connection. Some weeks later, I aimed to transcribe his audio recording. Upon hearing his voice, I immediately wondered how he was doing. However, I swiftly discovered that he had passed away a week prior. Navigating through these audio recordings was a struggle; my impetus stemmed from a moral obligation to honour the significance of his input. Hence, I decided to limit my presence in the field to a maximum of two days scattered throughout the week and transcribe one interview from residents or family members per day.

A few months later, I entered a room of another palliative environment to ask whether a resident wanted a drink. I was immediately struck when I noticed that this person's hands and feet were completely black. Additionally, due to this person’s intellectual disability, communication was challenging, making it difficult to find out her beverage preference. I felt overwhelmed and uncomfortable because I did not know how to handle this situation and because my lack of knowledge and experience might perhaps distress this resident. Despite these emotions, I was surprised by the cheerful spirit of this individual. Her smile was contagious. After eventually delivering the correct drink and receiving a broad smile of gratitude from this resident, I left the room feeling uplifted.

This incident highlights how ethnographic researchers can be caught off guard by situations they may lack sufficient knowledge or experience to handle effectively. However, from such situations, you learn both from a professional and personal level.

A few weeks later, a very young resident, approximately my age, arrived in the same palliative environment. I spoke with his wife and met his child, parents, and friends. That evening, I was overwhelmed by emotions, likely because I could relate too closely to his life circumstances. Soon, I noticed that other caregivers and volunteers were also emotionally affected by the presence of this young resident. Talking to them about these emotions served as a self-care solution for me.

Another event that struck me personally occurred when someone very close to me was diagnosed with cancer during my PhD. Although I had not yet initiated my fieldwork in palliative environments, I immersed myself in extensive reading during this period, exposing myself to literature where terms like 'dying' and 'cancer' frequently appeared. It was a situation I had earnestly hoped would never unfold. Confronted with this news, I contacted my supervisor, fearing that the subject of my PhD and this particular occurrence might become emotionally burdensome. She provided encouragement and stressed that it was acceptable to be there for my best friend, even if it meant I could not fully dedicate myself 100% to the research at that moment. Ultimately, and somewhat paradoxically, this PhD journey turned out to be a welcomed distraction from the wandering thoughts that occupied my mind at that time.

During interviews, several volunteers with extensive experience in various palliative environments shared with me that they were considering quitting due to the negative impact of the infrastructure on their tasks. These conversations made me realise the impact that I, as an architect-researcher, can have with this research on people on a longterm scale. In the short term, my greatest intrinsic motivation stems from making a meaningful impact, whether through listening, assisting, or providing companionship to users of palliative environments.

4.4. Flexible adaptation to sensitive settings

Palliative care, its environments, and the individuals within these environments are sometimes different from how society portrays them. Due to this distorted perception, I repeatedly encountered new facets throughout my ethnographic research that demanded re-evaluating my research approach. For instance, I learned that not all residents are aware of their stay in a palliative environment. Some individuals are in a state of denial regarding the severity of their palliative condition. Throughout the interview with a resident at the hospice, for example, the resident consistently expressed her belief that she would return home the following day, although that was not the actual situation. In another palliative environment, the daily briefings cover the residents, their situations, needs, and whether they are aware of being in a palliative environment. As I was not always certain about an individual's perspective on their situation, I often initiated a casual conversation before starting the interview, which frequently provided valuable insights. Moreover, the interview questions were framed to allow users the choice of which topics or experiences they wished to (not) discuss with me.

During interviews, I noticed that caregivers and volunteers often highlighted some negative spatial aspects of the palliative environment, whereas residents tended to emphasise the positive aspects. Some residents could not even point out a single criticism.

This may be linked to 'socially desirable responses', which is characterised as the tendency of participants to give overly positive responses, rather than expressing their genuine opinions and experiences [36]. These overly positive responses could be explained by the fact that residents are often grateful to and dependent on their caregivers [37]. However, these overly positive responses could also be connected to the residents' shorter stay than caregivers and volunteers, potentially resulting in the environment's shortcomings not always apparent. Nevertheless, I attempted to address the issue of socially desirable responses by underlining the confidentiality and anonymity of the interview. I also employed neutral questions like 'How would you improve this environment or what would you change about this environment to create an even better palliative environment?'. Furthermore, I empowered participants to choose the interview location, ensuring their comfort and ease during the conversation. However, this often resulted in interviews being conducted in communal spaces, leading to significant background noise on the audio recordings. However, in this scenario, prioritising the participants' comfort over practical convenience, was of greater importance to me.

Maintaining a schedule in a palliative environment proves immensely challenging. After numerous conversations with caregivers at the palliative day-care centre and following their recommendation, I arranged a focus group session with five residents instead of separate interviews. However, on the scheduled day, this approach turned out to be practically unfeasible. Some residents preferred not to participate, one had hearing difficulties in a larger group setting, and all residents required alternating care. Consequently, I swiftly had to adapt my approach to conduct one-on-one interviews. Furthermore, there were occasions when interviews were planned with family members or residents on a specific day, only to find out that the resident was too weak, had visitors, or possibly had even passed away on that day. Hence, it is crucial to integrate a significant degree of flexibility into your methodology, enabling quick anticipation and adjustment as needed.

4.5. Ethical considerations and dilemmas

The informed consent process posed several challenges. Firstly, since this study fell under the medical ethics committee, the ethical consent had to meet the same criteria as other medical studies. This requirement resulted in a lengthy document including sections like 'what are the disadvantages of participating in this research study'. Several participants indicated afterwards that such language made the interview sound worse than it actually was. Furthermore, while I managed to condense the document from fourteen to four pages, it was still extensive when going through it with a resident before starting the interview, often leaving them too fatigued to proceed with the interview afterwards. Scheduling the informed consent on a day different from the interview might seem plausible, but this remained an uncertain option due to rapid changes in the residents' conditions.

Secondly, my ethical committee did not allow alternative approval through audio recording. I encountered a resident who highly valued autonomy but could not physically sign the document due to his condition. I was advised to have someone close to him sign as a witness. Reluctant to relinquish his autonomy, he managed to put a shaky signature. Another incident involved a visually impaired woman. Despite reading through the informed consent together, she did not feel comfortable signing a document she could not read, causing her to opt-out. In general, within this palliative context, the informed consent document sometimes proved to be a hindrance. Some residents found it challenging to sign documents in the final stages of their lives.

Third, gatekeepers (i.e., caregivers assisting in participant recruitment) may provide guidance. However, it remains crucial for researchers to stay vigilant. For example, during an interview, I quickly noticed a participant did not meet the criteria, although a caregiver told me this could be a suitable participant for an interview. In such cases, ending the interview early was necessary. Lastly, most informed consent documents in other disciplines suggest informing participants of their ability to reach out for research result updates. However, this statement is best omitted for residents in palliative environments for ethical reasons.

Table 1. The good, the bad, and the ugly: the journey of an architect-researcher in palliative environments

	The good	**The bad**	**The ugly**
BIAS AND POSITIONALITY REFLEXIVITY	• Recognise your biases and positionality • Review your research journal • Embrace personal growth and evolving perspectives	• Drawing biased conclusions • Making judgments based on emotions	
FINDING A COMMON LANGUAGE AND VALUE EXCHANGE	• Start with participatory observations to build trust and gain insights • Use photo-elicitation to communicate about architecture • Pilot the interview guide with diverse individuals • Share sample questions beforehand • Provide therapeutic value	• Certain generic terms like 'architecture' and 'research' • Some participants have limited chances to see the study's outcomes	• Feeling you are a burden to others Struggling with a lack of mutual value
RESEARCHER'S WELL-BEING, SELF-CARE AND INTRINSIC MOTIVIATION	• Honour the contribution of participants • Reduce and space out the weekly field presence • Restrict the daily number of interviews and transcriptions • Feel uplifted by supporting people • Discover learning opportunities on professional and personal levels	• Too many interviews, days of fieldwork, or transcriptions in a short period of time places a huge load on a researcher's well-being • Lack of knowledge and experience can hinder the fieldwork	• Feeling overwhelmed • Feeling uncomfortable • Building a bond with individuals who might die soon • Listening to an audio recording of someone who might have passed away in the meantime • Situations or people you personally relate to

	- Talk to people in the field about your struggles - Make a meaningful impact on short and long term		can be emotionally burdensome - Receiving bad news in your own social circle during your research
FLEXIBLE ADAPTATION TO SENSITIVE SETTINGS	- Start a casual conversation before starting the interview - Provide participants freedom to select topics to discuss or avoid - Underline participants' confidentiality and anonymity - Employ neutral interview questions - Let participants chose the interview location - Facilitate rapid adaptation and adjustment	- Residents are not always aware of being in a PE - The risk of receiving socially desirable responses - Disturbing background noise in audio recordings - Keeping track of a strict time schedule in palliative care is challenging	
ETHICAL CONSIDERATIONS AND DILEMMAS	- Use gatekeepers to assist in participant recruitment - Remain vigilant about ethical considerations and the well-being of participants yourself - Avoid strong attention to mentioning in the informed consent that residents can have an update on the research outcomes	- Informed consent is often too long - Signing a document at the end-of-life might deter participation - No alternative approval available via audio recording - No alternative for those physically unable to read the informed consent	- Feeling powerless due to ethical barriers

5. Conclusion

The journey within palliative environments as an architect-researcher has been a deeply introspective and enlightening experience, marked by moments that embraced the good, the bad, and the ugly. This article aims to illuminate the challenging yet deeply fulfilling path for future novice researchers in palliative environments or other sensitive contexts by revealing my own unpolished hidden struggles and uplifting moments when conducting an ethnographic study within various (Belgian) palliative environments.

To capture the essence of this journey, I embraced the practice of maintaining a research journal, utilising it not only to collect field notes but also to foster reflexivity and find solace in my emotions. This article emerges from the belief that documenting these inner thoughts and experiences not only enriches the research process and outcomes but also nurtures researchers' emotional well-being. However, while the use of this method has been a huge support during my research journey, it is not ensured that it will bring sufficient support to all researchers facing the same challenges. Hence, this article also (shortly) reflects on, for example, other self-care tools such as an emotional support network and certain therapies. There is room for future research to reflect on these matters.

Despite the acknowledged benefits of journaling in research [30, 34], there seems to be a reluctance among researchers to share or publish these personal and vulnerable notes [30, 31]. However, this article argues that openly presenting authentic fieldwork experiences can aid fellow researchers in recognising that their own challenges and experiences are part of the fabric of a research journey. Therefore, I decided to share my personal journey to empower emerging researchers, urging them to capitalise on their strengths while not allowing struggles to impede their progress excessively. It is about acknowledging that many others navigate similar hidden struggles and utilising this awareness as a catalyst for confident strides in future research endeavours within sensitive contexts, such as palliative environments.

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