

INTO THE CLEARING: A PHENOMENOLOGICAL STUDY OF THE DEATH DOULA APPROACH TO END-OF-LIFE CARE

BY

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Abstract

Changing Canadian attitudes towards death and an over-stretched health care system have precipitated the emergence of the death doula role to fill in gaps of end-of-life care. Despite some traction in Canadian airwaves and social media, the novelty of the death doula role contributes to the challenge in providing a clear description of the role's scope and significance within the end-of-life care context.

This project endeavors to answer the question "What do death doulas do?" in two parts.

1. Lived experiences: Conversations from nine interviews with practicing death doulas were analyzed using the descriptive phenomenological psychological method developed by Amadeo Giorgi. Themes were developed from the conversations and were used to describe the breadth and depth of death doula work.
2. A phenomenological framing of the findings: The themes discovered in Part I of the research were framed within the ideas of phenomenologist Martin Heidegger whose thoughts around the concepts of human existence provide a rich foundation from which the role of the death doula can be understood.

My research findings suggested the death doula role consists of three complementary yet succinct components. First, a death doula tends to the practical needs of the client; secondly, clients are comforted by a doula's presence and the distraction it provides; and, thirdly, the end-of-life doula holds space for "the clearing," a time and space where death is anticipated, and the full spectrum of life is revealed.

Keywords: Phenomenology, A. Giorgi, end of life care, death doula, the clearing

Table of Contents

Relevant Research	5
Project Goals	6
Research Design.....	6
Methodology	6
Phenomenological inquiry	6
Framing of findings within Heideggerian philosophy.....	9
PART I.....	10
Analysis	10
Findings.....	11
1. Practical Support and tangible tasks	12
Comfort	12
Distraction.....	13
Coaching and advocacy.....	13
Documentation.....	14
2. Being present with the dying client	14
3. Holding space for deeper conversations	15
PART II.....	18
Heideggerian Phenomenology.....	18
Practical tasks: Concerned, client focussed everydayness.....	23
Being present – Being-with, attunement, entanglement	25
Holding space – Temporality and the Clearing	27
Implications for Doula praxis	31
Practical Tasks.....	31
Being with the Client	31
Holding space for the Clearing.....	32
Future directions for research	32
Changing cultural attitudes towards death.....	33
The philosophical nature of being with each other – pandemic upheaval	33
Application of virtual environments to end of life doula care.....	33
Client focussed research.....	33
The necessity of entanglement.....	34
An examination of the clearing	34

Into the Clearing:

A Phenomenological Study of the Death Doula Approach to End-of-Life Care

Discussions about death are not always welcome. Consequently, for those practicing in the emerging role of death doula, it has been a challenge to raise the profile of a profession focussed on end-of-life care. Part of the difficulty lies in the esoteric nature of the role and the lack of broad knowledge about its care giving potential. As an instructor of an end-of-life doula course, I am often challenged by students to explain how I go about being a death doula as the scope of practice and codes of ethics often describe the parameters of the role but not the breadth of skills and knowledge essential to its praxis. Several colleagues have shared similar sentiments. To address this, the first part of this study is geared towards understanding the role's purview through an examination of stories from those who consider themselves as practitioners, and to hear first-hand how the role is performed within care environments.

Due to the hesitation in addressing topics of death and dying, I feel that Canadian society is deprived of a rich death care vocabulary. As a response to this, Part II of this project examines how the ideas of phenomenologist Martin Heidegger provide insight into how we can approach talking about death. His examination of human existence and our presence in the world presents a meaningful starting point for death care language. The goal of Part II of this study is to use Heidegger's phenomenological language to explore each of the themes generated from the death doula narratives which, in turn, will add to the lexicon and understanding of the death doula approach to end-of-life care.

Relevant Research

A comprehensive literature review revealed that while the talk of death and facing death is on the rise, an examination of the role of death doula has been lacking, particularly in Canada. Researchers such as Doyle (2015), and Wong et al. (1994), have explored attitudes towards death and death care in Canada but not in relation to the death doula role. Doyle (2015), for example, advocated for more research in death care management, “the monitoring of the expansion of death services, as well as the evolution of cultural approaches from a phobia and fear of death into the proposed reintegration of death into life, could be observed through participant research” (p.73). Other studies highlighted different approaches to the topics of end-of-life care, human agency in health care decisions, and the philosophical basis behind critical decision making, but the findings concentrated on existing institutional health care praxis within end-of-life contexts and did not extend the examination to include the end-of-life doula role. This could be attributed to unfamiliarity with the role in general. Rawlings et al (2019) conducted a systematic literature review of the role death doulas play in end-of-life care and concluded, “this systematic review has revealed a dearth of published academic literature about death doulas in end-of-life care...further research into the role played by death doulas is sorely needed” (p.e91). Therefore, clarity surrounding the role’s scope amongst those who practice, and more extensive language for explaining the role to others would be of benefit to this emerging role in death care.

Two studies were analogous to my own research. The first was a phenomenological exploration of doula voices (Trzeciak-Kerr, 2016); the second focused on a model of care (Rawlings et al., 2020). Both studies were specific to death doula work, however they were situated within an institutional context rather than based on the wider context of lived experience and used mostly secondary sources of information to describe the death doula role rather than

hearing from the doulas first-hand. Therefore, minimal literature specific to the death doula role combined with little study of firsthand experience provided an opportunity to examine the Canadian end of life doula within and beyond the borders of health care institutions and to frame its praxis within the context of Heidegger's philosophy of being, thereby adding to the lexicon of death care work unfettered by oft-used medical death care jargon.

Project Goals

This research project makes the following contribution to end-of-life care literature:

1. A description of the Canadian death doula role generated from the voices of those who practice within its scope.
2. Clarity for the role within the Canadian health care context by developing language around praxis.

Research Design

The research design divides the study into two parts:

- I. Qualitative interviews with end-of-life doulas, who self-identified as practicing in the role, using Giorgi's (2012) method of phenomenological inquiry.
- II. An examination of the themes discovered in Part I within the context of phenomenologist Martin Heidegger's ideas of human existence.

Methodology

Phenomenological inquiry

This type of inquiry suspends any a priori assumptions of the subject matter, meaning it requires researchers to describe the subject being studied without attaching pre-conceived meaning or judgement to the data and to speak plainly about the results. As phenomenologist

Robert Sokolowski puts it, “only from the phenomenological perspective can we get the right terminology to speak about the world as the context for the manifestation of things” (2000, p.50).

Phenomenology is an intentional reflection as it “proceeds through a methodological reflection on experiences and indeed it reflects not on experiences as actually occurring or having occurred but on what such experiences *may be like*” (Moran, 2013, p.354) [emphasis added].

Phenomenological inquiry necessitates an imagining by researchers of how experiences unfold in order to fit the findings into an explanation of wider societal context; consequently, researchers should prevent themselves from approaching a problem looking *for* something, and, instead, read the data with the idea of allowing ideas to *appear within* the context of study.

The Descriptive Phenomenological Psychological Method used in this project was the method outlined by Amadeo Giorgi, (Giorgi, 2012, 2010, 1997; see also 2000, 2004, 2008, and 2014), and is summarized as follows:

1. Researchers read the entire body of data and descriptions in order to get a sense of the whole.
2. Researchers re-read the data and mark transitions of meaning into meaning units.
3. The meaning units are then transformed into expressions that elicit the full import of what the subjects have said.
4. The expressions of meaning are used to reveal the essential structure of the experiences.
5. The essential structure is then used to help re-interpret the raw data.

(Giorgi, 2012)

The predominant influence in Giorgi’s descriptive method was the Husserlian concept of the reduction, understood to be a process by which researchers set aside any preconceived notions of the subject matter and adopt a “deliberate naiveté” (Bevan, 2014, p. 138) towards the

data. Giorgi described the reduction as a putting aside or bracketing of past experience which renders any prior knowledge of a subject as non-influential, (1997, par 13). Descriptions of research participants' experiences were the data that informs researchers and "...when one encounters in experience things and events that 'obviously' have existence, the reduction directs one to step back and describe and examine them as a presence" (Giorgi, 1997, para.12). It is important to note that research participants do not enter into the reduction as their experiences are meant to be generated from the world in which they *are*, thereby ensuring that the resulting findings are grounded in the world of lived experience. For researchers, the initial step of the reduction requires them to inhibit the tendency to apply meaning or interpretations while the data is being gathered. Instead, researchers should understand data as information. "She does not engage her own understanding of the phenomenon and remains open to what the participants tell her" (Giorgi, 2008, p. 40). I applied the reduction to my own research through the use of open-ended questions and prompts with participants that elicited descriptions of visits with clients rather than reflections upon the effectiveness of a particular way of being with a client, for example. The goal was to use these descriptions as the basis of explaining the role rather than assessing its effectiveness.

Essential to Giorgi's method was an imaginative approach to the reading of the data. Initially a phenomenological reading looks for phrases common to several descriptions of an experience, at which point the phrase is set aside as a meaning unit (Van Manen, 1997). These meaning units become key descriptions of the essential structure of the phenomenon being studied (Giorgi, 2012). To ensure that the descriptions encapsulate the phenomenon as a whole, researchers should apply alternative scenarios and concepts to the data, the goal being to verify if they also agree with the general descriptions of the event. Husserl named these

alternative scenarios and the process of applying them to the data as imaginative variation and when employed it “can help in explicating the phenomenon due to actively imagining the phenomenon in different forms, shapes and being” (Skea, 2016, p.1136). This is largely intuitive as researchers examine meaning not only from the descriptions from the data but also from applying possible explanations from situations unrelated to the subject at hand, “one considers multiple other meaning possibilities that could have emerged instead of the one that actually did, and the consideration of these other possibilities helps the researcher to intuit and describe a more general meaning” (Giorgi, 2008, p. 46).

The combination of the reduction and imaginative variation methods allows for an open-minded approach to the research topic, one which allows for not only an expansive, exploratory approach to understanding the phenomenon, but also a comprehensive structure from which more understanding and language can be applied.

Framing of findings within Heideggerian philosophy

The language of philosopher Martin Heidegger, found primarily in his work *Being and Time*, are presented as a framework within which the findings of Part I can be understood. The use of the Heideggerian study of human existence and what it means to be in the world, allowed for a deeper exploration of death doula work as well as the introduction of philosophical terms from which increased understanding of the role and its effectiveness within end-of-life care contexts was generated.

PART I

I conducted nine Zoom (virtual, in-person)¹ interviews with Canadian end of life doulas who had self-identified as practicing in Canada by listing their services on publicly accessible websites. I began each interview by requesting detailed descriptions of how one or two work situations unfolded from start to finish. Additionally, each doula was shown a photo image of an end-of-life situation and was asked to describe what they felt was happening in the picture. The goal in using the image was to elicit descriptions of doula work in an unmet situation which, in turn, could provide new descriptors or common methods used in the death doula approach. The final few minutes of the interviews were used to re-visit any of the previous events described or to have an informal back and forth conversation about doula work.

In the initial reading of the completed interviews I made no attempt to isolate data sets or settle on particular terminology. During the second and third readings, predominant words and phrases were marked as meaning units. A fourth reading of the data was used to organize the highlighted words and meaning units into explicative phrases. Finally, these phrases were shortened for clarity, and a comparison between the themes and the interview transcriptions was performed to ensure the themes encapsulated the raw data in its entirety.

Analysis

Something shifts in our attitudes towards death when we face our own. Research participants described hearing clients state how they really did not appreciate life until they heard

¹ I commenced my research at the advent of COVID-19. Safety and the pandemic's travel restrictions precipitated a move from in-person interviews to online interviews. The pandemic's influence was felt in the data in some discussion about the impact on doula practices, however, has not been included in the scope of this research study. The impact of COVID-19 has been added to the directions for future research.

the word “terminal” and then dying became “more real”. In the documentary, *The View from Here*, Linda, a woman facing an imminent death, described this shift,

There’s a big difference between knowing in general that you’re going to die, and knowing exactly what you’re going to die of... You know with just more practical certainty that you’re not immortal, you always knew that, but now you *really know it* [emphasis added] (Burns, 2018. Ep. 1, 2:18).

This newfound certainty of dying, whether encountered at the beginning of a diagnosis or when one knows that death is imminent, can leave individuals looking for answers around care provision options, along with emotional support for the idea of dying. This is typically the time when an end-of-life doula is contacted by a potential client. What proceeds is a supportive relationship which, according to the stories told by the doulas interviewed, can be succinctly described by three categories of end-of-life doula care.

Findings

The following three categories of end-of-life doula care emerged from the data:

1. Practical support and tangible tasks that support the client and loved ones.
2. Being present for the dying person to provide comfort and honour the existence of the individual.
3. The creation of a safe time and space for deeper conversations around end-of-life issues.

It was necessary to explore the nuances of each theme in order to understand how they were differentiated from each other and represented doula care as a whole. In practice, each type of care could be present at any time, but they did not occur concurrently. This lack of concurrence was a key indicator of the margins of each type of care.

1. Practical Support and tangible tasks

Practical and tangible were pivotal descriptors for this type of doula care and the common thread between them was that they were considered the “doing” part of the work and the work was done *for* the client.

Comfort

The idea that we can help someone who is ill by taking care of them appeared intuitive to those practicing as doulas as all felt that “you know how to do it, or you don’t.” Less apparent was the notion that the performing of simple tasks for someone could be so comforting. The doulas I interviewed talked of helping a client choose clothing for the day, building a rapport with staff, opening windows, providing snacks etc. They were on the alert for their clients’ immediate needs or what many described as “doing what needs to be done.” No matter how simple the task, clients felt taken care of in a way that was vastly different from the general routines of medical health care provision.

The support and comfort generated from simple actions can be inconspicuous. In his TedTalk, *What Really Happens at the End of Life*, Dr. B.J. Miller described his experiences of recovering from severe burns in a hospital burn unit. He referenced being brought a snowball by one of his palliative care nurses, and that the act of holding the snowball while it melted had a profound effect on his state of mind, “I decided then and there that it was ok if I died and if I did not” (TED, 2015, 10:33). Miller named these “stolen moments” (11:15), instants in time which can be understood as joyful or ecstatic and come about through thoughtful, simple actions. Behaviours like closing the door before being asked, dimming the light if the client feels unwell, or taking pictures of a shared moment with loved ones, demonstrated a doula’s ability to

anticipate and react to their client's needs and were described by the doulas as the "little touches," crucial to care.

Distraction

During questioning, doulas recounted intentional efforts to distract the client from the discomfort of worry or physical pain. Working together on legacy projects such as photo collages, parsing up possessions, recording voice diaries, doing jigsaws, reading from favourite books, and cleaning up the room with the client's direction were examples of actions taken to create a positive sense of purpose which was a welcome relief from routine hospital visits, medical procedures, fatigue, pain, and fear of dying.

Coaching and advocacy

Doulas described how necessary it was to coach clients and their families through end-of-life planning by empowering them to discuss end of life care options amongst themselves and with their medical team. The goal was to establish relationships and conversations amongst all those involved in client care about what may or may not be working for the client at that time but also to build consensus on what to expect and provide later on. Normalizing the dying process for everyone was high on the list of each of the doula's expected tasks as death can be shocking for those not familiar with its process and the presence of an end-of-life doula helped to "reduce the scariness – the strange smells, sounds, and idea of death."

Many of the doulas interviewed felt strongly that the normalization of death was a task that extended beyond the work with their clients and was part of a wider societal conversation about aging, long-term care, dying and death. Promoting societal awareness of dying and death as a normal process was seen to be essential in securing options in care for their clients and part of a responsive approach to the care needs of the dying in society as a whole.

Documentation

Documenting changes in the client's physical state and mental demeanor was understood by the doulas to be important to giving a voice to the client in end-of-life care situations. While other medical teams were busy with the concurrent health care needs of multiple patients, death doulas described a personal one-on-one relationship with their clients. The familiarity with the client's situation allowed for increased awareness of the client's changing care needs. Doulas felt that they were uniquely positioned to provide personalized care and alert others if care needs changed.

The common thread in the above examples was a sense of service to the client enacted by the doula "*doing something for*" the client in response to an expressed or anticipated need.

2. Being present with the dying client

In every interview conducted it was extremely important for doulas that their clients have someone with whom to share their concerns about dying. Unlike the activity found in practical tasks, the exercise of being present with the client was less tangible: "I create positive energy in the room," or "I walked with her to ease her loneliness," suggested that the client was *worked with* rather than having something *done for* them. "I spent the night sleeping beside her so she could reach out and touch me and know she wasn't alone," was a common description. It was important to the doulas interviewed that their clients have someone with them even in situations in which the client was unresponsive. "I deal with the moment; I live in the moment" spoke of a lack of projecting ahead into what could happen and more of being present with the client in the now.

Furthermore, the being present of doula work was described as “seeing the person as they die” or “bearing witness to their passing.” This notion of bearing witness appeared to honour the individuality of the client’s existence and the relationships they have had with the people in the room even when clients were in the final stages of dying and unable to speak for themselves. For example, one doula mentioned, “When you sit with someone, they cease to be a room number.” In those situations, the doulas encouraged family members to talk softly or sing to their loved ones rather than be on their phones or engaged in conversation, so as to recognize not only that the dying individual was still present in the room but also that they were to be the focus of the family’s attention.

Being with the client, then, did not appear to demonstrate the overt activity of practical tasks nor was it anticipatory in that no one was preparing for the next activity. Instead, the idea was to provide a calm presence dedicated to the accompanying of clients as they were dying. It was focussed, dedicated time *with* the client in the present.

3. Holding space for deeper conversations

The phrases ‘creating space’ or ‘holding space’ are descriptions of care that have blossomed throughout end-of-life doula literature. Wright Glen (2017), in her book, *Holding Space: On loving dying and letting go*, used the term throughout to explain the unique nature of the end-of-life doula role, “the act of holding space creates a circle of care that says...I am here with you and I will companion you as you name, navigate and work with your fears...” (p.82). Her description of naming, navigating and working with fears conjures the expansiveness of this time and given the term’s increased use, I was intrigued to witness the difficulty interviewees experienced when trying to describe how holding space actually transpired. I wondered if the

term had become a catch-all phrase, used by death doulas to describe an important part of intentionally being with a client and the meaning had, over time, been taken for granted as understood and encapsulated only part of the intention.

When probed further as to the nature of the term “holding space” the conversations and verbal descriptions ceased. Instead, doulas used arm movements to indicate a widening or expansion of the physical space around them. Confronted with this apparent difficulty in defining the term, I encouraged those who were struggling to envision instead *how* they would step *into* this space in the hope of prompting new descriptions of the space’s essential nature. For example, when I imagine holding space, I see myself stepping into a pool of light, an image I shared with the research participants as an example. As the interviewees slowed their thoughts and approached the term in this alternative way of thinking, they were able to work with their words differently, working with their meanings and contexts to create something new (Petitmengin, 2006). Verbal sketches of a “field of calm energy in the room,” a “liminal space,” a “contemplative, calm place to be,” “a warm, glowing stillness,” and “bringing someone into a space where the hard work is done,” depicted a space of intention and reverence whose depth and breadth set it apart from other ways of being with the client.

“*Bringing a client into*” denoted a demarcated time and place for doula and client. The intensity and separateness differentiated this space from other forms of care provision. Doulas described their clients’ frantic pacing or obsession over the smallest of planning details along with lack of sleep, bursts of irritableness, and anger. All interviewees described these behaviours as common reactions to the knowledge of dying. Doulas recounted clients’ increased reflections upon important events and people, an ability to imagine how the time remaining will unfold and, finally, what they will have accomplished when they die. Holding space involved clients

working through tough, oft forgotten, traumatic or personal events as well as the anticipation of future, unattended milestones. The space encapsulated a myriad of emotions and reactions.


Holding space for the dying did not appear to necessitate the dying person's presence for the space to exist. Descriptions of the dying person's loved ones creating reverent times at home, spending time alone with photos and creating ceremonies of loss, demonstrated others' ability to hold the space of reflection *for* someone. I can recall one of my own client's siblings calling and informing my client that "I will be thinking of you every day at 4pm. That is my time with you". At 4pm, the client and I would enter into a space of stillness and my client would tearfully address what her sister had meant to her. The holding of space extended beyond the physical realm of the client and manifested in an intentional setting aside of *time* for a shared experience.

The end-of-life doula's role in holding this space appeared to be one of encouraging the possibility to not only enter the space, but also to engage with the client while in the space and ascertain how long they wished to remain there. This deep, philosophical work was described by research participants as requiring ongoing encouragement and was often exhausting for both client and doula. For these reasons, it was important to manage the expectations of what could be accomplished each time the space was entered.

Upon examination of the three categories of end-of-life doula care, I propose that each category be understood by both the objective of care and depth of the experience generated. Summarized in the diagram below, the primary function of practical tasks was to provide comfort in response to current care needs and to build a relationship with the client. The results tended to be responsive, immediate and functional experiences that were done *for* the client. Being present with the client involved a more intentional, focussed witnessing of the client's dying experience, the primary goal being the provision of comfort through accompanying them

or being present *with* them. Finally, holding space for a client suggested a deeply imaginative, reflective, and explorative approach to end-of-life which permitted the doula, loved ones and client to *enter into a place* of far-reaching reflection and focus.

Table 1.1. Summary of End-of-Life Doula practice



Practical Tasks (for)	<ul style="list-style-type: none"> • Immediate comfort in response to care needs • Overt, active engagement • Relationship building
Being Present (with)	<ul style="list-style-type: none"> • Provides comfort and distraction • Focussed attention on the client • In the present/now
Holding Space (enter into)	<ul style="list-style-type: none"> • Explores the full spectrum of life • Deeply imaginative and reflective • Intentional

PART II

The categories of care generated from Part I of this study and outlined in Table 1 will now be further examined within the context of Heideggerian phenomenology, the goal being to provide a descriptive framework from which the role of the death doula can be better understood.

Heideggerian Phenomenology

Heidegger's extensive exploration of the concept of human existence and the meaning of being has provided a rich foundation for the study of life and death. His works, *The Concept of*

Time and Being in Time in particular, explored what it means to be *in* the world as a being and, in particular, the type of being capable of appreciating its own existence.² Heidegger was careful to differentiate that the ability to appreciate one's own existence stemmed from human beings finding themselves already encountering people and things in their world rather than beings who regarded themselves detachedly as if looking down on themselves from an observational standpoint. Human beings do not see the world and then enter it or see a space and then walk into it; rather we are already in the world and make sense of it as the space and things in and around us make themselves known.

Dasein [human existence] as such is always engaged in one of its possible ways of dealing with the world in concerned fashion. The most familiar forms of this are working on or with something, arranging something, producing something, taking something into use, keeping something safe [...] we encounter the world through such concerned dealing with it" (Heidegger 1924/2011, p. 14).

Concerned dealing with the world defines the world for human beings but, in doing so, hides the ability to do just that. Caught up in what Heidegger referred to as the *everydayness* of daily activities (1953/2010), human beings are more concerned with the use of things rather than how they, as humans, exist as a being that uses the things. It is only when things break, or when human beings feel out of sorts with events happening around them, or a vague feeling of concern arises, that human beings are able to appreciate the thing about which they have been concerned – that of their own existence in the world, how this existence makes itself known to them, and how they will continue to exist within this new awareness.

² Heidegger used the German word Dasein to denote this type of being that could appreciate its own existence in the world. For simplicity sake, and to avoid having to explain how this word is used throughout Heidegger's extensive body of writing, for this project I have chosen to refer to this type of being as a human being, the exception being when direct quotes from Heidegger's work are used.

If the thing we are concerned about is obvious, then human beings can quickly deal with it and return to the everydayness of the world. However, if we experience the nebulousness of something not quite right in our world, our attention is raised but there may be no immediate resolution. Heidegger referred to this vague feeling as anxiety, a generalized, inexplicable knowledge that something is amiss, with no immediate obvious redress. (1953/2010). He explained that anxiety removes us from the comfort of the familiar and into a sense of “uncanniness” with the world.

Anxiety, on the other hand, fetches Dasein back out of its entangled absorption in the “world.” Everyday familiarity collapses. Dasein is individualized [vereinzelt], but *as* being-in-the-world. Being-in enters the existential “mode” of *not-being-at-home* [*Un-zuhause*]” (Heidegger, 1953/2010, §40, p.182).

Key to the understanding of why human beings find themselves anxious was the recognition of anxiety as a fundamental part of being a unique person, something not felt or appreciated as we go about the daily minutiae of our lives (Heidegger, 1953/2010). Anxiety draws human beings away from the meaning and activity we create with others and things in their world and into the ambiguity of their own being, and, importantly, the knowledge of their *potential* for being a unique person. Anxiety positions human beings so they may appreciate the possibilities of life rather than being limited by the “average everydayness of taking care of things becom[ing] blind to possibility...” (Heidegger, 1953/2010, §41, p.188). This not being at home in the world can be disconcerting, but it is the discomfort that shifts the perspective as to how we can be in the world.

Anxiety and its ability to bring human beings out of the everyday and into the state of appreciating ourselves as unique also has implications for how we perceive our mortality. In the

everydayness of human activity, we view death as something that *will happen sometime*, “the ending that we have in view when we speak of death, does not signify a being-at-an-end of Dasein, but rather a *being toward the end* [*Sein zum Ende*] of this being” (Heidegger, 1953/2010, §48, p.236). Similar to the manner in which a human being’s attention is drawn to something when it breaks, anxiety is a signal that something is wrong with the world at hand and instead of being able to hide within the everyday world, human beings are confronted with the awareness (one they have had but not specifically connected to their own being), that they exist in a world as finite beings who die. Instead of death happening at any time to anyone, which is the manner in which human beings accept death as being part of life, anxiety forces one into an encounter with one’s death as an imminent possibility, even though the knowledge of dying has always been part of living.

The entangled everydayness of Dasein knows about the certainty of death, and yet avoids *being-certain*. But in the light of what it evades, this evasion itself bears witness phenomenally to the fact that death must be grasped as the own-most nonrelational, insuperable, *certain* possibility” (Heidegger, 1953/2010), §52 p.247).

In other words, in brushing off death as “something that happens” in a general sense, human beings demonstrate the commonplace knowledge that life entails death. However, it is the anxiety of the more imminent nature of a personal death – one that happens to me rather than others, that when recognized, makes possible a more authentic, deeper understanding of the personal nature of death.

A final, important element of Heideggerian thought was his notion of our temporality or how we exist in relation to our time and space in the world. He asserted that if human beings are beings that know themselves to be in the world due to the things and people that constitute

meaning, then they must, at one point, appreciate the fact that there will be a time when they are not in the world. In this sense, Heidegger frames the mortality of human beings as the “ultimate possibility” that they must “*hold onto and endure*” so that they may “run ahead towards it’s looming possibility” (2004/2011, p. 43). By doing so, human beings are forward facing beings, able to project their existence up to the point of departure from the world known as the ultimate possibility of existence. (Heidegger, 1953/2010). This projection permits human beings to recognize the breadth of experience of their own life, as while forward facing in the present, they can reflect back on what has happened and what is happening. “Dasein runs ahead to its own death and then ‘comes toward itself’ out of the future.” (Inwood, 1997, p. 90). Human beings ‘look forward’ to activities and plan for the future. They have a myriad of options open to them until they run up to the final possibility, their own death. The finality of their own death is the mechanism for appreciating ‘what *I* will have been’ and brings them back to where they are in the world at the time of this understanding. This brief understanding of mortality encapsulates the full spectrum of a life lived, in which the possibility of a future that is uniquely theirs as no one can die for them meets with the life lived up until that moment of understanding. Where the future and past meet is in an equally unique present, situating the person in their world, as no other human being can come back from another’s death and therefore experience the same life up until that point.

*Only a being that is essentially futural in its being so it can let itself be thrown back upon its factual there, free for its death and shattering itself on it, that is, only a being, that, as futural, is equiprimordially **having-been**, can hand down to itself its inherited possibility, take over its own thrownness, and be **in the Moment** for “its time”* (Heidegger, 1953/2010, §74, p. 366).

As forward-facing human beings, letting anxiety and concern tune them into the final possibility of death, human beings can essentially time travel as they are the *time* they have spent, are spending and will spend in the world.

To do justice to the entire works of Heidegger is impossible within the scope of this paper, however the above ideas are useful as a lens from which descriptions of end-of-life doula work and its implications within the context of end-of-life care can be appreciated and will be used to examine the three categories of care introduced in Part I.

Practical tasks: Concerned, client focussed everydayness

As concerned human beings, immersed in our everyday world, we make meaning for ourselves by taking care of things.

Dasein as such is always engaged in one of its possible ways of dealing with the world in concerned fashion. The most familiar forms of this are working on or with something, arranging something, producing something, taking something into use, keeping something safe... (Heidegger, 2004/2011, p.14).

This occupation is not limited to inanimate objects. Human beings encounter other human beings, also taking care of things in the world and see them for what they are and what they do (Heidegger, 1953/2010). When doulas entered clients' rooms to greet them, answered phone calls, or brought gifts, for example, both client and doula saw each other as *the person who does 'this' task*. For the doula, providing a service for the client suggested an entering into a state of concern for their client's well-being. While the clients appreciated the doula as the provider of care, the results were a focussed, concerned care provision and reception. Doulas discerned their clients' needs and offered up solutions. Heidegger described these acts as "in-order-to" where "the different kinds of 'in order to' such as serviceability, helpfulness, usability,

handiness, constitute a totality of useful things” (1953/2010, §15, p.68). Concerned care provision provided by these in-order-to’s were understood by both doula and client as situational as they were unique to the present time, place, and relationship in which the client and doula found themselves, (tasks that were useful one week may not have been useful another, and something that was necessary for one client may not have resonated with another). By taking care of things for their clients, the doula approach to care demonstrated a concerned and personal approach unique to the client’s world and the time and place in which both doula and client were meeting. The space shared between doula and client appeared to be the physical space and present time within which the doula and client built a sense of trust, something mentioned in all interviews as extremely important to doula work. Consequently, paying attention to the needs at hand for each client’s situation required an observing eye and a strong sense of adaptability.

The “gaps in care,” described by research participants in regard to problems with medical provision or lack of emotional supports, were analogous to Heidegger’s belief that human beings encounter problems when the “in-order-to’s” do not function as expected. Compassionate doulas, working within the context of long-term care provision, ascertained gaps by watching and interpreting their client’s verbal and non-verbal clues. An increase in their client’s anxiety, for example, invoked a problem-solving response in the doula.

Practical tasks often involved items or actions familiar to the client which established a welcome, comforting routine. Heidegger considered the familiarity of tasks and others to represent the comforting tranquilizing nature of the everydayness of life, in which little is questioned, “when, in everyday being with one another, we encounter things that are accessible to everybody and about which everybody can say everything, we can soon no longer decide what is disclosed in genuine understanding and what is not” (Heidegger, 1953/2010, §37, p.167). He

noted that the everydayness of being with each other in the world produces averageness, a state of being in which the uniqueness of our own self is subverted by the needs and characters of others (1953/2010, §27, p. 123). Concentrating on the demands of the myriad everyday tasks of living, even while undergoing medical care, can become the norm and it is uncommon for human beings to take a step back and view the exclusive manner in which they occupy their place in the world. For the most part we stick with the known and remain in its comforting reliability.

Being present – Being-with, attunement, entanglement

Following a terminal diagnosis, a variety of moods and emotions surfaced. Often there was confusion on behalf of the client as to what was the root cause of the mood, especially when anxious. Words often failed clients when asked if there was something that could be done for them. Research participants described “working with the fear,” “receiving the anger,” and “giving my client the time to be however they need to be.” In facing their own deaths, clients were irrevocably changed from their past selves, as, according to Heidegger, “anxiety individuates Dasein to its own most being-in-the-world, which, as understanding, projects itself essentially upon possibilities” (Heidegger, 1953/2010, §40, p.182). In the knowledge resonant of Linda’s “now you *really* know you are dying” in the documentary *A View From Here*, the clients were set apart from others in their lives who were not yet facing imminent death. Time and space provided by the presence of a doula, during which the tranquilizing entanglement of friends, medical personnel and procedure, and the minutiae of everyday life were set aside, was a time for the client to be encouraged and supported to sit with their anxiety and explore its root cause, most notably that of knowing they were facing death and the particularity of dying.

Deliberate, focussed examination of pending death, however, could only persist for as long as was comfortable for the client and, after a short period of time, doulas described clients feeling the need to talk about something else or to be distracted by something. Heidegger “found that it was possible to only have rare and fleeting glimpses (*augenblick*) of authentic presence” (Bradford, 2006, p. 9). Perhaps the fleeting nature can be attributed to the discomfiture of imagining a world in which one’s presence is no longer found. Facing death can be overwhelming. Research participants described the need for soothing activities not only when death was imminent, but also immediately following an unexpected diagnosis or subsequent to an end-of-life planning session. Doulas reported of sessions during which clients grappled with the knowledge of a much-shortened sense of their time left in the world and the pursuant anxiety becoming unbearable and painful for both the client and their loved ones. Distraction came in the form of talking things through or guided mediations and permitted a return to a calmer state of mind. It appeared that the client gathered energy from the alleviation of anxiety and the return to everyday immersion in the world with others. Doulas being present with the client through actively listening to rambling stories or simply remaining calm, had a tranquilizing affect and permitted peace of mind.³

Knowing one was dying appeared to precipitate an opportunity to explore the meaning of existence. The trick, it seemed, was to find the balance between the tranquilized respite of everydayness and the deep exploration of a life review. In order to provide personalized care,

³ For Heidegger, anxiety and the resulting attunement towards death as possibility was considered favorable as he considered it to be part of living authentically. I have found, however, through practice and from the interviews in this study, that the anxiety of facing one’s own death is mentally exhausting. Distraction is a necessary form of care provision. As a result, more research would be helpful in understanding the necessary and often positive role of entanglement in care circumstances.

end-of-life doulas required a sensitivity to this unique balance between anxiety alleviation and prolongation.

Holding space – Temporality and the Clearing

The exploration of the full breadth of one's time on earth and the facing of its end seemed to be an evocative, arduous task. "*Existing in the face of nothing*, [*Sein vor dem Nichts*], in a state of anxiety about *itself*, a state that provides no basis for immersion in the world, Dasein may be directed back to itself ..." (Heidegger, 2004/2011, p. 35). While anxiety may have brought clients to the point of appreciating their own mortality, they had no past death experience from which to cultivate understanding and the result was the need for someone with whom to discuss and explore this new reality. To initially hold space was depicted as the provision of a safe, accompanied period of time for deep reflection by or upon the client and Doulas described this space as being the "client's time" and a place for "tapping into inner strengths," or "keeping the dying client front and centre in our thoughts."

Initially the space was created by the thought of death and the subsequent impression that death was closer than before. Similar to making meaning in life by using things that are close to hand, thinking of death appeared to bring it closer and into its own unique space for its contemplation.

In terms of the way we exist in the world among things which appear in terms of that world horizon, what may be 'objectively' more distant can be brought near and so 'closer,' phenomenologically speaking, than something which is objectively less distant. (Kisner, 2008, p. 19).

Death was not necessarily close for clients, especially for those whose death was not imminent, but the thought of death precipitated the need to reflect upon dying and did bring the idea of

death closer ‘to mind.’ This, in turn, prompted anxiety and the need for a time and place to deal with death’s nearness.

When prompted to describe how holding space was performed, again, research participants struggled to find words to accurately represent the process and substituted physical movements depicting a large, circular, extra corporeal space. I interpreted the actions as representative of a space which occupied a physical area but was not confined to the limitations of bricks and mortar. “It was everything” was one doula’s response yet she could not find the words to characterize “everything.”

This “everything” could, however, be considered an accurate description of what was happening to the client and space holder. As Heidegger suggested, fully appreciating the horizons of one’s life from the past and into the future is a profound experience.

The unity of the horizontal schemata of future, having been, and present is grounded in the ecstatic unity of temporality. The horizon of the whole of temporality determines *that upon which* the being factically existing is essentially *disclosed*” (Heidegger, 1953/2010, §69, p. 347-348).

The conjuring of a space within which the horizon is only determined by the limits of one’s lifetime, hints at the sweeping breadth of being in the world as a human being. Interviews divulged times of heart-wrenching grief, shame, guilt, regret, the fear of being forgotten, and much more as joys and sorrows of a life lived were contemplated and imagination was applied to the time left in which to enact final wishes. Intentionally setting aside time for this type of deep reflection allowed for an arcane combination of time and space to occur in which Doulas encouraged a full appreciation of the breadth of life. By doing so, they deliberately aimed for more than Heidegger’s ‘*augenblick*’ or moment of insight (1953/2010) and endeavored to keep

the client engaged in this meaningful space. This appears to be the crux of “doula-ing,” - by coaching clients or loved ones to intentionally occupy this space, doulas held the tension of “the Moment” (Heidegger, 1953/2010), maintaining the borders of comprehension that can, very easily, slip into the tranquility of everydayness.

While “*in*” this contemplative space it was impossible to comprehend everything all at once. Instead, the client was encouraged to examine whatever came to mind. In doing so, many things such as memories, experiences or knowledge of oneself remained obscured, just as things remain hidden in the everyday world of living, until they matter to us, “when we see the “world” in an unsteady and wavering way in accordance with our moods, what is at hand shows itself in its specific worldliness, which is never the same on any given day” (Heidegger, 1953/2010, §29, p. 134). Clients who found themselves in the space of a life review or loved ones who gathered into shared space of loving contemplation of the person dying, were coached by doulas to discuss or think about whatever they wished, but to also be open to letting go of each thought as another made itself known. Heidegger’s idea that human existence was a form of clearing resonates with this notion of a flow of thoughts, “this means that the open place in the midst of beings, the clearing, is never a rigid stage with a permanently raised curtain on which the play of beings runs its course...” (Heidegger, 1977, p.179). King, in his study of Heidegger’s concept of the clearing, described this interplay between focus and hiddenness,

In the clearing, a dance is in progress, a duet between light and shadow, the interplay being unconcealing and concealing ... The clearing is that liminal space where the ebb and flow of unconcealment takes place at its own pace (King, 2015, p.110).

Throughout the doula narratives there was the occasional admission that some topics were not approached or did not come up. It was felt that the “journey was the client’s, the client dictated

the conversations, and there were some stories you simply left alone.” There was a recognition that the topics meant to be avoided held tremendous potential for exploration, but doulas felt that supporting their clients in finding the “flashes of insight” (Van Manen, 2014, p. 235), through which clients could see themselves as having lived a rich life was a more effective tactic than pushing clients to explore an area of personal difficulty or intense emotion. It was noted, however that a doula should be ready to gently guide the client into a difficult conversation if an openness to exploring painful subjects was shown.

From the results of this study, it is possible to understand that even for those who work with the dying, the tendency was to default to comfort measures when clients demonstrated anxiety in the face of death. Doulas wrestled with the idea that they may remove the last morsel of their clients’ hope when they requested them to truly examine death. I would argue that in NOT facing death individuals are prevented from the chance to understand themselves as a unique human being *because* they remain focussed on the now or the time they have left. Facing and absorbing the knowledge that time on earth is finite allows clients to appreciate, more authentically, the impact their life has had on others and the richness they themselves have experienced. It may also prompt them to entertain other possibilities yet to come, “anticipating one’s own death in life and in this assumption choosing one’s own authentic existence, because in facing the possibility of my own impossibility I will have the courage to do something with my life...” (Large, 2015, p. 92). Interviewees recounted how much healing took place between previously estranged family members as the contemplation of reduced time rendered conflict meaningless. A client who wrote letters to those he had wronged was described by his doula as having felt relief in his effort to address a relationship, even though it remained one-sided. The ability of doulas to hold space and create a clearing for reflection and authenticity produced rich

responses and opportunities within which to face death and, in combination with the practical tasks and being present with the client as they faced dying, provided a comprehensive approach to end-of-life work.

Implications for Doula praxis

Practical Tasks

In taking too much care, or doing too many things for the client, doulas may be, as Heidegger described, “taking the other’s ‘care’” away from him and put itself in his place taking care, it can *leap in* for him” (1953/2010, §26, p.118). In the desire to ‘do’ for the client, the doula may undertake all of the “in order to” tasks and leave nothing for the client to enact in order to feel present in the world. Empowering the client to make decisions or arrange their space can validate their existence.

The comfort provided from practical tasks is rooted in this averageness of the everydayness of life and has implications on how well doulas can assist clients with facing death. To over-program the client or to only focus on the tasks at hand may inhibit opportunities for deeper reflection and meaning making. Too much doula or family presence has the potential for diluting clients’ appreciation for their unique place in the world.

Being with the Client

Being with a client can provide respite from the anxiety of facing death. Throughout the interviews, some doulas maintained that respite from the strong emotions generated from deep reflection is exactly the reason for engaging a doula as a doula provides a comforting presence, the goal being that the client remain calm and peaceful as they die. This approach has tremendous value if, upon experiencing some deep reflection, the client wishes to be distracted.

However, while helpful, the distraction provided by soothing activities may prevent the client and their loved ones from exploring authentic relationships and emotions. To hamper an authentic response to dying with everyday diversions prevents the client from responding to the call of the clearing and the resulting opportunity to appreciate their life in its breadth, depth and uniqueness.

Holding space for the Clearing

Death doulas, in allowing time for and coaching clients to be open to the intensity of the clearing, can provide an opportunity for deep reflection and resilience, “we rise up to meet turmoil with confidence in our client’s ability to travel through the murk and come out the other side with newfound fortitude” (Arnoldy, 2018, p. 12). The clearing is important not only for what is examined but also for what remains hidden or unaddressed. Unexamined issues may be of great important to clients’ understanding of their lives and a skilled doula will be able to take note of the untouched subjects and provide feedback to clients, so that whatever is being avoided can be recognized and dealt with. Even a brief foray into the clearing may result in profound connections between loved ones, an increased understanding of fears around dying, and, perhaps, an appreciation for one’s place in the cosmos. The importance of this coaching suggests that those thinking of becoming end of life doulas or doulas who, up until now, have relied on soothing and distraction techniques rather than sitting with the discomfort and deep emotion of others, may require their own coaching in this important facet of doula work.

Future directions for research

This study has been one of hopefully many forays into the world of an end-of-life doula and how doula practice can be understood. As the role continues to evolve, with the advent of

societal disruptions such as COVID-19, and changing attitudes towards dying in general, there will be much opportunity to study these topics further. The following ideas are, I believe, worth pursuing.

Changing cultural attitudes towards death

This research comes from a western philosophical viewpoint. It is also mono-cultural in that the majority of individuals who identify as a practicing end of life doula are predominantly white females. It would be interesting if not essential to compare the findings to other cultural attitudes towards death and the language surrounding death care.

The philosophical nature of being with each other – pandemic upheaval

With the nature of being with each other being so dramatically changed by the pandemic, an exploration of the essence of what being with each other is becoming in this new world would be intriguing. The pandemic's effect on aging, connection, communities and other sociological constructs may point to the need for an entire shift in thinking how we are together while apart.

Application of virtual environments to end of life doula care

An applied project for which the goal would be to explore the potential for technology to create meaningful contact with our loved ones in this post pandemic world could be of great use to both doulas and anyone involved in compassionate care. A similar application could be used for end-of-life doula training and the teaching of compassion in virtual environments.

Client focussed research

This study focussed on the stories narrated by end-of-life doula practitioners in order to understand their role in end-of-life care from their perspective. A comprehensive study of end-of-life doula care from the perspectives of the dying individual or families of loved ones would produce greater understanding of the role's efficacy and breadth.

The necessity of entanglement

The idea that entanglement can be used as a soothing element of care provision contradicts Heidegger's notion that entanglement inhibits authenticity. From the study we saw that facing death was often mentally exhausting and distraction a necessary tool in the Doula toolbox. An examination of entanglement as a positive influence would be interesting.

An examination of the clearing

A focussed, philosophical study on the nature of Heidegger's clearing and how it manifests for clients and their loved ones would allow for a greater understanding of our ability to appreciate our mortality.

In an effort to answer the question, "what do death doulas do?" it was necessary to allow those who practice as doulas a voice in explaining the nuances of this type of end-of-life care. Using Giorgi's Descriptive Phenomenological Psychological method of analysis allowed for this personal and comprehensive take on an emerging role as those who lived through an experience are most likely to be able to describe how the experiences unfolded. The notion that there are layers of connection and depth associated with end-of-life doula work does not initially seem surprising, but as the layers were examined from different viewpoints it became clear that there were succinct, philosophical difference between each type of interaction with clients. Practical tasks fulfilled the immediate comforting needs of the present, something that seems quite natural in a health care setting. The difference between being present with the client and the holding of space emerged less easily.

Viewing the findings through the lens of Heideggerian thought allowed for the idea of holding space to be understood through the notion of the clearing, which, in my opinion offers

the most insight into the uniqueness of the death doula role. The death doula nurtures a deep, professional relationship with the client, one that encourages a personalized approach to end-of-life care as the client is encouraged to step away from the everydayness of the world and into a space in which their unique presence in the world is understood.

I suggest the ideas of holding space and the clearing could be used to reimagine what being in each other's presence means within the end-of-life care context and underscore the doula role as an approach to care, applicable to a variety of care environments. Encouraging families, health care teams, volunteers and anyone involved in care settings to entertain a different philosophical approach to what it means to be with each other could be, in my opinion, the crux of our ability to create nurturing, in person and online care environments. I see the potential for death doulas to be at the forefront of this new way of being.

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