

Be-ing with Dying:

A Researcher's Use of Phenomenological Writing Protocols

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1st Global Conference

The End of Life Experience:

Dying, Death, and Culture in the 21st Century

March 17 & 18, 2018

Lisbon, Portugal

Abstract

Death comes to all of us at one point or another. In old age it is expected, in the young it is tragic. Regardless of the when, it is a process we all go through. How do we face it? How do we help another who might not be ready to die? How do we choose to *be with* dying? This paper illuminates the phenomenon of *be-ing with* dying through the self-reflection facilitated by phenomenological protocol writings. The sample writings articulate an exploration of what it means to *be with* dying. Using my own experience as the data of a case study, I have begun preparation for doctoral research with emerging adults who are dying from terminal cancer. As a first step in the research process, phenomenological protocol writings provide form and structure for self-reflection, much like a guided meditation provides form and structure. This article is intended to describe this process for professionals to apply in their own research or in their practitioner domains.

Keywords: being with, dying, lifeworld, phenomenology, researchers, young adults

Why Engagement by the Researcher First?

For thousands of years, scholars and laymen alike have been reminded to “Know Thyself (γνώθι σεαυτόν, or *Gnothi Seauton*).” Originally, it was meant to remind us human beings of the divine spark that is within each of us. This age-old maxim is inscribed on the remains of the Temple of Apollo at Delphi, in ancient Greece. There, worshippers were to take notice of their mortal nature before coming face to face with the gods. Socrates speaks of knowing oneself, as does his student Plato. Moving closer to present time, the American poet, Ralph Waldo Emerson (1831) implores us in his poem, *Gnothi Seauton*, to remember that God is part of us, and that through knowing ourselves we come to know God.

In academic circles, Van Manen (1984, 1990) suggests that it is useful for researchers and investigators themselves to become acquainted with their own lived-experience before reaching out to others; in other words, to know themselves first. By doing so, social science researchers gain an understanding of the nature of that which they are asking of their participants. If researchers want up close and personal answers to their interview questions, it is helpful for the researcher to understand and have the same kind experience with their own probing questions beforehand. Behar (1996) supports this idea of developing a deep connection between personal experience and the research project. She encourages scholars to understand aspects of self that act as lenses through which they perceive the world and the topic being studied. Josselson (2013) recommends that qualitative researchers take a reflexive stance before engaging in participant interviews. It is within this enduring, centuries-old framework of knowing ourselves first, knowing where we come from, and where we now stand, that a bridge of connection can be constructed between researcher and participant, “the observer and the observed” (Behar, 1996, p.14). In this sense, qualitative research benefits when researchers themselves invest time in a

methodical self-reflection before engaging with participants. This brings me to how I came to apply these phenomenological writing protocols.

Arriving at *Be-ing with Dying*

As a case in point, my youngest son was diagnosed with cancer (Hodgkin's Disease) at age 19 and died a short four years later, at 22. It wasn't supposed to go that way. He, like most young adults, was full of vim and vigor. He thought of himself as invincible and it truly seemed that way for a while. He started chemotherapy and easily went into remission. But when the cancer returned 18 months later, it was resistant to high-dose chemotherapy, indicating that the disease was likely to take a turn toward an end-of-life (EoL) trajectory. He wasn't ready! We weren't ready! What was I going to do if he died? How was I going to lead him on a path he was unprepared to traverse? How would I choose to *be with* him (Estrada, 2016)?

This loss, coupled with the statistic that 20% of young adults don't have positive outcomes to cancer (Smith et al., 2016), has led me to this field. Annually there are 70,000 new diagnoses of cancer within the adolescent and young adult (AYA) population in the United States alone (AYAO PRG, 2006). Statistically this amounts to the deaths of 14,000 AYAs each year. The Adolescent and Young Adult Oncology Progress Review Group (2006) states that AYAs are an understudied and underserved patient population. Since the publication of their report, the focus over the past decade has been on survivorship. However, there has been a distinctive lack of qualitative investigation into the needs and experiences of those who die so young. Research is needed. One of the ways that researchers, healthcare professionals – doctors, nurses, palliative care specialists – and caregivers can thoroughly prepare themselves for research in this area or for professional practice is through the use of phenomenological protocol writing.

Use of Phenomenological Writing

Phenomenological writing protocols are designed to result in a rich, textual description of a lived-experience (van Manen, 1990); they are not intended to shed light on any causal relationship nor to become a cognitive meandering about an experience. They aren't narrative storytelling. The structure of the protocols provides a logical, systematic, and coherent method to arrive at the essence or the nature of the lived-experience itself (Moustakas, 1994). The protocols elicit a description. How did it feel to the person? What emotions were present – in whom? Were there particular smells or tastes? What was the space like? Were there noises or lighting present that created a certain atmosphere or setting? What was the experience of time? What thoughts or concerns rose to the surface? Each writing protocol focuses on a specific facet of the topic or phenomenon, so that in the end, a gestalt perspective – one that is more than the sum of the individual parts alone – emerges.

Before beginning a research project or work in a particular field it is useful to apply this concept of self-knowledge. By taking the time to explore our own lived-experience with a topic or particular phenomenon we can achieve a heightened awareness of our own views, biases, and emotions. In other words, we come to know what we are bringing to the table. This knowing of ourselves frees us to be fully present to listen, observe, and inquire on a new level as we engage with those from whom we hope to learn. Phenomenology can also provide a vehicle of transformation by providing a lens of more than just understanding. It can provide insight into seeing ourselves in a new and unexpected way that “clears the focus, reflecting a truer image of who we are” (Rehorick and Bentz, 2008, p. 4).

Although this is neither the time nor place to tackle all the specifics of protocol writing, some overview is appropriate (see van Manen, 1984, 1990). First, we want to orient ourselves to

the nature of our topic of interest. We can do this by naming or formulating a question about the phenomenon that addresses the lived-experience. Second, we want to take note and make explicit our assumptions, understandings, prior knowledge gained from the literature, biases, and beliefs so that they don't color the process of reflection as we go about engaging with the protocol writings. This process, often referred to as bracketing (or suspending), is not ignoring what we know but an acknowledgement of it. This is followed by a dive into the etymology of the word or key components of the words we use to describe the phenomenon. Words and usage can change over time, so it can be enlightening to become informed of a word's history.

From there we are ready to begin the process of self-reflection. The phenomenon is explored by making separate reflections into our own lived-experiences using the following protocols as a guide: (1) the earliest (our first encounter with the phenomenon); (2) the most poignant lived-experience; (3) the not present or opposite (what cannot be present if our phenomenon is to be what it is); and (4) the essence or essential structure of the phenomenon (what must be present). Once those writings are complete, we then turn our attention toward (5) the lifeworld. The lifeworld(s) consists of the everyday-world in which our phenomenon exists and from which our lived-experiences are derived. As we reflect, we will want to pay close attention to the existential elements of any lifeworld: (6) lived space (spatiality); (7) lived body (corporeality); (8) lived time (temporality); and (9) lived other (relationality).

For the purposes of this paper, I will use my own lived-experience of *be-ing with dying* as illustrative of phenomenological protocol writing. I engaged in this self-reflection six years after my son died as I prepared to begin the doctoral research project. My lived-experience is readily available and easily accessible. Experience is data. It is also possible that my experience is the experience of others; just as it is possible that another's experience is my experience. This

binds together by the nature of human experience itself as we strive to “get closer to the things themselves” (Husserl, 1900-1901/1970, p. 252, in Wertz, 2011).

Etymology:

The experience of *be-ing with* is the basis of the self-reflection through the structure of phenomenological writings. Factually, *be-ing with* dying is my own lived-experience with my son. The suffix *-ing* is emphasized because it denotes either a continuing through time, or continuing over a time period. We had a period of time in which to continue to hope that death would not come or at least stave off for some time. During this continuation we also had time to adjust to the fact that it was on the horizon. This emphasis lent importance, to my actions and non-actions. I was consumed with the idea that I needed to proactively be there for my son; even when not physically doing, I was thinking ahead as to what might be needed or desired.

My subjective lived-experience was in sharp contrast to the lived-experience of a dear friend who lost her young adult son a few weeks prior to my son’s death. Her experience was one in which her son was alive and well one minute, and gone (from her) in another – the tragic result of a combination of prescription medication and an over-the-counter drug. For her, there was no *be-ing with* dying. A continuing of time or through time did not exist for her. Time was compressed. There were no saying “good-byes;” no preparation. The juxtaposition of these two very different lived-experiences created a heightened awareness within me of what *be-ing with* dying meant and how I wanted to *be with* my son. Her experience made me keenly aware that nothing should be taken for granted during whatever remaining time there was to be. It was a tangible reminder to treasure every moment and to make every moment count. It also provided a reminder of how we should be with each other every day – no need to wait till death is knocking at the door.

Earliest

Reflection on the earliest encounter of *be-ing with* dying took the form a premonition. It occurred after the consulting doctor (prompted by my son's relapse) left us alone in the stark and sterile hospital examination room to ponder the poor prognosis she had delivered.

Excerpt from the Earliest Protocol:

I wanted to tell him that we would fight this, that no matter how hard it seemed now, no consequence the discouraging odds, that we'd find a way to make his body strong, resilient, and invincible again. But what dared to sneak in and obscure those thoughts was the question "What if? What if my son dies?" I endeavored to push that thought away, but that was like trying not to think of the pink elephant in the room. The thought remained with me as I stood there holding him tight. It tugged at my sleeve, like a little child begging for attention. I had no choice; I refused it for another day and another time.

Most Poignant

Exploration of the most poignant moment of *be-ing with* dying began by delving into the etymology of the word *poignant*. True to its Latin root of *pungere*, poignancy elicits emotion of a pricking or piercing nature.

Excerpt from the Most Poignant Protocol:

The totality of my identity (body and soul) was pierced as I rumbled down the road in my son's Jeep to go grocery shopping. The Jeep – symbolic of his young adulthood identity – together they were invincible and indestructible, rugged, big and tough, cool and hip. Only now, in this time there was a new reality.

The day started out like every other day when I went out. But it was not like every other day! I hopped into the red Jeep and drove the mile or so to the store. As the

Jeep bumped and bounced along it hit me ... it overwhelmed me ... it smacked me in the face ... Ouch! ... It stung!

My boy would never ride in or drive his beloved Jeep again. Could he even muscle his way in by pulling himself up? I wondered if he could have even walked out the door of the apartment to the car parked so close by? I knew he couldn't. And with that, the world changed.

Big, salty tears began to cascade down my cheeks. I was inconsolable. It was here – the time was here! Ouch! I was stung again! There would be no more fun - no more fun in the way that he liked to have fun. No more would he flash that big smile from the Jeep as he whipped out of the drive. No more would he give the Jeep sign of brotherhood to a passing driver in another Jeep. Oh, such carefree times – times of aliveness and breath, of drinking in the sun and basking in its warmth!

There was no use holding back my tears. I didn't care that strangers might see me and stare. I was entitled. The life of my guy, with all his hopes and dreams was slipping away – from him, from me, from all of us. I couldn't stop it. I couldn't press pause and rewind – it would have been the same story anyway – all I could do was cherish every moment and be there with him in whatever way he needed me to be at the moment.

What It Is Not

The writing protocol of “what it is not” was one of the most difficult writings to tackle. My first attempt at describing what the phenomenon *be-ing with* dying was not, focused on birth/birthing/being born. I explored the beginning of life as the opposite of the end of life – dying and death. The *process* embodied what death is not; or what the objective of death is – the cessation of life. However, it eventually struck me that dichotomy created by looking at living

and what it means to be alive (as opposed to birth and death) better captured a fuller picture of what *be-ing with* dying is not.

Excerpt from What It Is Not/Opposite Protocol:

Be-ing with living – so full of life, energy, doingness. I see that big smile and the gleam in his eyes. I smile to myself. He’s all grown up. He dashes into the house and out again. I want to keep him here to enjoy his presence, but I dare not. This is his time. He’s finding out who he is, enjoying himself with friends, being young, growing up, making his life. I can hardly believe he is 6 feet tall. My baby is all grown up. He’d roll his eyes at me if he heard me say that! He is full of life and boundless optimism. I let it go. No need to cling; other moments are in the offing. Life is before him and I can hardly wait for him to share it with me again.

Much can easily be taken for granted as *be-ing with* living was explored and examined. Without attention that is mindful, I found it commonplace to rush around, to not be in the moment casually letting precious moments slip by unnoticed. While in contrast, when one is *be-ing with* dying, every moment is treasured, noticed, appreciated; a perspective from which living could benefit. In *be-ing with* dying time elongates and moments meld into one another; in this there exists a *quality* of time (Bergson, 1910/2015) as opposed to a *quantity* of time – moments to treasure and hold close.

Essence or Essential Structure

Phenomenology is the study of essences – the unified vision that makes a phenomenon or an experience what it is (Moustakas, 1994). Therefore, when engaging in phenomenological writing concerning the essence, we want to consider the intrinsic components of that which is being studied or, in the case here, being reflected upon. However, attempts at using prose as the

genre of expression failed to adequately capture for me the essential nature (essence) of the lived-experience. It was a struggle until the creativity of an acrostic poem format provided a way to reveal the purity of the act and actions of *be-ing with* dying.

Be-ing with Dying

Being present
Ever aware
Insisting on nothing
Not resisting
Giving into all that is sentient

Willingness to be with what is
Inviting flows
Time has history, presence, and future
Holding love close without restriction

Deepening of surrender
Yes! To all
Indelible imprints upon our souls
No grasping at attachment
GratITUDE

The Lifeworld

Van Manen (1990) asserts that the lifeworld is the exploration ground for human science research. In it, we find different experiences and points of reference that separate one particular lifeworld (as a reflection of lived-experience) from another. However, there are certain existentials that are common among all lifeworlds – lived space, lived body or embodiment, lived time, and lived relationships. Additionally, as roles change (even as frequently as throughout the day) so do our lifeworlds change – at varying times we are a parent to our children, a child (even as adults) to our parents, a teacher, a student, or possibly a business owner or an employee.

Multiple Lifeworlds: As I began to write about the lifeworld of *be-ing with* dying other lifeworlds came into sharp focus as well. Often these lifeworlds would exist in juxtaposition to one another revealing themselves as fundamentally different, not simply different aspects of the same world. When curative treatment was stopped, my son's lifeworld of living began to fade. His new lifeworld was a *lifeworld in transition*. Pattison (1977) refers to this period as the living-dying interval. This meant that there were transitions of all the existentials – transitions of space, time, embodiment, and relationships. This new reality was drastically different from his lifeworld even a few days before the transfer to home hospice care. Before hospice he was looking towards the future, planning his life (even if day by day), enjoying his friends, and cultivating new relationships. However, once hospice care began there was a new crisis: a crisis of the knowledge of inevitable death (Pattison, 1977).

Excerpt from Multiple Lifeworlds:

Even for me, on a day-to-day basis, there was the lifeworld that involved the livingness of my other young adult children as we gathered together in Florida. This contrasted with the very different lifeworld of *be-ing with* my dying son, who often floated seamlessly from the land of living into the land of dying – one minute here with us, the next off somewhere else in the time and space of a lifeworld to which we were not privy.

Lived Space: During the examination of the lifeworld's spatiality several facets of space itself were revealed. These facets are always present, but without the opportunity to self-reflect, some would have gone unnoticed.

Excerpt regarding Physical Space:

My son had his space in Florida. The small, student apartment was his in every sense of the word. He had made it a real home. The lease was in his name. He paid the bills

from the funds he received from Disability Services. He maintained control of that space throughout his illness. He was ruler of his kingdom. He exerted tangible control over his environment. He called the shots. It was his place.

Excerpt regarding Personal Space:

At times there were up to ten of us in that small, cramped apartment. Each of the boys had their own room. Ahhh, the luxury! The rest of us shared – one daughter on the couch, another on the floor; others on inflatable mattresses; me on a series of lined-up beanbags – each of us carved out our own little territories.

Excerpt of Interior Space:

A pot of simmering chicken soup on the stove warmed and nourished our bodies from the inside out, as did mountains of potato tacos replete with shredded cabbage and spicy salsa atop. There's nothing better for the soul than the perceptible and visceral taste and enjoyment of comfort food whatever it might be.

Excerpt of Emotional Space:

As one might imagine, emotions tended to run high and fragile as the end of my son's time with us grew near. It was hard to watch him stoically suffer through fevers that went off the chart. We stood by helpless, our hearts breaking in two. Our petty foibles irritated each another as we each dealt, in our own way, with impending loss. Emotional silence was broken and yet silence reigned. We all suffered and hoped he didn't notice.

Not a chance!

Lived Body: Phenomenology provided the vocabulary and the framework in which to place the experience of, what up till then, I had described as communal naptime. In a manner similar to the action of the mother of a newborn baby who sleeps when her baby sleeps, as a

family we all slept when my son slept so that we would all be ready for whatever activity, desire, or road bump might be in store upon waking.

Excerpt from Lived Body:

Tiredness washed over us producing a heavy, almost drug-like induced state. It seemed to emanate from my son; oozing from him as he was overwhelmed by his own body (the cancer spreading) and his own mental fatigue. The mental fatigue brought about by a combination of the medications he was taking, his fears and anxiety of the unknown-ness of death, as well as the extreme sadness and frustration of having to face his mortality at such an early stage in life. My heart was breaking. I gave into the heaviness and let the lids of my eyes shut out the world. I knew this was happening to others. This overwhelming consumed all present. We were re-enacting on a daily basis the slumber scene from *Sleeping Beauty*. We were the visceral manifestation of his mental and spiritual worlds.

Lived Time: I was traveling across the country every three weeks to be with my son when he checked into the hospital for another round of chemotherapy. I'd stay a week or ten days, then fly home. A short three days after returning home he called. He said, "Mom I need you."

Excerpt from Lived Time:

That was all it took. I didn't miss a beat! Time was marching on and it wasn't going to march on without me. My boy needed me. He had asked. I couldn't get time to move fast enough. There was so much to do. I wanted to be on that plane right that same day, but that was a bit unrealistic. Get me out of here my body was screaming. Despite my impatience time flew as I completed cycle after cycle in preparation to be with my

son. I even slept fast! It seemed the faster I worked the more I got done, but there was always more to do. Now I was putting my life on hold; his couldn't be. Time didn't slow till three days later when I stepped off the plane. For the first time I welcomed the heat and humidity of summer in Florida. The weather itself beckons all to slow down and take one's time. That's just what we needed - more time together; more time to cherish.

Lived Other: Differences between our family and others rose occasionally to the surface. They boasted of conflict and disagreement and always needed kid-glove handling and management. This was one of the most difficult areas with which I had to deal with while *be-ing with* my son.

Excerpt from Lived Other:

The room spun. I was standing in the middle of it, near the foot of the bed. My son had died a short time ago and yet I knew he (the spiritual being) was in the room with me. Tears were streaming down my face. I shook. I knew what needed to happen. I needed to hold it together, to be gentle, and to not scare him away. I sensed that he was upset (he never did like disagreement), but there had just been one. I was certain that I had to hold my position so as not cave to the demands of others. This was my family, my boy, and what I knew were my last minutes together with him. I'm feeling crazy, but I don't care ... I turned to where I sense him to be and make verbal promise to him that I would make this right. He just needed to give me a moment ... please.

I think to myself. Everyone knew; I had told everyone myself. I knew I had said that caring for our newly dead was a family thing. It was private, special, a time for delicate intimacy, a time for closure, a time to say "Good-bye." It was part of the ritual

that had gone on for decades, maybe hundreds of years in my family – a connection of past and present. I was going to honor it, to honor him. I simply needed a moment to rein in the chaos and explain it all over again.

Application

The phenomenological writing protocols have been a driving force in shaping my current approach towards the dissertation. The self-exploration in which I engaged set the stage for the next steps in the research process – the formulating of a research question and research design. I am decidedly more interested in rich description than narrative storytelling; although I remain open to anything the participants want to share. The writing protocols form the basis of the interview questions. I am acutely aware of the potential emotional burden I may be asking of the participants (emerging adults with a terminal cancer diagnosis) and have therefore tailored the questions and prompts in such a way as to be thought provoking, but gentle. My own engagement with the protocols have provided me with a frame of reference from which to approach the participants much in the same way I was able to *be with* my son. Reflecting on *be-ing with* dying and knowing what it entails, what is its essence, places me in a unique and qualified position to ask these gentle, probing questions. In this sense, there is concrete value to the use of phenomenological writing protocols prior to engaging in sensitive qualitative research.

Conclusion

Phenomenological writing brings to the forefront our personal knowledge; knowledge derived from our own lived-experiences; and knowledge that can serve as data. It involves the effort to articulate of the details of our everyday life (van Manen, 1984). Bentz and Shapiro (1998) point out that taking a phenomenological approach is desirable when one wants to learn and understand a given phenomenon. Engaging in self-reflection through the various writing

protocols as set forth by van Manen (1990) is a meaningful first step to in-depth exploration of *be-ing with* dying and other research that surrounds the experience of death. The exercise of self-reflection on *be-ing with* dying has flushed out and raised awareness of biases, perspectives, and lived-experiences that I bring to this particular research area. The process has delineated precisely where I am in relation to the phenomenon of *be-ing with* dying. This has paved the way so that now I may more readily see and understand where others are without imposing on them my subjective experience.

Phenomenological protocol writing is a solo exercise. If, as researchers, we write *our* lived-experience, we are better prepared to know what it is that we are asking of our participants. Together, with those who join us, we can create an understanding of the human experience – of its depths, its reaches, and its boundaries. Starting with each of us individually, our experiences become a co-created social construct that can lead us to an existential view of increased knowledge and understandings of our world.

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