

Living While Palliative: The Experience of Ontological Insecurity

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Abstract

The purpose of this article is to examine the concept of ontological insecurity. Ontological insecurity involves anxiety and insecurity, feeling destabilized and disoriented in regard to the relationship with self, and that one is no longer effective in the world. The term ontological insecurity was coined by R.D. Laing to represent those with schizophrenia. Others have used this term to describe the experiences of those with mental illness, breast cancer and dementia. Within this piece, I first describe what this concept entails, then offer a short literature review of the contexts within which ontological security has been examined, and then describe how ontological insecurity has impacted my life with Stage 4 breast cancer. Ontological insecurity is a normal response to extreme life experiences, such as being a palliative patient with cancer. Other concepts, such as temporality, bifurcation of consciousness, and the balance of doing and being, can help those with ontological insecurity to understand what they are experiencing, as well as help those who are assisting these individuals. The term ontological insecurity is very helpful to understand what palliative patients are undergoing.

Keywords: Ontological insecurity; Palliative; Cancer; Risk management; Bifurcation of consciousness; Temporality, Being and doing

Introduction

Living with a palliative diagnosis feels precarious. While the length of palliation can be considerable, the threat of death always looms. One scan revealing nefarious results can throw a person into turmoil. Within this short article, I consider what ontological insecurity means, how it is examined within the research, and how living with this insecurity challenges the resilience of palliative patients. I offer my example of living with Stage 4 breast cancer which initially had only spread to the bones, but now is present in my liver. My purpose in writing about my Stage 4 cancer is to inform others about this difficult trek, but also, to try to existentially make sense of what has happened, is happening, and will happen to me.

Literature Review

What does ontological insecurity mean, particularly within the context of palliative care? The term ontological insecurity is an existential one and was first coined by R.D. Laing. In working with individuals with mental illness, Laing felt that those who were diagnosed with schizophrenia were experiencing ontological insecurity. This involved a sense of not being alive or real and distinct from others [1]. While the concept of ontological insecurity was meant to describe psychosis or madness, its application is broader than what may have been initially intended [2,3].

Newer work commenting on ontological insecurity suggests that this concept involves insecurity; fear that others will squash their existence, feeling that the past self is no longer effective in the world, and experiencing disorientation or the perception of being destabilized in our everyday sense of self [3-5]. According to Bondi, we all experience ontological insecurity at times [6].

Because of its origin, literature often examines ontological insecurity within the confines of mental illness [3,7,8]. However, other work examines this type of insecurity within other illnesses, such as breast cancer, and dementia, as well as managing co-morbidities [4,9-11].

Broadly speaking, a number of studies examine ontological insecurity within the context of risk management. For example, some studies examine risk management in communicable illnesses such as COVID, HIV and influenza [12-14]. Another growing body of research addresses ontological insecurity when living within precarious

situations. How individuals attempt to manage or lower ontological insecurity is examined for individuals living as refugees. Refugees having experienced trauma in their pasts, now having to wait with uncertainty and stress, can experience aggravated mental health and somatic issues [15]. Hertzog et al. examined feelings of security within poor neighbourhoods in Brussels; ontological insecurity was gendered with women feeling less safe than their male counterparts [16]. Others have examined similar risk factors, but also examined HIV status for individuals living within South Africa (where the incidence of HIV positive status is high) [17]. The ability to manage racism is also categorized as risk management; this includes minimizing, accepting, or reinterpreting racist behavior, is described by Aboriginal individuals within Australia [17].

Risk management of ontological insecurity considered is within the context of war or large-scale disasters, such as Chernobyl [18,19]. Interestingly, war and disasters are not just considered through the lens of physical harm, but also, how they impact countries' views of themselves, as evidenced by social discourse.

Ontological insecurity is also addressed within the context of religious beliefs. For example, one study looked at ontological insecurity related to losing the Mormon faith; others addressed engaging in pilgrimage tourism within secular societies or religious nationalism to reduce ontological insecurity [20-22].

Discussion

The concept of ontological insecurity often entails individuals experiencing both the inside and outside world as threatening and indecipherable [2]. The outside world may be difficult to navigate due to the challenges in managing the internal world, such as sense of identity, autonomy and having confidence in being able to control oneself and respond to the external world [2]. For those with incurable cancer, the "inner" world is unsafe, and at times, gravely alarming. Health discourse

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promulgates the idea that if we engage in specific habits, we will be rewarded with good health and a body which accurately represents who we are and what we do. The incongruence with current health care discourse for those like me, who exercised obsessively and engaged in other health promoting behaviours, is stark. What did us, or specifically I, do wrong? When cancer cells run amok within our bodies, how can we “read” our symptoms and trust our bodies to take care of us?

It is also not easy to navigate the outside world in relation to our inside world. While we realize that our inner and outer worlds are not always congruent, we try to have some harmony and balance between the two. But for a person who is experiencing incurable cancer, it is not exactly socially acceptable to say what is actually going on. Friends or peers may ask, “How are you doing?” This question is sincere and well-intentioned. The truthful answer would be something like this: “Well, I have terrible fatigue, my brain is slower than it used to be (as an academic, this is embarrassing), my body hurts and I’ve lost my future...but other than this, I am quite good!” For most people, hearing an answer like this would be cruel. How can an unsuspecting soul respond to that? It means that I temper my responses to shield others; it isn’t their fault that this has happened to me. It leaves me though, with a deep sense of loneliness inside. Despite being a patient, I feel I must protect those who are healthy from my experiences, or at very least, the distress caused by my illness experiences.

Further, those with a palliative diagnosis need to navigate the health care world. This is really a challenge, even though I am a nurse. While health care professionals have been very good, my issue is the volume of activities to coordinate. This involves keeping track of multiple appointments with multiple health care professionals and multiple treatments (medications and other treatments such as chemotherapy and radiation). Keeping important details straight is a challenge, particularly when still working full-time, but even now when I am working part-time. More than once I have made mistakes, such as missing an appointment for “marking” (tattooing for radiation), or assuming an appointment with an oncologist was *via* phone, when actually, my husband and I should have attended in person. Fortunately, health care professionals have understood, but because of an overall sense of loss of control, I panicked.

I suggest that part of navigating two worlds, an inside and outside world, includes managing a couple of identities; this can be represented by an interesting term coined by sociologist Dorothy E. Smith-bifurcation of consciousness. Smith proposed this concept to refer to the disparate worlds of her life as a sociologist/academic at a university and being a single mother to children at home. The worlds were starkly incongruent. The world she taught about in academia included many sociological abstractions, but these did not at all connect with her realities in raising her children at home. She had to hold these diverse ways of thinking and being within her consciousness [23]. My world as an academic seems worlds apart from my life as a palliative patient. Within academia my work requires intelligence, knowledge, and swiftness of converting thought into words. Within health care, my success as a palliative patient depends upon attending appointments at multiple sites, taking multiple meds, coping with side effects and so on. Hence, I have competing demands between my work and addressing the cancer; sometimes, this results in frustrations in both realms. When I cannot perform up to my standards as an academic, I feel demoralized. As a palliative cancer patient, I become concerned when I cannot attend to work expectations due to multiple appointments and extended travel time to the appointments; these may not be my employer’s expectations, but mine. (Clearly, at times I need to manage the intersection between

responsibilities related to health and those determined by work).

Temporality, or the experience of time, also changes. The past no longer feels connected to the circumstances of the present, the present may feel vacant and meaningless, and the future is lost [10]. When temporality is altered for those with incurable cancer, relating to others who have continuity of the past and present, as well as have future plans, may seem awkward. Hearing others describe their plans such as travel, education, other possibilities for work, reinforces that I don’t have a future; at least, even if I have some years left, a short and finite period of time has been prognosticated. My future is truncated and under the control of the cancer cells; while the chemo seems to be working right now, there will come a time when it no longer is effective. As such, my future goals entail trying to stay alive, to honor God and people, and to live as meaningfully as possible.

In palliative care, the concepts of being and doing are described. Doing involves the acts that we regularly engage in within our daily lives. Being, however, involves who we are. When palliative “who I am” is emphasized rather than what I can do. Truly, it is a beautiful concept and one that should be practiced more in daily living, even when individuals are not significantly ill. It is a challenge though when the palliative care delineation may last years; it’s also difficult when my identity has been experienced and reflected in what I do rather than who I am. I have loved to work as a nurse academic. I loved to run half-marathons with my identical twin sister. These activities have imparted meaning, fun, and provided events to prepare for and greatly anticipate. They also have imbued me with a sense of identity. This was terribly discouraging for me when diagnosed with Stage 4 breast cancer almost 5 years ago. How I conceptualized who I was could no longer be expressed in my activities. Hence, my being could not be expressed through my doing, at least not to my expectations. However, with the metastasis to my liver, I am more tired; who I am is becoming more important than what I do. I am grateful for this, and interestingly, feel less ontologically insecure

Conclusion

Those who live with incurable cancer may experience ontological insecurity. My understanding of ontological insecurity is that it should not be considered pathological, but rather, related to the struggles and sufferings of life. Having those who will listen attentively to those struggling with ontological insecurity, including dealing with incurable illness within a “well” world, navigating how perceptions of the present and future have changed, and understanding the challenges of being and doing, is a gift sorely needed by palliative patients.

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