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## Invited Editorial

# The Haunting of Long-Term Care: Understanding Healthcare Aides' Experiences with Death and Dying During the COVID-19 Pandemic

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As an institution meant to care for older adults nearing the end of life, the long-term care home is, unavoidably, a place of death and dying. Yet death and dying are often kept in the shadows of long-term care, tucked into dark corners where the experiences of those who receive and deliver care remain largely unacknowledged, unexamined, and unquestioned. When the COVID-19 virus entered these homes, it did so like a kind of ghost, claiming the lives of older adults in ways that were unfamiliar, sudden, and deeply frightening. Healthcare aides were the first to encounter these ghosts and the strange, yet familiar, forms of death and dying they brought with them. In my encounters with healthcare aides, there was something unsettling in the way they spoke about death and dying – in the looks on their faces, the way the room seemed to cloud over and darken, and the way I found myself gripping my pen and leaning in. In undertaking philosophical hermeneutic research, I often thought about how I would interpret what healthcare aides told me about death and dying, and about the unexpected insights I might come to understand. What I did not anticipate, however, was how their accounts would make me look over my shoulder, question my surroundings, and even their testimony itself. It seemed there was a hiddenness of my topic: healthcare aides are a hidden workforce; death and dying is hidden in long-term, during both pandemic and non-pandemic times; residents were hidden from the outside world during times of visitor restrictions; and residents were hidden from others within the long-term care home when dying. In the years since the pandemic, this hiddenness persists. I have been invited to present my doctoral research in a serialization in the *Journal of Applied Hermeneutics*. In this editorial, I share how I came to present my philosophical hermeneutic research as a kind of story, a frightening one, and healthcare aides' experiences as a haunting of long-term care.

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## The Presence of Suspicion

New to research, with each healthcare aide, I sat down to the interview eager, excited, and a little nervous. I placed the audio recorder on the table, pressed record, and anticipated a conversation that would offer clarity and familiarity. What happened during those interviews, however, was not what I expected.

It felt as though there were a third party present at each interview – a silent figure who pulled out a chair and leaned back, the chair creaking under their invisible weight. Although silent, the presence of suspicion was undeniable. The atmosphere darkened, the air clouded into a haze of smoke, and at times I squinted to make out the healthcare aides' faces across the table. With suspicion sitting beside me, the interviews unfolded in moments of tension and contradiction.

The topic of each interview was death and dying, yet healthcare aides rarely acknowledged long-term care as a place of death and dying. Instead, they spoke of it as only a place for living, even as they recounted the many residents who had died there. They described loving residents like family members while also telling me how residents were left alone in their rooms, crying out for help, and without food or drink. They told me how family members were kept from knowing a resident was dying, even in their final moments. They told me that death from COVID-19 was different from *normal death*, and that this difference explained why residents died alone, without palliative care, or even humane care. They described inadequate resources, chronic understaffing, and at times negligence and, just when I expected them to name the institution as responsible, suspicion shifted in its chair, and the room fell quiet.

When the interview ended and I turned off the audio recorder, suspicion often disappeared. The clouds cleared, the room brightened, and healthcare aides wanted to share something different, something other than what had been said during the formal interview: *something more truthful*. At the end of each interview, I thanked the healthcare aide for their time. If suspicion was still present, it left with me. If it was not, it reappeared in my car, lingering as I tried to make sense of what I had been told.

Holding a precarious position in long-term care, healthcare aides are not in a position of power and may find themselves powerless when it comes to the needs and bottom lines of the institutions in which they work, and unable to question institutional practices and policies. It seemed that, to make sense of healthcare aides' experiences, I had to also make sense of how I distrusted their immediate meaning as being influenced by the institutional context in which they worked. I came to understand this as a kind of institutionally mediated testimony.

It seemed I needed to approach their interviews with both openness and suspicion – trust and distrust. For this, I turned to Gadamer and Ricoeur, exploring Gadamer's understanding of trust and belongingness alongside Ricoeur's distrust and distanciation – fusion and fission. It was through both Gadamer and Ricoeur that I came to understand the role of suspicion in my research, and how it complemented and strengthened my application of Gadamer's philosophical hermeneutics. As such, suspicion became the thread through which my interpretations were drawn together, shaping my understanding of healthcare aides' testimony as institutionally

mediated. Ultimately, suspicion *is* an interpretation of my research topic and is what allowed me to be critical of the long-term care home. I did this through a metaphor of a haunted house.

Confronted by both openness and suspicion, long-term care began to take shape for me as a kind of house, one that was both familiar and unfamiliar, home and hostile. It was a place I thought I knew, yet one that made me hesitate, gripping the railings as I moved through its corridors. At times, I felt uneasy inside it, unsure of what I saw or heard. It was healthcare aides who pointed me towards its doors, drawing my attention to what lay hidden inside, and it was suspicion that opened the doors and invited me inside.

### Entering the House: The Use of Metaphor

The imagery of a haunted house in gothic literature is a familiar one. A traditional way of storytelling, the ghost story often serves as a symbol or metaphor in literature for the wider historical, social, and cultural happenings of the day, or a persons' internal struggle, their experiences or fears better understood in the physical manifestation of ghosts haunting old houses. Well known examples of this kind of metaphor in literature are Emily Brontë's (1847/2003) *Wuthering Heights*, the ruggedness and enduring nature of the haunted manor symbolic of its inheritor Heathcliff's impenetrable nature, and Edgar Allan Poe's (1839/2006) *The Fall of the House of Usher*, the decrepit mansion symbolic of the decay of its inhabitants' morality. As often happens with the trope of the haunted house in literature, what haunts the house does not make itself known on first sighting, in the daylight. It is only by walking the halls, opening secret passageways, and listening in the quiet of the night that such things reveal themselves. After all, what is frightening about a haunted house is that which is hidden, withheld, or willfully ignored – the invisible element that goes bump in the night, causes a prickle of cold air on the back of the neck, makes tree branches tap against a window on a still night, or produces dark shadows that only disappear when held up to candlelight.

If a word is applied to a sphere to which it did not originally belong, the actual "original" meaning emerges quite clearly. Language has performed in advance the abstraction that is, as such, the task of conceptual analysis. Now thinking need only make use of this advance achievement. (Gadamer, 1960/2004, p. 103)

The use of the metaphor is common in interpretive writing: "Well-placed metaphors draw the reader in and an original metaphor suddenly throws open an unexpected insight" (Moules et al., 2015, p. 133). In the writing of my thesis, I was confronted by such a metaphor: the haunted house. It came to guide the entire work, suddenly throwing its doors open to me and then slamming shut behind me, leaving me convinced that the topic of my research lay within its walls. Once inside, I grappled with tensions that emerged through the research: between what healthcare aides told me during their interviews and what they said when the audio recorder was turned off, between what was spoken and what lay hidden in their transcripts, and between what healthcare aides told me and what I knew from my own experience of working in long-term care.

Metaphor helps us make sense of what is uncanny – what is at once familiar and unfamiliar. Like the uncanny, a good metaphor unsettles us in how it draws us toward something we recognize but take pause in the strangeness of its unfamiliarity. In this way, metaphor can bring to attention

what has been overlooked, traditioned, or marginalized. Freud (1919/2003) described the haunted house, or the “uncanny house” (p. 148) as the most potent example of this tension between familiarity and strangeness. For Freud, the uncanny “belongs to the realm of the frightening, of what evokes fear and dread” (p. 123), not because it is wholly unknown, but because it is already known, repressed, and has now returned to haunt us.

By understanding long-term care as a kind of haunted house, I was able to bring attention to the uncanniness of death and dying within it. Death and dying appeared as familiar and unfamiliar ghosts: familiar in long-term care’s long and well-established history as a place of death, and unfamiliar in the lethal strangeness of the COVID-19 pandemic. Ultimately, the metaphor of the haunted house grounded the interpretive chapters of this thesis, offering a way to better understand death and dying in long-term care and to see differently the position from which healthcare aides were required to make sense of their experiences during the pandemic.

### **The Power of Gothic Storytelling**

The Gothic is a distorting lens, a magnifying lens; but the shapes which we see through it have nonetheless a reality which cannot be apprehended in any other way. (*The Literature of Terror: A History of Gothic Novels*, Punter, 1996, p. 98)

For each healthcare aide I interviewed for this thesis, I began the conversation with the same question: Could you tell me your COVID-19 story in long-term care? I had thought this question was a good way to break the ice with participants and allow them the freedom to share what first came to mind about their experiences. What I had underestimated about my phrasing of the question, however, was how healthcare aides would really tell me a *story*, at times a *scary story*, often reliving the death of a particular resident in ways that were haunting. On the importance of prose and poetry in nursing, McCaffrey (2020) wrote:

Human beings compulsively tell each other stories of how this was and how that went and why things turned out that way; we meet each other in stories, we bind our communities, sometimes heal, sometimes wield them as a weapon against outsiders – but all that is to show that they are potent and we are caught up with stories as we are caught up with language. (p. e115)

Storytelling seemed to be a way for healthcare aides to make sense of the things that were difficult to make sense of – things that were slippery, or did not easily give themselves up. Although the intent of my inquiry was not to explore storytelling, what healthcare aides told me was a kind of storytelling, and I felt pulled to piece the interviews together as a story: “Narrative is such a basic mode of human communication that it takes on a profusion of forms and functions” (McCaffrey, 2020, p. e116). As each healthcare aide recalled the horrifying events of the pandemic, their facial expressions sometimes revealing pain, fear, and even guilt, I could not help but think of the discernable mood of gothic storytelling, and how it also has a kind of “affinity with gloom and anxiety, terror and horror” in ways that disclose to us something about death (Afrougheh et al., 2013, pp. 1389-1390). Not unlike the way Freud (1919/2003) considered haunted houses and gothic literature as a means of helping us make sense of the uncanny, my

reading of healthcare aides' interview transcripts gave me a sense of estrangement from the text at times:

By creating disturbing images, insane characters, and unsettling environments, writers of the Gothic genre impress upon the darkest parts of our being. Gothic literature startles us from the utopian dream that "life is fine the way it is." The effects of Gothic literature, ingrained in our curiosity to understand deep primal fears, allow readers to face the uncomfortable boundary of the unconscious where the unseen is suddenly revealed. (Deal, 2020, p. 75)

As a lover of Gothic literature, I find myself drawn to the tropes of the genre, the familiar literary techniques and dark imagery calling me into a world I can anticipate. Having experienced a strange unfamiliarity in what also seemed familiar about death and dying in my research, I was reminded of stories about haunted houses, and as such, I knew I had found a meaningful avenue for better understanding healthcare aides' experiences.

At the heart of story about a haunted house is a very real anxiety about a fear of death and dying. Perhaps the reason gothic literature of the haunted variety resonates so profoundly is because it continues to pose death as a question to humanity for which there is no answer: "it seems to be the unrelenting striving of humanity to keep this question alive" (Gadamer, 2016, p. 60), and "not conceal from themselves the unintelligibility of death" (p. 70). In the telling of a ghost story about a haunted house, the tradition of hiding death and dying is always operative, posing itself as a question to the reader.

Gothic literature also poses questions of historical significance that relate to issues of power and struggle, or as Mighall (1999) wrote, "That which is gothicized depends on history and the stories it needs to tell itself" (p. 25). The telling of ghost stories, haunted houses, treacherous monsters, and things that go bump in the night, the gothic novel often reveals the social, cultural, political, and economic anxieties of the day, helping its readers to understand differently that which has been repressed, or those that have been marginalized or misunderstood (Brown, 2005). Throughout my research I was suspicious of healthcare aides' testimony, for how it was shaped and influenced by the institution of long-term care and their marginalization within broader society. To consider the long-term care home to be a kind of haunted house is to suggest it is still wrestling with its own history, and in ways that still need to be addressed or understood.

Ultimately, hermeneutic writing that draws on the mood of Gothic literature echoes Gadamer's (1984) understanding of rhetoric, for how we seek to persuade through conversation, or persuasively pull readers in through writing or storytelling. It is my hope that interpreting healthcare aides' stories through the lens of gothic storytelling works persuasively on the reader, opening possibilities for different understandings and, in turn, the potential for change.

### **Interpretations: Encountering Ghosts**

In the coming months, the interpretive chapters of my doctoral thesis will be published in the *Journal of Applied Hermeneutics* as a serialization that, when read consecutively, tells a kind of gothic story through the metaphor of the haunted house. To tell this story, I draw on my own

experiences during the research process alongside passages from some of my favourite gothic novels, most notably *The Haunting of Hill House* (1959/2016) and *The Turn of the Screw* (1898/2021), to accompany the powerful testimony of healthcare aides. Across the chapters of this story and academic papers of this thesis, I position healthcare aides within a narrative arc, interpreting their experiences as unfolding through distinct stages of a story.

In the first paper, *A Suspicion of Healthcare Aides' Experiences with Death and Dying as a Kind of Institutionally Mediated Testimony*, the story begins with suspicion. Here, I first come to regard long-term care as a kind of haunted house and healthcare aides' accounts as institutionally mediated testimony. Death and dying appear as both familiar and unfamiliar ghosts, long present in long-term care, yet newly unsettling during the pandemic. The events of COVID-19 brought a suspicious kind of death while also awakening ghosts that had long slumbered within the institution's walls.

In the second paper, “*All Families Banned from the Building*”: *Making Sense of Death and Dying in an Isolated House*, tension builds as I explore the idea of isolation, and how not only is the long-term care home isolated from society – a haunted house on a lonely hill, far from the hustle and bustle of everyday life – but those who live and work inside its walls also experience isolation, which was keenly felt during the COVID-19 pandemic. No longer a place of hospitality, but a place of hostility, healthcare aides had to occupy the uneasy position of both host and stranger. In their isolation, death and dying was both an unknowable Other and familiar stranger, entering the home like an infestation of ghosts, familiar old death having greeted them with doors wide open.

In the third paper, *COVID “Wanted to Snatch Life Out”*: *How Healthcare Aides Feared an Unfamiliar Ghost and Understood Residents’ Fear of Death and Dying in the Context of Palliative Care*, the story reaches a kind of reckoning, with healthcare aides now fully subsumed under the haunting of long-term care, their fear taking hold. Where death may have long been a familiar ghost in long-term care, quietly roaming the halls or lurking in the shadows, the ghosts now seemed to come in hordes. Coming face to face with these ghosts, healthcare aides had to navigate their own fear alongside the guilt of witnessing residents left to face death alone.

In the fourth and final paper, “*It Is Hide-and-Seek*”: *Falling Back into the Status Quo and the Inauthentic*, the story descends without resolution. In the years since the pandemic, long-term care appears to have returned to the status quo, with few meaningful changes made to improve death and dying. I return here to the structural integrity of the institution, the haunted house itself, and to how healthcare aides locate their experiences within enduring institutional failures that prevent them from providing quality care to dying residents. Still remaining in the house, healthcare aides are understood as playing a game of hide-and-seek, where the structural problems laid bare during the pandemic have once again been hidden in the dark corners of the house.

### A Note on Rigour

The power of hermeneutic research lies not in producing generalizable explanations of human reality, but in attending to the beautiful particular—the concreteness of experience that speaks to

understanding rather than explanation (Moules et al., 2015). Hermeneutic rigour, then, is found not in certainty, but in the careful treatment of a topic such that the work engenders trustworthiness and believability (Moules et al., 2015). As the researcher, I am therefore asking the reader of this work to *trust* what I have interpreted as being something true of the topic, namely, to have “reliance on the veracity, integrity, or other virtues or sound principles of . . . something” (Online Etymology Dictionary, n.d.). Across the papers presented in this serialization, I offer the reader my own experiences, substantial engagement with hermeneutic philosophy, and careful consideration of the institutional spaces, socioeconomic factors, and policies that shaped healthcare aides’ experiences, and most importantly, healthcare aides’ haunting testimony. Together, these elements are intended to strengthen the reader’s trust in my research.

Interpreting healthcare aides’ experiences through the metaphor of a haunted house, and the COVID-19 pandemic as a haunting of long-term care, is admittedly a bold and creative exaggeration. Yet exaggeration in interpretive writing is purposeful, intended to disrupt and render the familiar newly visible (Moules et al., 2015). What sustained trustworthiness in this work was ongoing reflexivity and prolonged engagement with the data, particularly through my work with my supervisor, Dr. Lorraine Venturato, whose expertise in long-term care consistently affirmed something true in how the metaphor illuminated healthcare aides’ experiences. I am deeply grateful to my entire supervisory committee, Dr. Venturato, Dr. Moules, and Dr. McCaffrey, for their support and guidance, and for encouraging me to be creative and follow the research into the house I felt compelled to enter.

### To Knock on the Door

*One need not be a Chamber — to be Haunted —*

*One need not be a House —*

*The Brain has Corridors — surpassing*

*Material Place.* (Dickinson, 1862, lines 1–4)

Interpretation is never concluded; it is never a closed book, placed face down on a nightstand without a bookmark. No, interpretation is a book that, although placed down, still has the spine cracked wide open, the pages bowing to support the still visible cover that beckons for it to be picked up once again. Although I have concluded the writing of my thesis, and it has found its home in the *Journal of Applied Hermeneutics*, what Caputo (2018) wrote about the never-ending art of interpretation in hermeneutic work also enlivens for how the conversation of the topic remains open to me, and to us all:

Interpretations live on in the plural and the lower case, always exposed to the dangerous ‘perhaps’. We pass our lives mingling with the mystery, discerning what is being asked of us, struggling to name the shifting shapes of the clouds. (Caputo, 2018, p. 322)

Ultimately, it is my hope that the reader of this serialization bears a kind of witness to healthcare aides’ experiences with death and dying during the COVID-19 pandemic. By better *seeing* healthcare aides through this research, and within the haunted house, I hope the reader thinks

differently about death and dying in long-term care and are ultimately persuaded to knock on the door, and venture inside.

Not unlike reading a gothic story about a haunted house, the reader of this research should be cautioned that the bridge they will cross into the topic is one that groans, creaks, and possibly shifts beneath their feet. It is a travelling that makes the reader take hold of the railing at times, but as Moules (2022) would encourage, they must be “prepared to meet the unexpected and, more importantly, to respond to it” (p. 380). For the healthcare aides who comes across this research, it is my hope they feel their voices have been heard, and that those in positions of power, who may better understand their experiences, have been called upon. Ultimately, it is my hope that the applications of this thesis to research, practice, or policy are propelled by a haunting that surpasses the material place of this work.

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