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## The Hidden Nature of Death and Grief

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### Abstract

Western culture can be described as death-denying and youth-obsessed. Yet this has not always been the case. Only a few generations ago, death was very much part of life where people died at home with their families members caring for them. A shift occurred, in part, because of the unprecedented advances in medical science that the western world has seen over the past 40 years. Health care professionals now have the knowledge and the technology to prolong life in ways that were previously not only unattainable, but inconceivable. Regardless, the reality that death will eventually come for each of us has not changed; merely our perception of it has. This perception is influenced by the hidden nature of death in our society. This begs the questions: if death in our culture is something to hide, to conceal, and to keep secret, then what does that say about our ability to express grief? What does this mean for those who face it as part of their chosen profession? How might we understand the nature of suffering for those who turn toward the suffering of others? This paper interpretively examines the nature of hidden death and hidden grief in our society.

### Keywords

death, grief, hermeneutics, hidden, pediatric palliative care nursing

*Death is the ugly fact which Nature has to  
hide, and she hides it well.*  
Alexander Smith

Through my\* years of practice as an acute care nurse at a large pediatric hospital, I have often been in the presence of dying children and grieving families. I have learned how to care for these children and

how to talk about death with their family members. I have also learned about the culture of hiding death and grief from not only other patients and families in the hospital, but also from my colleagues, friends, and family members. The expectation that nurses

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and other health care providers are somehow immune to loss and grief intrigues me and has inspired me to examine death and grief beyond the confines of the hospital and to explore the topic within the larger context of society.

Western culture can be described as death-denying and youth-obsessed. As a result, people go to great lengths to disguise even the signs of natural aging. One quick look at popular magazines and television advertisements will support the truth in that statement. The natural process of aging is hidden and so, too, is the dying process and death itself. Ever more, the elderly are hidden in nursing homes; the dying are hidden in hospitals and hospices. In fact, Daniel Callahan, a philosopher who has written extensively on topics related to ethics and health policy wrote that “The present period might best be characterized as a revolt against death itself” (Callahan, 2009, p. 106).

Only a few generations ago, death was very much part of life. For instance, in Canada in 1926, one in five children would not survive to their first birthday (Statistics Canada, 2008). As a result, just about everyone would have lost a child close to them: son, daughter, niece, nephew, or grandchild. By comparison, today in Canada fewer than one in 100 children die before reaching the age of one (Statistics Canada, 2008). Therefore, today fewer of us are directly affected by the death of a child. Death was closer; death was familiar. Family members cared for their dying loved ones at home. Death was not a

private loss but was taken as a blow to all those who survived, both family and strangers. Death required public affirmation of human solidarity against a harsh and indifferent nature. It was not to be hidden: families should be there when

death was at hand, and the door thrown open to neighbors and even those passing by in the street. (Callahan, 2009, p. 104)

Death is no longer perceived to be so close. People do not seem to live with the “ancient belief that [death] is inevitable, an immutable and unchangeable fact and human fate” (Callahan, 2009, p. 104). A shift occurred, in part, because of the unprecedented advances in medical science that the western world has seen over the past 40 years. Health care professionals have the knowledge and the technology to prolong life in ways that were previously not only unattainable, but inconceivable. The reality that death will eventually come for each of us has not changed; merely our perception of it has. Advancements in medical science and technology have given us a false sense of being able to defy death, to avoid it, and perhaps even to postpone it indefinitely. William Haseltine, CEO of Human Genome Sciences, once said that “death is nothing but a series of preventable diseases” (Callahan, 2009, p. 107, citing Fisher, 1999) which is absurd, but this statement does highlight our cultural desire to conquer all diseases. It also draws attention to our cultural expectations around death and dying—the expectation that the ultimate goal is to keep people alive at all costs. Increasingly, we see examples where “our technology has surpassed our humanity” (Ferrell, 2006, p. 927). We see instances where patients are kept alive through the use of machines and medication which surely prolong suffering and certainly do not prevent the patient’s inevitable death.

### **The Hidden Nature of Death**

The word “hidden” means “being out of sight, not readily apparent, concealed” (Merriam-Webster, 2012). As the word “hidden” is closely related to “conceal” it is also relat-

ed to the idea of *aletheia*, which is the Greek word meaning truth-as-unconcealment (Online Etymology Dictionary, 2012). *Aletheia*, whose etymological roots are connected to the word *Lethe*, which literally means “forgetfulness, oblivion” (Online Etymology Dictionary, 2012) is also, according to Greek mythology, a river in Hades. Western society has become accustomed to the concealment of death from our lack of knowledge of what goes on behind the scenes of a funeral home, to our euphemistic language when talking about death, to keeping our grief out of sight.

Some may argue that death is not hidden in western culture as our fascination with death is obvious in popular media: from movies and television to crime novels and even in news reports. Stories of death attract interest and attention, yet when it comes to the death of someone close to us, when it comes to experiencing a “real” death, this fascination is often replaced with not only grief, but also disbelief and a desire to hide from experiencing emotional pain. Western society increasingly caters to this desire to hide and to avoid facing the reality of death and grief. For instance, this is demonstrated in the decreased popularity of open-casket funerals in favour of “soothing ceremonies of remembrance” (Callahan, 2009, p. 103). I have attended many funerals, particularly of children who I came to know through my work as a nurse. Frequently, the memorial services for children from traditionally western families have been focused on a “celebration of life” with photos and toys, but no caskets or urns to be seen. Often at these services, those in attendance are somewhat restrained in their outward expression of grief. I have also attended open-casket funerals of children from other cultures where handling of the body was common as was the public display of grief. For instance, I attended one funeral where the

mother literally screamed in emotional agony through the entire service and at one point actually got into the casket of her dead child. The image of that haunts me even today. I now wonder if that event was particularly troubling because of our society’s desire to hide death and grief. Am I merely uncomfortable with being denied the protection and luxury of concealed death and grief?

### The Hidden Nature of Grief

If death in our culture is something to hide, to conceal, and to keep secret, then what does that say about our ability to express grief? The message is simply “in a word, dear friends, keep your grief to yourself” (Callahan, 2009, p. 105). It would seem then that hidden death is accompanied by hidden grief. The expression of grief, even by those who are identified as the *bereaved*, is not welcomed to be openly displayed for all to witness. Furthermore, grief in our society is expected to have a time limit, despite the research that would suggest that grief is never overcome, but adapted to (Attig, 1996; Moules, Simonson, Prins, Angus, & Bell, 2004; Neimeyer, 2001). It would be impossible for me to recall all the times I have heard statements such as “My dad died six months ago and I thought my mom would be doing better by now” or “If her son died three years ago, then why is she still not over it?” As a result, grieverers are forced to hide their grief - - to keep it a secret.

Despite the expectations of society to conceal grief, the expression of grief is not always hidden intentionally. Grief has a way of evading description (Moules et al., 2004) as it lacks clarity and is difficult to define just by its very nature (Cowles & Rodgers, 1991; Jacob, 1993; Rodgers & Cowles, 1991). The challenge in articulating grief is apparent through the use of metaphors (e.g.,

describing grief a journey, a neverending fall, or an uninvited houseguest) as well as silences when those suffering talk about their experience of grief (Moules et al., 2004). This is the inarticulate nature of grief (Moules, Simonson, Fleiszer, Prins, & Glasgow, 2007). It would seem then that grief itself at times seeks to be concealed.

### **The Obligation of Those Who Face Death**

Even when our culture encourages us to hide death and grief, some people refuse to do so. In fact, they turn towards it. Interestingly, “to hide” means not only “to conceal” but also “to turn away” (Merriam-Webster, 2012). There must be something special about those people who choose to go against the norm and face death, something different about those who choose to turn toward death and not hide from it.

Some people are attracted to professions that encounter death because they have a personal history of loss, while others have spiritual reasons for wanting to work with those who are approaching the end of their lives. Having met a variety of professionals who care for the dying, I do not believe there is any one reason why people do this work. Some nurses, physicians, social workers, and chaplains devote their life’s work to caring for the dying and the bereaved. Others work hard at it, but after a few years they move on to other jobs. Nevertheless, what I have experienced and observed when faced with death and dying is that there is the sense of obligation to the patient and family. “Obligation” means “something one is bound to do,” a commitment, and a responsibility to another (Merriam-Webster, 2012). Caputo wrote that obligation is a feeling that comes over us when others are in need (Caputo, 1993). Obligation happens before we enter the room and stand at the patient’s bedside (Caputo, 1993). We are suddenly

overcome by something that demands our response (Caputo, 1993). The power of the obligation is strong enough to override our desire to run from the room, to cover our eyes, to pretend that death has not come to call. Despite wanting to close the door and avoid witnessing tremendous pain and suffering, our sense of obligation will often take over and demand our presence. This is despite the fact that there may be no tasks to complete, no conversations to have, no charting to write.

Yet our sense of obligation compels us to remain at the bedside and to simply bear witness to what is transpiring. The term “bear witness” means “to testify” and “to authenticate” (Merriam-Webster, 2012). There seems to be an obligation to witness times of suffering and death. Etymologically, the word “witness” is related to the word “martyr” (Online Etymological Dictionary, 2012) meaning someone who constantly suffers (Merriam-Webster, 2012). In the current vernacular, being a martyr is not considered to be a particularly good thing; however, if we consider its use as someone who suffers with others, the term is particularly appropriate.

I would be remiss if I did not also explore the meaning of “to bear” as I have with the word “witness.” The meaning of “to bear” is particularly appropriate in the context of supporting the dying and the bereaved: “to support a weight or strain” and, with this meaning, it is a synonym for “to suffer.” It would seem that suffering is a fundamental part of bearing witness as both words are linked to the word suffer. Furthermore, the word “bearer” has the historical meaning of “one who helps carry a corpse to the grave” (Online Etymological Dictionary, 2012). Nurses usually do not literally carry a corpse to a grave. Nevertheless, I do think the work of nurses, and oth-

ers who work with the dying, carry the patient and family through the experience by way of the care and presence we provide in times of suffering and grief.

Interestingly enough, if I take the word “bear” yet one step further and examine the homophone “bare” it further enriches the meaning of bearing witness. “Bare” means “lacking appropriate covering” with synonyms such as “to uncover, to reveal, to expose, to uncloak” (Merriam-Webster, 2012). Not only is “bearing witness” the idea of authenticating suffering, but also revealing the suffering through our presence. I have been a witness to dying and grief, but found I had neither words of consolation nor gestures of comfort. I could simply bear witness - - to be present, to carry, to authenticate, and to suffer.

### **The Hidden Nature of Working with the Dying and the Dead**

When we witness pain, suffering, dying, and death, we are changed. What does this mean for those who face it as part of their chosen profession? How might we understand the nature of suffering for those who turn toward the suffering of others? Is this experience of witnessing suffering as complex as the experience of grief itself?

I have spent my nursing career working with the pediatric palliative care population. While I had once aspired to be one of those nurses who spend their careers caring for dying children, I came to realize that this was not to be my journey. I am not one of those nurses. I am no longer able to sit with the dying and the bereaved. I have been with families in moments of intense grief and suffering. When I hear others talk of their experiences with the dying, my own stories begin to resurface, begin to reveal themselves. My own memories of suffering are no longer

tightly contained in a box in my brain marked “I wish I could forget.” Why is that? Why not tell these stories rather than conceal them? Is there a burden to these stories? Does the burden lie in telling stories that others do not want to hear? As a newly graduated nurse, I very quickly came to realize that my friends and family were interested in the cute and uplifting stories about the children I cared for at the hospital. They were not, however, interested in the stories of death and dying. They did not want to hear about suffering and pain. The burden, then, is mine to carry—a burden that cannot be shared. Even if I wanted to tell some of my stories, I would not know where to begin. Such is the inarticulate nature of grief (Moules et al., 2007).

Yet I have heard families of children who have died tell their stories. What makes my version of the story inarticulate? I want to understand this better. I had the opportunity to interview two of my colleagues on this topic for a research project. One nurse spoke at length about a palliative child with whom she had developed a special bond. The nurse even went so far as to say “[child’s name] and her family were like family to me.” Then I asked her how she reacted when she learned of the child’s death, and she said that she was devastated by the loss and was overcome with sadness. Then she quickly added, “But I don’t have grief.” Why deny the existence of grief - a universal human experience that is completely appropriate in the face of loss and death? Perhaps nurses are not experiencing grief, but rather something else? If not grief, then what? Or perhaps nurses simply believe that the ownership of grief is held by the patient and family and not by the nursing staff? This notion is consistent with some of the work of Doka (1989) on disenfranchised grief. In the case of nurses, they are often not seen to be a member of the bereaved

family. Therefore, they hesitate to express grief, thus often forcing them into silence (Kuhn, 1989). When nurses experience loss through their work, they often believe that they neither have the right to grieve nor is it their place to do so (Lev, 1989). Even when nurses have developed a close relationship to a patient who dies, they are denied the opportunity to grieve; such is the hidden nature of nurses' grief (Clements & Bradley, 2005).

There may be something else at play here. The combination of the inarticulate nature of grief and disenfranchised grief would seem sufficient to begin to understand the phenomena. Yet I am drawn back to the work of Caputo on obligation. Certainly there is an overwhelming sense of obligation to bear witness to death and suffering. However, in the context of nurses' work, particularly in the acute care setting, there are also the issues of managing conflicting obligations, responsibilities, and expectations. The pain of turning towards death is intensified in the chaos of acute care. I vividly remember a shift when I was assigned three patients: two with treatable illnesses (one with a urinary tract infection and the other recovering from a tonsillectomy and adenoidectomy) and one who was actively dying. I badly wanted to be available to the dying child and her family in those last precious moments. I wanted to have the time to try to make those moments count. Yet because of my obligations to the other two children and their families, I kept being called away by those other responsibilities and compelled to respond to the demands imposed upon me. In comparison to the needs of the dying child, the demands of the other families seemed trivial. One father yelled at me for being 10 minutes late giving his son Tylenol. Because of our duty to protect the privacy of others, I could not tell him why I was late. I could not tell him that I was making hand

and foot prints of a dying child. I wanted to scream at his selfishness, at the unfairness of parents having to watch their children die, and the failure I felt for not being able to protect a child from death - - the ultimate human failure.

### **When Grief Refuses to Remain Concealed**

We all seem to play a part in this concealment. Nevertheless, the stories of death, dying, and suffering live within us - - stories that may be hidden, but are never completely forgotten. We all carry grief. We all live with grief, which seems to need to expose itself every so often. I have worked very hard to keep my stories of grief hidden. Even so, they find their way out. Often at unexpected times, stories of grief take over my vocal cords and make themselves known to an unsuspecting audience. Perhaps it is unnatural for grief to be hidden indefinitely for it is not its true nature. Grief likes to appear and disappear as it sees fit. Grief is a trickster. Grief is unpredictable. It hides between our words, refusing to be captured, then comes tumbling out unexpectedly at another time. It would seem then that, on occasion, grief wants to be let out through our stories. In a sense, grief itself wants its burden to be shared.

### **Footnote**

\*Although this paper is co-authored, it is written in the first person of the first author: McConnell.

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