

The Art of Dying: A Global Nursing Perspective

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Abstract

The purpose of this paper is to explore how people from diverse backgrounds and places, who are severely ill, disabled, or facing death, use art to help themselves and others not only make sense of such experiences but live fully with loss and the limited time remaining. The humanbecoming paradigm is used to provide a language to talk about Western and non-Western experiences of life-threatening illness, disability and death, and art. The persons discussed in the paper suggest that age and place, although influences, are not particularly relevant, nor is severe illness, even those associated with significant failing capacities, because they cannot contain the human spirit or relationships.

Keywords

art, death and dying, global, nursing

The purpose of this paper is to explore how people from diverse backgrounds and places, who are severely ill, disabled, or facing death, use art to help themselves and others not only make sense of such experiences but live fully with loss and the limited time remaining or, as Mark Van Doren referred to it, taking “one last look” (Serafin & Bendixen, 2003, p. 1173). The authors will use the humanbecoming paradigm (Parse, 2014) to provide a language to talk about Western and non-Western experiences of life-threatening illness, disability and death, and art.

Many people seem to accept death because for them life has lost its purpose or has become so unbearable that dying seems to be a reasonable option. This reflection focuses on individuals who take a different path, who although facing life-threatening illness, significant loss of capacities, or death find a meaningful sense of purpose right up until the end and who paradoxically live more fully and creatively despite living with significant decline in strength, functional capacities, and facing death. These individuals reveal that death and dying can be as meaningful as birth and that art can provide a vehicle for “cotranscending with the possible,” as Parse (2014) describes it. Jung (1960) once noted that some persons, even in the face of the increasing domination of empirical science as a worldview, are able to “remain convinced that the sun even as it sets strives to illuminate distant races with the same logical consistency it showed in rising to its zenith” (p. 400). Or in the fiction of Tolkien, Gandalf holds his ground against the Lord of the Nazgûl, who represents the abyss, nothingness, death, and the “vast menace of despair” (Tolkien, 1954/1994, p. 811).

The authors here consider examples of persons both lay and artists who used art when faced with severe illness, disability, and end-of-life situations. In other words, people from diverse backgrounds can become more fully engaged with the world via the aesthetic dimension, either by creating art or appreciating artworks. Aesthetics at the end of life and when severely ill, is as it is throughout life, relate to the human virtues of openness and pleasure (Baumann & Goldberg, 2018). This includes, but is not limited to, writing novels; painting; taking pictures; creating music, poetry, or film; or enjoying nature and other people more richly, because the time remaining is limited.

It is interesting to recall that in the aftermath of the death and destruction that occurred on 9/11, two twisted pieces of steel were found amid the rubble that were in the shape of a cross. Draped in an American flag, it became for many a symbol of hope and peace in a difficult time. It can be seen as an artform, like finding a flower amid garbage or hero in the seaweed, as Canadian poet and musician Leonard Cohen (Cohen & Simon, 1966/2018) wrote and sang in his song

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“Suzanne.” The cross, like many other religious and secular artforms, is for many a powerful symbol, paradoxically reflecting life and death, comfort and sorrow. The meaning of the ground zero cross was co-created by the workers and visitors; its power to rise from the ashes continues as its defenders won a legal challenge by a group that wanted to keep it out of the National 9/11 Memorial and Museum, where it stands today.

Harvi Carel (2008), herself dealing with a disabling and life-threatening illness, wrote that in “extreme disability there is always a freedom of thought, imagination, emotion and intellect” (p. 70). This freedom is aided by one’s imagination, which allowed her to roam free, if only for one last time. This exemplifies living being-nonbeing, which is human, honest, and searching for who we really are at the end of life, as well as during microdeaths, such as when ill or disabled existence threatens autonomy and dignity, or during painful endings, separations, and disappointments. One of the authors (S.L.B.) recalls the moment he first understood that one of his daughters was not just a very quiet person but processed information in a very different way, revealing that her path would not be like his or follow the path he had assumed it would, which is one of the paradoxes of joy-sorrow, for many parents. It also calls forth courage to face things as they are truly. In the humanbecoming paradigm view, such paradoxes represent shifting rhythmical patterns as the “humanuniverse emerging with connecting and all-at-once separating with others, ideas, objects and situations that enable and at once limit the opportunities and restrictions inherent in all choosings” (Parse, 2014, p. 34).

Human freedom allows for the opportunity to find meaning in whatever context we find ourselves, and art provides for the expression and celebration of purposeful living while dying. While denying religious beliefs, Sartre (1948/2007) held that we can surpass ourselves and “pursue possibilities outside of ourselves,” and by so doing, we are being truly human (p. 66). He described this way of being as being-for-itself, which he contrasted as the way we are when acting in a role, such as café waiter, or perhaps as a nurse who no longer is fully present to her patients, which is described by Sartre (1948/2007) as being-in-itself, bad faith, or being inauthentic. The latter way of being serves to protect some degree of illusion that lifting the burden of freedom, which for Sartre, is inescapable. Nothingness, as he stated, is the experience of absence of what was expected, as when a friend who promised to meet you at the café does not show up (Sartre, 1948/2007).

Religious writers, such as Saint Anselm of Canterbury (1033-1109) (as reported in Thomas, 2016), suggested that human freedom reflects divine freedom, and we should seek to preserve it by freely choosing to live in the presence of the highest being, the supreme good, and to be conscience of it. For Anselm, choosing otherwise is a deprivation of our true being, or the absence of what we ought to have been, which is somewhat like Sartre’s notion of nothingness. The sentiments

of the stoics, such as by the first-century Roman Seneca, are that pleasure late in life is a freedom from the need for pleasures that one sought to fulfil earlier in life (Seneca, 1887).

Thanks to the internet, people can upload their artworks related to death and dying and share it with the public, and we can access such personal creative works that capture and provide various perspectives on living with illness, disability, and dying. One such video was made and uploaded by Sarah Phillips (2010), who in the video bears witness to her mother’s death from cervical cancer in England by singing “Autumn Leaves.” The song is attributed to Scottish singer, songwriter, and musician Paolo Nutini and is available on YouTube (Duguid et al., 2006). At the time of October 7, 2018, Sarah Phillips’ video had over a half a million views and was recorded and made available on CD by Amazon. According to Walter (2012), Sarah took a recorded pop song that her mother liked and added videos of her favorite family vacations and photographs of her mother and family to create a commemorative tribute to her mother and their time together. Walter (2012) pointed out that in the process she was both consuming and creating art. One stanza from the song she sang is:

Autumn leaves have faded now
That smile I lost well I’ve found somehow,
Cause you still live on in my father’s eyes.
(Duguid et al., 2006)

This song suggests how a life can live on after death, although in a different form, for those who were close to the person who died, via a created and shared artwork. Walter (2012) wondered if the globalization of media and music and the new cosmopolitanism are weakening the association of certain groups, like some African Americans and spirituals and the blues, which commonly included themes of loss, sorrow, and hope. It is likely that personal and group identity and history remain important to one’s self-definition, even in the face of the globalization of art and culture. Walter (2012) maintained that the main point is that in everyday aesthetic practices of people facing life-threatening illnesses, disability, and death are rich resources that can inform practice disciplines and transform lives. He also warned health practitioners not to professionalize or instrumentalize artwork in later life, especially during illness or by the dying.

While more a reflection on aging than dying, Simon de Beauvoir’s (1972) view can also be considered true of dying as well: “There is only one solution if old age is not to be absurd ... to go on pursuing that which gives our existence a meaning—devotion to individuals, groups, causes, social, political, and to intellectual and creative work” (p. 540). Meaning is an important part of the humanbecoming paradigm, and it is described as “the remembering-prospecting valued images languaged in the becoming visible-invisible becoming of the emerging now with and without words,

with and without movement” (Parse, 2014, p. 33). Such a view of meaning invites and welcomes the creation and consuming of artworks at the end of life, both art that creates beauty and conceptual art that provokes thought, reflection, and communication.

The Child Poet as Philosopher: Mattie Stepanek

Mattie J. T. Stepanek died on June 22, 2004 at the age of 13. He was the youngest of four children; he and his siblings had a genetic type of muscular dystrophy, dysautonomia mitochondrial myopathy (Stepanek, 2005). While he never met two of his siblings, Katie and Stevie, because they died before his birth, their life and death were a part of his life. He did know and deeply mourn the death of his brother Jamie, who was a preschooler when he died. By the time Mattie was 7, he was wheelchair dependent; by age 10, he relied on a ventilator to breathe; and on several occasions, he almost died. Once at the age 9 after nearly dying, he spent several months in a pediatric ICU and thereafter required home schooling to preserve his limited energy and better manage his progressing disease. His mother, who suffered from a less severe version of the disease, was his primary caregiver and teacher. So Mattie witnessed not only his own progressive decline but also the death of his brother and was very much aware of his two other siblings’ deaths.

Mattie learned to read from his speech therapists and was encouraged to tell his story and write at a very early age by his mother. His personal philosophy was to accept that storms were a part of life but that one should play after each storm rather than wait apprehensively for the next storm (Stepanek, 2005). He had a simple but profound faith: He dreamed of being a peacemaker, like Jimmy Carter, whom he had learned about in school. At the age 10, he got the chance to talk to the former president on the phone. President Carter ended up writing his epitaph. Despite his short life and struggles, Mattie had enjoyed some level of celebrity status, having become a special guest on *The Oprah Winfrey Show* and *The Larry King Show* as well as a regular on the *Jerry Lewis MDA Telethon*. Thanks in part to this television exposure, his books were *New York Times* bestsellers. He turned school assignments, such as one on the Vietnam Memorial Wall, into poems tuned into the sadness and fear as well as the relief and hope the Wall represented. Mattie wrote poems on ordinary pleasures of childhood like being on a swing, which he saw as a symbol of living and dying, being everywhere and nowhere, at peace, yet lonely, and facing the prospect of his own death with courage (Stepanek, 2005). In the face of all of this, Mattie remained an optimist and grateful spirit; he was able to share his story in poetry, which touched many persons deeply, as it inspired and embarrassed others, who complained about having minor setbacks and frustrations. He did not claim to be a victim or play on a person’s emotions; even while others around him did to some degree, he retained enough of just

being a child that others could connect with him and recognize something of their own story in his.

Mattie did refer to his poems as heartsongs, a term he seems to have gotten from a conversation he had with this mother, who told him she liked his poems because they came from his heart (Stepanek, 2005). The poems had authenticity, deeper meaning, and were true to him. They also speak to his living-dying that in the language of the humanbecoming paradigm can be expressed as separating-connecting while enabling-limiting and revealing-concealing (Parse, 2014). Mattie’s lived cotranscending with the possibles was captured by his story and poetry. In Parse’s (2014) paradigm, cotranscending is “powering of unique ways of originating with sureness-unsureness of living the familiar-unfamiliar of transforming, while conforming and at once not conforming with the expected” (p. 34). The creation of art played a significant role in his living and dying; it afforded him a means to face limitations and threats to his existence with courage and spirit. Mattie provided new possibles for him and others through poetry. In his final poem, Mattie wondered if people will “peacefully ponder the undying essence of his echo” and “appreciate the silhouette of his legacy that spirits the memory after death passes” (Stepanek, 2005, p. 205). Wallace Stevens’ poem *The Hermitage at the Center* also included reference to last looks, ending and beginning, and as if referring to Mattie, the lucent children (Stevens, 1954).

Stevens (1954) suggested such poets have “binocular vision” such that while near death they can “do justice to both the looming presence of death and the unabated vitality of spirit” (p. 4). James Merrill, as discussed by Vendler (2010), was one of many people and artists who in the early years of the AIDS crisis had created poignant art while dying from AIDS. The art and voice, like the AIDS Quilt, had both personal and political value. Vendler (2010) drew attention to Merrill’s use of dead-alive metaphors in his poem titled *A Scattering of Salts*, which spoke to being both healthy and frail, saying it “echoes Dante’s *terza rima*” (rhyming verse stanza) of the afterlife (p. 119). Christopher Hitchens (2012), the Anglo-American writer, a few months before his death from esophageal cancer, wrote, “My chief consolation in this year of living dying has been the presence of friends. I can’t eat or drink for pleasure anymore, so when the offer to come is made its only for the blessed chance to talk” (p. 54). Well known for his ability to engage in debates, Hitchens lost his ability to speak but continued to write essays for *Vanity Fair*. Hitchens questioned the famous Nietzsche quote that “all that does not kill you makes you stronger” by pointing out that for him having cancer and its treatments only made him weaker.

Anoushka Shankar’s Tribute to Her Father: A Hindustani Raga

Music is commonly played and sometimes created by people living with severe illness, disability, or dying, be it for themselves or for others. As mentioned above, Sarah Phillips (2010)

created a music video tribute to her mother's memory, with her singing one of her mothers' favorite songs. Such use of music is common in the Hindu community. Music and chanting, such as the sound Om, are seen as means to help release the soul's path into its next metaphysical state. According to Hindu beliefs, the soul is invisible, unconceivable, and unchanging (Bhagavad Gita, Chapter 2, verse 27, as cited in Johnson, 1994), death and rebirth are inevitable, and Brahman is the underlying creative principle of all that exists. One should not lament but play music and sing chants (bhajans), which are similar to requiem, dirges, and hymns in other faiths. For one of the authors (D.B.), when it was decided to take her father off the ventilator, with his body failing, this family sang a popular Hindu bhajan, *Jai Krishna Hare*, until he died; they sang for him and themselves. It is also common for Hindu families to gather and sing nightly with instruments, such as the dholak (drum) and harmonium (pump organ), until the funeral rites are completed, which is usually a period of 2 weeks. Music is a part of mourning, shifting the rhythms of connecting-separating of persons with others in light of the Hindu truths, called "Brahman," which is considered an omniscient, uncreated, eternal principle in Hinduism that is in the universe and each person.

One particularly beautiful example of such music was composed by Ravi Shankar's daughter, Anoushka Shankar (Shankar & Ota, 2017), as a tribute to her father. It included scales created by him, some of which he performed into his ninth decade of life. Pandit (which means master) Ravi Shankar's music and beliefs became known in the West because of his influence and relationship with George Harrison and the Beatles as well as others such as Robbie Krieger of the Doors and John Coltrane. Ravi Shankar was also the father of singer musician Nora Jones. The George Harrison songs "My Sweet Lord" and "Give Me Love" not only use the sitar but also reflect the influence of Hindustani classic music, but the music for many evokes meditative ways of being present with the universe, shifting rhythmical patterns and value priorities. From the Hindu worldview, such music is liberating, lifting humans above the agonies of this world, including when ill and dying, and helping them be free from the here and now. The music style and form mastered by Ravi and composed by Anoushka Shankar as a tribute to her father's life and death is referred to as a Rega, a melodic framework for improvisation (Shankar & Ota, 2017). Anoushka's music today remains tuned into her father's, who was her guru. Such melodic scales or themes are played with passion and concentration that celebrate the living presence amid absence. Like Mattie, Ravi and Anoushka's music is a vehicle for chant and meditation, reflecting on what is most important, healing and creating peace with oneself and others.

Art as a Source of Life While Dying

Willem (Bill) de Kooning, the Dutch American abstract impressionist, immigrated to the United States from Holland

with, as the saying goes, nothing in his pockets, when he was 21 years old. He was particularly creative after he was told he had dementia and was losing his vision (Stevens & Swan, 2004). His art, like the watercolors of Nell Blaine, who in the middle of her life contracted polio, became simpler in lines, form, and color, which Bill de Kooning attributed to "becoming freer" and doing "miracles with what you have if you accept it" (Stevens & Swan, 2004, p. 604). He described his living with dementia as cutting away the flesh and getting down to the bone, where he could uncover and express the essence of things. He became alive and lost in front of his easel. Others described his later works as "emptying out," revealing his ability to let go, as if he was "saying good-bye" (Stevens & Swan, 2004, pp. 602-607). Those close to him said he was kept alive by creating art. His art for him, in the language of the humanbecoming paradigm, was enabling-limiting and separating-connecting, while revealing-concealing (Parse, 2014). Dementia can be described as a mode of living being/nonbeing in light of the person who is transforming.

Kongsuwan (2009) studied the lived experience of nurses caring for persons who had a peaceful death in intensive care units in Thailand. As part of her dissertation report, she wrote four poems, capturing the corporeality, relationality, spaciality, and temporality of caring for persons who had a peaceful death, and she illustrated each of them with drawings of lotus flowers and butterflies. She said the "butterflies symbolize their expression of caring 'freely' since the intensive care nurses were free to care and had the wisdom in caring for persons who had a peaceful death. The wisdom made their worlds of caring be light and bright. Lotus flowers also symbolize respect" (Kongsuwan, 2009, p. 125). She also said these aesthetic expressions enhanced her ability to understand and communicate caring for persons who had a peaceful death. In the Buddhist tradition, repeating mantras and creating images of the Buddha, Kannon Bodhisattva (Goddess of Mercy), and mandalas when approaching death reveals one of the impermanence of what is and is an effort to achieve liberation that is needed to not have to return as another life form.

As in the humanbecoming paradigm, Buddhism holds each person accountable for choices and actions as well as encouraging each to live goodness and kindness to create peace (Blackman, 2005). Blackman (2005), who died less than 2 months after she finished compiling and editing her book of the death stories of Hindu, Tibetan, Buddhist, and Zen masters, included the story that Swami Ram Tirth, who an hour before his death, wrote with tears of joy, "O death, go and strike my body: I have millions of bodies to live in. I will dress myself in the moonbeams, in the gauze of the fine silvery threads, and pass my time in tranquil rest. I will sing my songs in the form of hill streams and brooks, in the forms of the rolling waves: I will move on" (Blackman, 2005, p. 60)

Conclusion

It is a well-known trope that when facing death, one's life passes before one's eyes. If this is true, life review and reinterpretation of the events of one's life is also a spring board for creating and consuming art. The advantage of hindsight combined with poignant contemplation gives rise to beauty and new meaning for those open to it. Gadamer (1991) wrote that art was an activity that "reveals the human experience of finitude in a unique way that gives spiritual significance to the immanent transcendence of play as an excess that flows over into the realm of freely chosen possibilities" (pp. 46-47).

The persons discussed in this paper suggested that age and place, although influences, are not particularly relevant; neither is severe illness because they cannot contain the human spirit or define relationships. The language, assumptions, and principles of the humanbecoming paradigm provide a conceptual space that welcomes the value of art and the humanities when living with severe and disabling illness and when facing death.

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