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Palliative Care and C.A.R.E.®

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ABSTRACT

Palliative care focuses on improving the quality of life for those going through a chronic or life-limiting illness. It requires conscious and compassionate engagement to serve the needs and concerns of the patient while continuing to provide treatment and minimize suffering. Although they share core objectives, hospice and palliative care were developed separately and are distinct from each other. While hospice care is palliative by its very nature, palliative care is not necessarily hospice care. And, because the patients' experiences and their immediate care environment are inseparable, palliative care must address not only direct care, but also the design and quality of the physical environment. With its stunning nature imagery and beautiful music, The C.A.R.E. Channel supports the environmental qualities most valued by palliative care patients.

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How we are born and how we die.

How we treat our infants and how we treat our elderly.

How we treat the poor and how we treat the wealthy.

How we treat those who are able and those who are disabled.

Each of these circumstances is a reflection of the quality of our healthcare system and the character of our communities. And beyond the biomedical practice that dominates healthcare today is the lived experience of chronic and life-limiting illnesses. Without a doubt, this experience requires more than medication and surgery to remove fear and motivate positive living.

Palliative care focuses on improving the quality of life for those going through a chronic or critical illness. It requires conscious and compassionate engagement to serve the needs and concerns of the patient and family. Medical treatments and modalities may continue with the goal being to minimize suffering. This is regardless of whether the condition is curable or not.

Although they share core objectives, hospice and palliative care were developed separately and are distinct from each other.

Hospice is palliative by its very nature. However, palliative care is not necessarily hospice care. At its inception, hospice required that the patient be diagnosed as terminal and have a life expectancy of six months or less. Now, patients may stay under hospice care for as long as needed. Nonetheless, all curative procedures are stopped and replaced with “comfort care,” including pain relief and other support to optimize the quality of living.

Palliative care has never assumed a defined lifespan nor does it require that patients forego curative or life-sustaining treatments. Palliative care is whole-person care that relieves symptoms of a disease or disorder, whether or not it can be cured.

Palliative care is about quality of life, identifying and supporting the patient’s goals, pain relief, and social/spiritual structure. It is appropriate across the continuum of care and lifespan of the patient.

Where Palliative Care Started

Before there was any understanding of how the body worked, and when most patients succumbed to whatever infection or virus hit them, the environment was a primary tool to provide palliative care. It is where all of healthcare and medicine started long ago. Supporting patients’ emotional, spiritual, and physical needs was essential.

The Aesclepiian Temples of Ancient Greece modeled the use of all things healing, such as music, nature, and humor. These temples were places designed to facilitate these activities, with outdoor spaces and theaters. Curing was left to the gods. In fact, throughout history, each civilization had its start in medicine, some leading directly to what we have today, and others being overtaken as new knowledge came to light and science replaced myth.

It was not until the mid-19th Century when Florence Nightingale looked at the sick dying unnecessarily from what she considered the assault of the “sick room” that the place where patients were cared for took on an acknowledged role in medicine. Not without controversy, identifying the quality of the “sick room” as primary to survival was only taken seriously when the epidemics of cholera, Crimean

Fever, and infections were mitigated by Nightingale's environmental interventions.

In her monograph, *Notes on Hospitals* (1863, p. III), Nightingale starts by writing:

It may seem a strange principle to enunciate as the very first requirement in a hospital that it should do the sick no harm. It is quite necessary, nevertheless, to lay down such a principle, because the actual mortality in hospitals, especially in those of large crowded cities, is very much higher than any calculation founded on the mortality of the same class of diseases among patients treated out of the hospital would lead us to.

In Nightingale's day and before, there were no drugs, CT scans, radiation therapy, surgical suites, tablets, or computer monitors. There was only the patient and the physician. Any room could become the "sick room," where the patient was to be restored to health.

And, patients died. They died of infections and cholera. They died from the plague and from epidemics with no name. They died in childbirth and from falls, accidents, and wars.

Then, after antibiotics were introduced, infections were not necessarily terminal. Patients did not automatically die in childbirth or from falls. There were fewer epidemics. And the new challenges facing healthcare occurred between injury and death, which could be hours, days, or years

The Environment Must Be Palliative

The patient's life-world is his/her lived experience integrated into a set of assumptions, values, and perceptions that are culturally, socially, and individually preset. It occurs within a context defined by character and the impact of the environment. And, it is this context that controls the behavior and actions of everyone within it -- patients, family members, nurses, and physicians.

Because the patients' experiences and their immediate care environment are inseparable, palliative care must address not only direct care, but also the

design and quality of the personal care environment.

In essence, the environment in which patients find themselves -- in which they create and recreate their identity and sense of self, and consider their present and future options -- must reflect and support their goals. Palliative care, therefore, cannot successfully optimize the quality of life factors of patients if the environment itself is not palliative.

In studying the environmental qualities most valued by hospice and palliative care patients, Rasmussen and Edvardsson (2007) arrived at the overall quality of "at-homeness" being dominant. This term has been used and discussed since the late 19th Century to identify a sense of familiarity, a relief of tension, a confidence in a kind of memory of experience (Titchner, 1899). In the discussion about palliative care environments, the concept is further defined and broken down into three factors: welcomeness or hospitality, safety, and everydayness.

Welcomeness is described as walking into the room feeling that the environment had a place for you that was comfortable. This includes the built environment and the atmosphere, the very character of the space. It also is the experience of being expected, having the room prepared for the patient's arrival and customized to accommodate the patient's needs.

Being immediately welcomed is also about making obvious the fact that the staff has prepared for patients in advance. According to the research, personalizing admitting procedures and then moving the process quickly into a sense of knowing and understanding is a dominant part of at-homeness for patients and family members.

Multiple factors should be considered for patients to feel safe. This includes privacy and security, physical safety in the design of the room itself and the furniture, and having staff be very detailed and intentional in all aspects of the patient's care. If the plants are suffering, whether outside or inside, or the doors are chipped and need painting, patients might wonder if they will be cared for the same way. Furthermore, being in a calm environment, where staff

members move around with confidence, providing deliberate caring, creates a sense of security that everything that is needed will be provided.

Finally, everydayness is described by the researchers as “the ordinary and everyday...‘everydayness’ includes experiences of being able to keep one’s own personal rhythm; that people can walk, talk, eat, and shower at their own speed. Being in a calm environment devoid of loud alarms, telephones, screaming voices and unfamiliar noise, and where movement is at a calm and comfortable pace contributes to the feeling.” (Rasmussen and Edvardsson, 2007, p. 127.)

In total, the feeling of at-homeness dramatically eases the fear and discomfort common when having a terminal or life-limiting illness. It offers patients and families a sense of the familiar in unfamiliar circumstances. And it is that sense of recognition that is itself comforting.

C.A.R.E. in Palliative Care

With its stunning nature video and soothing instrumental music, The C.A.R.E. Channel relaxation programming for patients helps create a quality of “at-homeness.” Here are the ways C.A.R.E. Programming supports palliative care:

1. Welcomeness

Having The C.A.R.E. Channel turned on in the patient room prior to the patient being admitted, or returning from bathing, creates a prepared space, personalized by the intent to comfort. Having nothing on risks leading to a sense of isolation. Commercial television playing in a room prior to entry can make the room feel preoccupied, prepared for someone else. Other ways of preparing the room are to have the bed turned down, with a small light on next to the bed.

2. Safety and Security

Having and maintaining a clean room, with equipment and beds in excellent condition, and the staff being visible and accessible, makes patients feel safe. The C.A.R.E. Channel provides a defined and consistent, life-enhancing focus. It makes obvious the intention to provide what is needed so that patient and family members need not be concerned. Because the music is consistent and restful at night, fears and ruminations that can arise when patients are alone are

distracted and calmed.

3. Everydayness

The C.A.R.E. Channel is a 24-hour multi-sensory experience, providing natural landscapes that follow the day-night cycle with accompanying instrumental music. According to biologist, researcher, theorist, naturalist, and author E.O. Wilson, there is a familiarity about natural elements that is part of our evolution. His Theory of Biophilia states that all human beings are inherently attracted to all living things (Kellert and Wilson, E O, 1993). As their acuity rises, most patients experience less and less of the outdoors. C.A.R.E. Programming is produced to allow a viewer to experience themselves in these environments. Adopting the philosophy of Ansel Adams, there are no people or human-made objects in its content. Rather, as Adams suggests, the person in the picture is the viewer.

C.A.R.E. Programming allows patients and family members to reclaim their own identity and experiences by viewing stunning natural landscapes as a cue to the natural world and all that is alive.

C.A.R.E. in Hospice

A study published by McMaster University (You, Dodek, Lamontagne, et. al., 2014) about what patients find most valuable to discuss at end of life care revealed that most of the time decisions are based on what is prescribed rather than what is preferred. To know patient preference, patients must share their most personal desires and fears. This requires an openness and trust that allows for intimate, candid, and often painful conversations. It also requires an environment that is conducive to having these types of conversations.

Patients and family members want to feel that staff is aware of the stress of the situation. They want an environment of care that respects and accommodates for the seriousness of the process of living and dying. Noise, glare, tangled sheets and blankets, clutter, four walls that do not change — the room can close in on patients who are unable to move from the bed or care for themselves.

For the family, what staff does for patients in their personal care environment at the end of life is more important than anything they say to them. A palliative environment provides the opportunity for patients to find themselves in the environment, to feel “at-home” in spite of illness and disease. The room “speaks” to

patients for endless hours, reflecting the concern and compassion of the staff. Because it comforts and conditions the environment to be healing, The C.A.R.E. (an acronym for Continuous Ambient Relaxation Environment®) Channel becomes the ongoing therapeutic intention and presence of the caregiver and family.

Palliative care and hospice patients should have a physical environment that is responsive to their needs, which are not about hours or periods of the day. The combination of nature and music offers a powerful therapeutic tool that helps ease pain and suffering for patients, families, and caregivers.

"The calm within the storm is where peace lives and breathes. It is not within perfect circumstances or a charmed life... it is not conditional. Peace is a sacred space within, it is the temple of our internal landscape." Jaeda DeWal



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About the Author

Susan E. Mazer, Ph.D. is acknowledged as a pioneer in the use of music as environmental design. She is the President and CEO of Healing HealthCare Systems, Inc., which produces The C.A.R.E. Channel. In her work in healthcare, she has authored and facilitated educational training for nurses and physicians.

Dr. Mazer has published articles in numerous national publications and is a frequent speaker at healthcare industry conferences. She writes about the patient experience in her weekly [blog](#) on the Healing HealthCare Systems website and is also a contributing blogger to the Huffington Post's "[Power of Humanity](#)" editorial platform, dedicated to infusing more compassion into healthcare and our daily lives.

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