

## NARRATIVE AND PALLIATIVE CARE TEAM IDENTITY FORMATION

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### ABSTRACT

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*Palliative care is whole person care that attends to the physical, psychosocial, and spiritual needs of persons with a serious or life-limiting illness. This care is provided by a team of clinicians from several disciplines including physicians, nurses, social workers, and chaplains. The palliative care team functions as a dynamic system whose ability to provide quality care is dependent upon the ability of the team members to form and maintain an ongoing collaborative alliance. This alliance requires that team members maintain dual commitments to both the care receivers and to their fellow team members. Just as persons with illness express the human propensity toward meaning making in the face of suffering, so palliative care teams thrive when they are supported in reflective processes that enhance their ability to find meaning in their work. Creation of and attention to team narratives and their role in team identity formation can enhance team members' flourishing by placing team identity in the context of a larger story. Narratives of rescuing and fixing foster a sense of control and expertise while narratives of containing and healing nurture attention to mindful presence and human-to-human encounter.*

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In a commencement speech to the 2011 Harvard Medical School graduating class Atul Gawande, MD stated, "Making systems work in health care—shifting from corralling cowboys to producing pit crews—is the great task of your and my generation of clinicians and scientists"<sup>1</sup>. Gawande's challenge for clinicians to envision themselves not as "cowboys" but "pit crews" highlights not only the necessity of team collaboration in the future of healthcare, but also the use of a guiding narrative to influence clinical practice. In Gawande's economy the solo, independent cowboy was the appropriate metaphor for 20<sup>th</sup>

century medicine. In contrast, 21<sup>st</sup> century healthcare will only be as successful as the highly coordinated, interdependent pit crews who produce specific outcomes in a timely manner.

Palliative care literature is peppered with its share of guiding metaphors. In a 2012 interview with Prevention magazine, Ira Byock MD was quoted as saying, "Palliative care providers are like firemen. In situations which everyone else wants to flee, we rush in to help"<sup>2</sup>. Later in his most recent book *The Best Care Possible*, Byock describes the palliative care physician's role as akin to a "captain of a passenger liner" or "pilot of a plane" leading the way and providing "safe passage," during the patient's "journey" of illness<sup>3</sup>. Sarah Friebert MD and her pediatric palliative care team at Akron Children's Hospital refer to their team as a "palette of care." She elaborates:

*We have chosen to call our program "A Palette of Care," because we feel this image best represents the totality of the impact we hope to be able to have in serving families. In this metaphor, patients and families are given a canvas, brushes and paints with which to paint a life of quality, free of suffering. The colors on the painter's palette represent all the different disciplines or specialties of caregivers on the palliative care team. With the child and family at the center, palliative care is truly the effort of a transdisciplinary team, including, but not limited to: physicians, nurses, social workers, case managers, bereavement specialists, chaplains, child life specialists, psychologists, volunteers, and physical and expressive therapists. Each child and family can pick and choose the colors they need or want to create the most beautiful painting possible of life and hope<sup>4</sup>.*

Peruse the literature and notice the metaphors: wounded healers, jazz musicians, solid ground in shifting sands, and a place of refuge are only a few examples of images used to describe the work of the palliative care team.

Why all the metaphors? Why such vivid images to describe the day-to-day, not-so-glamorous work of a palliative care team?"

Danai Papadatou, palliative care psychologist, has written extensively on the human need for narrative. Human beings appear to be primed to make sense of our experiences by crafting stories that make meaning out of the mass of sensory data and sequential experiences that make up our lives. This human propensity toward meaning making is accentuated in the face of suffering and meaninglessness. As Victor Frankl quoting Nietzsche writes, "He who has a why to live for can bear with almost any how"<sup>5</sup>. Meaning making is key to our survival as human persons. Whatever theological, philosophical or metaphysical explanations may be offered, the meaninglessness of human suffering is often softened with a story—and most good stories are extensions of a key image or metaphor. Whether it's the hero's

quest, the damsel's distress, or the villain's treachery, metaphors make stories, and stories make meaning. For, in the end it is, "not so much what happened as the story we tell that matters"<sup>6</sup>.

Palliative care clinicians are often instinctively aware of this deeply human need to attribute meaning to what would otherwise seem meaningless. The cancer patient who describes herself as a "fighter," and the family members who insist on continuing treatment because dad "would never give up the battle" are just a few examples of guiding metaphors that make up the personal patient narratives heard day after day.

If meaning making through story is not an if, but a how then the question becomes: can we choose one narrative over another? And if so, does our choice make a difference? Or, put another way, does the story we tell matter? Does it matter to the young dying policeman who describes himself as "Superman of sickness?" What happens to patients and their family members who choose battle or superhero images to narrate their experience of illness? While these images may serve the patient well when the prognosis is good, what happens to meaning making when the illness recurs or treatment "fails?" As Abraham Fuks notes, battle images for illness lead to winners and losers and potentially cast the transition to hospice or death as defeat "after a courageous battle"<sup>7</sup>.

And what about us—the palliative care clinicians? As witnesses to suffering, how are we engaged in making sense of the tragedies that confront us day after day? How many palliative care teams are affectionately nicknamed the "death squad," "drug pushers," or "angels of death" by their colleagues? Assuming those are not narratives we would choose for ourselves, what metaphors do we use to describe our team? Do we use images of rescue like Byock's firefighters? Or images of repair like Gawande's pit crews? Or images from the arts, like Frieber's "palette of care"? In discussing the "good enough" team, Papadatou suggests, "team narratives...are shared representations of events that have a lasting impact upon the team, its development, and its history"<sup>8</sup> and greatly contribute to healthy team functioning. The narrative used to describe the team's role, function and purpose can provide "support in the construction of meaning,"<sup>8</sup> an essential component to team flourishing.

Michael Kearney, in his book "A Place of Healing", describes the palliative care team as a "secure-enough container for the patient in suffering" where containing, "means psychologically holding the one who suffers even when there is nothing left to do, no matter what happens"<sup>9</sup>. Comparing the palliative care team to the alchemist's vessel of old, Kearney describes the palliative care team as *vas bene clausum*, or well-sealed vessel, where transformation may occur. Using metaphors from the medieval science of alchemy, the palliative care team's role is "to prepare and hold the space where the miraculous may happen"<sup>10</sup>.

If we are story-making beings, and if we have some agency in choosing what story we tell and how we tell it, why would a palliative care team choose Kearney's narrative over another? Firefighter and pit crew

metaphors cast the clinicians in the role of technician, expert, and leader. These narratives evoke images of teams working together where lives and important outcomes are on the line. It would follow that effective communication skills and team collaboration would be essential to success. But what these narratives fail to address is what happens when we bring our best game (sports metaphor intended) only to watch patients and families continue to choose non-beneficial care. Likewise, these narratives also fail to account for those sacred occasions when healing comes in spite of the absence of cure. We need a way of narrating our work that can encompass “the thrill of victory and the agony of defeat.” (sports metaphor intended again).

On the other hand, Kearney's metaphor of the alchemist's well-sealed vessel not only evokes images of team expertise and technique, but also reminds us “healing is not something we do, it is something that happens”<sup>11</sup>. Our role as a team is often no more than to be mindfully present to the patient's mysterious and often miraculous movement toward healing. Yet Kearney's metaphor also acknowledges that we are not in control of all outcomes—transformation may or may not happen. We surely do not make it happen, but merely create the conditions where it may, or may not, occur.

Kearney has also written extensively on the narrative of the wounded healer. Based on the mythical tradition, Chiron, the centaur wounded by an arrow to his leg, becomes an expert in the healing arts while never successfully being healed of his own wound. Thus, Chiron is an image of balance between our wounded part and healer part<sup>12</sup>. Most healthcare clinicians, palliative care clinicians not exempted, tend to over identify with their role as “healers” and under identify, or even suppress, their own woundedness, or vulnerability to sickness and death. Likewise, most patients, especially in the presence of a healthcare team, tend to over identify with their woundedness or illness and under identify with their body, mind and spirit's own drive to heal itself. In contrast to Jon Kabat-Zinn's famous mantra: “As long as you are breathing, there is more right with you than there is wrong, no matter how ill or how hopeless you may feel”<sup>13</sup>. Those diagnosed with life-threatening illness tend to feel vulnerable, powerless or even victimized by their illness.

Following this narrative, the interaction between the palliative care team and the patient takes on a different tone. Instead of expert healers empathically solving problems for the passive, ill recipient/patient, the encounter between team and patient becomes a meeting of the wounded, vulnerable, powerless parts alongside the innate physical, psychological and spiritual healer parts that live in each of us. The mystery of the encounter centers on awareness, acceptance and compassion toward oneself and toward the other. Empathy flows both ways as power over is exchanged for surrender to.

What kind of narrative will provide the meaning and therefore the sustenance to remain engaged, attuned, and self-aware in the midst of the challenging work of palliative care? Narratives of rescue, fix-it, and even healing can contain the ingredients for professional and personal depletion. What happens if

things get worse after our interventions? What happens if we aren't able to save the patient from a bad outcome? What if healing doesn't happen? How will we explain failure? Statistics on burn out, compassion fatigue and secondary traumatic stress abound in the literature. Research on team flourishing continues to be scarce. More exploration and research is needed on the practices that will sustain the palliative care clinician and palliative care teams.

Team and individual guiding narratives are one such area of exploration. Adopting a team guiding narrative that fosters meaning making is but one way to thrive in our work. But how? If every change of mind is first a change of heart and every change of heart is soon a change of mind, adopting a team narrative involves an ongoing practice of heart and mind driven reflection. In addition to team debriefings, this involves cultivating team self-awareness by asking ourselves the deeper questions such as: did we bring a quality of mindful presence to the encounter? If so, or if not, how do we know? Did we prepare and hold the space where healing could happen? Did we allow ourselves to stay in touch with our own limitations? Did we find any healing in the encounter for ourselves or for the other? What drains us is not suffering, but suffering without meaning. How we make meaning of this work matters—for us, for our patients and for their loved ones. ■

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