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Creative Arts as Companion Therapy in Cancer Treatment Marion Nesbit and Susan DeCristofaro

A Patient Partnership

Editor's Note: In their joint article, "A Partnership in Creative Arts and Healing" Nesbit and Decristofaro "document the formation of a community partnership between Lesley University and Dana-Farber Cancer Institute in the creation of a hospital-based arts and healing program." The article features the journey of the late Lesley alumna M.L. O'Connor, whose vision and passion for the use of creative arts in her own healing process served as catalysts for development of the program, and whose values and beliefs served as the tenets of its foundation. "In M.L.'s vision of the hospital-based arts program the patients were engaged, each in his or her own creative process, expressing fears, fantasies, and hopes through their poems or drawings in ways for whatever reason, they could not through vocal expression."

The purpose of this article is to document the formation of a partnership between faculty and staff of Lesley University and the Dana-Farber Cancer Institute, a Harvard University affiliated research hospital, to pioneer a graduate student and patient's vision toward creation of a hospital-based arts and healing program. The article features the journey of the late Lesley alumna M.L. O'Connor, whose insight and passion for the use of creative arts in her own healing process served as catalysts for development of the program, and whose values and beliefs served as the tenets of its foundation. The article chronicles both highlights and struggles of situating an arts-based individualized program in a hospital environment and underscores the importance of the partnership in a process that continues to unfold toward gaining recognition for patients' personal expression through creative arts as a value-added supplement to medically based treatment.

Ten-year anniversaries can reveal important characteristics about a relationship. On reaching a decade, the relationship has survived its nascent years of discovery and positioning for visibility, and yet it is still in its youth with a promise of many years ahead to strengthen the connection and explore possibilities. This article celebrates one such anniversary of the tenth year of the Creative Arts Program situated at the Dana-Farber Cancer Institute (DFCI) and honors a relationship between two institutions by retelling the story about the tenacity and wisdom of the individual who connected them.

While many partnerships are forged out of shared need or mutual benefit, it was more serendipity than strategic planning that led to the unique partnership between DFCI, an internationally reputed hospital and research institute specializing in the treatment of cancer patients and the Independent Study Degree Program (INDS) of Lesley University. INDS is a renowned graduate program in which extraordinary adults, driven by humanitarian values, construct unique programs of academic study. The connection came through a graduate student named Mary Louise McMahon O'Connor, herself a cancer

patient, who planned an academic program rooted in Jungian theory, a belief in the power of expressive arts, and a desire to help cancer patients move through the pain and angst of illness. Her integrative master's thesis became the starting point for the DFCI Creative Arts Program.

Mary Louise O'Connor, or ML as she preferred, was a gifted poet, artist, dancer and humorist, and a pioneer who would not let her vision be clouded by others' doubts. With the realization that painting and writing poetry corresponded with a positive change in the course of her illness, she imagined a cancer infusion clinic where patients like herself could similarly benefit from expressing themselves through the arts. ML conceived of herself as a choreographer of a program in which individuals could dabble or delve deeply into a mode of artistic expression as she walked among them, tambourine in hand, facilitating their process with a generous and loving spirit.

In ML's vision of the hospital-based arts program, patients were engaged, each in his or her own creative process. They expressed fears, fantasies, and hope through their poems or drawings in ways that, for whatever reason, they could not through vocal expression. For ML, participation could be in writing a poem while waiting in the chemotherapy suite or in listening to music following surgery. ML was resolute that participation in any visual or performing art benefited patients and would help them find meaning and relief from stressful circumstances. In her own words, "Discovering and expressing what images and ideas appeal to us is a path to our own deeper worlds, and connections to what inspires the human spirit." ML wanted individuals who had cancer to be present in their bodies and to have the opportunity to use art to "take deeper notice of what images...words or pictures come to mind—that might assist healing".

Inspired by Carl Jung's psychology and spirituality, ML posited that individuals have common archetypes and forces of creativity within that can be tapped as reservoirs of healing. Describing her experience of illness as inhabiting the inner and underworld, ML decided to experiment with Jung's ideas by exploring her dreams, drawing and painting images that emerged, and writing about her reflections in a journal.

ML created poetry to communicate images that surfaced from her reflections. ML wrote, "...as a poet, I spiral around and play with facts, impressions, dreams. Just as researchers investigate through microscopes, making notes of what they find, I inspect and translate into sound and rhythm the nuance of under, inner, and over sides of things" (O'Connor, 1997, p.5). She was the first to say she was "not a doctor" as she attempted to support the medical interventions of surgery, radiation, and immunotherapy by participation. Like Katz (1993) and Kabat-Zinn (1990) she believed healing was a process toward connection and balance, and that the arts were a means for her to achieve a wholeness that she could not obtain through medical treatment alone.

ML remarked that her Irish heritage provided a gene for poetic expression, and she saw her ability to create a poem as an invaluable gift that even the disease could not take away. ML was not afraid of the darker depths of her spirituality, brought on by the fear and tightness of panic she felt as sickness seeped up through her in the chemotherapy room or when she waited in the hallway outside the operating room, within which her life would open vulnerably to the unknown waiting below the melanoma. During the worst of times, she cherished her private time with God and practiced her belief in the power of prayer.

One poem, *Cathedral*, expresses her spirituality and thoughts poignantly in what she referred to as "a deep signature of her soul".:

Once we built cathedrals, and lived assured of alignment and of worship of duty in a place, where one still hears resonance of stone unleashed by bleeding hands, the visions satyrs, saints, projections of the medieval god heads hovering not far from the grids we build atop decaying streets. As disenfranchised pilgrims we climb from city squalls into vaulting worlds of stained glass mystery seduced by tabernacles flame we lay desire down in the quiet shade of a dark Madonna's face.

Stone eyes lock on fumbling lips, leaving judgments and words to us, saints stay in the listening silence as immobile offspring of all our foundered gods.

We seek sanctuary though we know Akhenaton was mistaken to worship the sun as were all pharaohs and kings who believed in sustenance from image.

Ishtar, Osiris, Atum
left residues in dreams
Ninto, Baal, Zeus
carving gold wrapped icons
charted imagings of search
the artists of Lascaux, the Sistine Chapel
the architects of Knuf's Pyramid,
New Grange, Stonehenge
all reaching to touch the spirit maker, if
there ever was
or is
such industry, still

We seek sanctuary plumb the white horizon altars wishing for worthier chalice fashioned for some reason from this time a gold from which to drink believing tending is a lasting good we make.

Despair paints tears that do not fall genuflecting in aisles of slanted light we become like carvings shaped through time peopling the altars objects of art momentarily alive in the flicker of a candle. (1998, first draft 1995)

Artistic creations that ML called "soul speech" brought her insights and emotional release, leading to strength in the midst of chaos and inner peace. In her thesis literature review, ML credited many writers whose work influenced her thinking. She spoke about a Jungian-inspired inquiry into the archetypes of Ariadne and Inanna, and the biblical Job, and how much she gained by Nouwen's sense that "...words must emerge and awaken the deepest longing of the human heart" (1990, p.56). She loved the poetry of Joyce and waded in the writings of Hillman (e.g., 1989), among others, in search of meaning or wisdom to unlock her "predicament". She learned about societal context for individual suffering from Frankl (2002), particularly resonating with *Man's Search for Meaning*, and about the juxtaposition of suffering and possibilities for personal gain from reading the work of physician Siegel (1990) and a fellow cancer traveler.

ML drew from eastern wisdom the belief that she, rather than her disease or pain, ruled her body and that creative movements replenished her energy. She appreciated the expression of life force in Asian art and, from that perspective, she approached her out-of-balance predicament as an artist's blending of art in life. Inspired by reading From the *Mustard Seed Garden Manual of Painting* (Sze, 1977), she strove to find "the balance of disharmonies inside the harmony of nature" and recognized that it was important

(n)ot to be unmindful of the full import of dire diagnosis, ... to be aware of the patterns of our being, and gently compassionate toward learned coping strategies ... living one's life being the artist of one's life—we dab into the ink, we swish the brush of our bodies, move the line across the page, make the shape and so use and strengthen the ch'i (sic)—(0'Connor, 1998, p 126)

Encouraged by how interdisciplinary readings in the humanities and social sciences validated her powerful personal experiences, ML convinced her faculty committee that she could take her arts and healing ideas to others at DFCI. Since there was no formal administrative connection between Dana-Farber and Lesley University and she had her own contacts as a result of her patient provider relationships, ML chose to operate from a framework of personal encounter and set out to see what doors she could open at DFCI to transform her vision of the hospital-based healing environment into reality. Her faculty team had become aware that a cancer patient's sense of time has an urgency about it and, thus, supported ML's unconventional approach to initiate her creative arts ideas. With her medical prognosis, there was not the luxury of time for crossing bureaucratic bridges.

Because of her mostly favorable personal experiences with western medical clinical staff, she was puzzled as to why something so harmless as inviting a patient to draw or write a poem rather than just to "pass time" would raise concern or caution. She reported to her faculty committee that while she believed her efforts were clearly value-added and the patients she met affirmed that the art experiences helped them, some staff led her to believe the contrary. ML grew frustrated by references to art as "superfluous" rather than a means for healing.

With the pressure of limited life expectancy, ML redirected her energy toward completing her master's thesis to root her ideas in theory and evidence-based practice so the scientific community would pay attention. Additionally, she became clear that she needed to consolidate her program development efforts in order to conserve her limited physical energy. She explored ways to educate staff and gain support for her ideas whenever she visited DFCI for medical treatment. She approached physicians, nurses, and staff she knew for their support. Later she recruited employees who were artists themselves.

Not surprising to anyone who knew her, ML succeeded in recruiting one of her doctors to sponsor her cause of using the arts as a healing tool, and he responded by leading her to the clinical oncology nurse at the Blum Family Resource Center. While pursuing research on her melanoma condition and options for treatment, the oncology nurse had responded compassionately as one who understood her journey and appreciated her creative ideas.

Responsible for running the Blum Center, a repository of information located behind the information desk on the first floor at DFCI, the nurse became the DFCI "mover and shaker" who succeeded in formalizing ML's program and shoring its foundation during the early years.

Sadly, it was not long before ML headed back to DFCI to investigate a lump on her neck, only to learn that the cancer had resurfaced as an advanced Stage IV malignant melanoma. ML was given a life expectancy of 24 months. Nevertheless, she called her INDS faculty to say that she did not want to give up and, contrary to medical advice, planned to pursue her thesis writing in full force.

ML completed her master's degree during the same semester that she applied for admission to doctoral studies. The INDS faculty committee encouraged her to use the master's work as a springboard to doctoral study and to stay at DFCI for her doctoral field placement to hone her integrative art and healing ideas. To provide continuity, ML asked her INDS faculty chair to continue as doctoral faculty. She also asked a renowned Jungian analyst to join her committee, and the two became her field-based doctoral faculty. Strategically, ML maintained the Lesley University and DFCI connection, strengthening the professional relationship through establishing a significant doctoral internship.

The path of doctoral studies was mired by ML's experience of refractory disease, which led to her enduring more trials, painful side effects, and toxicities of experimental research. Still, she worked indefatigably to realize the relationship between scholarship and practice in fulfillment of her personal dream to help others heal through the arts. At one point, ML attributed remission of metastatic disease to colorful and vigorous drawings of her dying liver. Her DFCI research fellow was surprised to notice the medically inexplicable change and acknowledged that, at the least, making art kept her focused and appeared to improve the quality of her life.

Even the language ML used to approach her treatment embraced the power of the arts. Her lifeline lay in a vaccine that, in her words, could "paint a target" on her cancer cells and prompt her immune system to fight back. For ML, the arts were not only for aesthetics; they were a base of personal power and a mode of communication.

ML's doctoral work coincided with facing her own challenges with the end stage disease, and the persistent threat of dying gave her the impetus that she needed to step up the pace of her work without yielding to tempting diversions. She was a student faced with a literal deadline. Her dissertation abstract captures her ideology, context, and purpose:

This work examines the nature of the unconscious and conscious connection, right and left brain hemispheric function, and body-mind unity as background for understanding personal creative process and its impact on healing. This work was accomplished in the underworld of my own disease process. Scholarship and art are used to meld language and image to what is a verifiable healing process. This work is intended as background and

enrichment for medical and health caregivers and most particularly for other persons similarly challenged.

Few graduate students excel in multiple aspects of scholarship and practice; ML was one who did. She capably read hundreds of sources in eastern and western philosophy, psychology, religion, art history, mind-body medicine, and expressive arts therapy; and, she lived out her beliefs and values as she painted, wrote poetry, and danced unhesitatingly in Isadora Duncan fashion as the spirit moved her.

With advancing disease, ML knew her energy would ebb. She hastened to use her intelligent, soft-spoken manner to succeed in engaging patients and converting medical staff one by one, encouraging each to dabble in the arts alongside her, in a group, or in a private space—wherever most comfortable.

In her final weeks, ML chose deliberately to exhaust her energy at DFCI to help patients get beyond their pathology, infuse their spirits into artwork, and display their uniqueness through artistic creations in celebration of living.

In her life, ML used creative expression as an extension of self. By example, she covered her emotional pain in public by wrapping a gorgeous scarf to disguise her neck tumor. Typical of her dramatic persona, she made an entrance into a room by accentuating style and not pathology. In preparation for her funeral, she fashioned a decorative box for her remains to be placed on the altar at her memorial service with a request that the congregation acknowledge her gift back to God. For ML, beauty was in both the expressive process and the creative product, even at death.

During the final week of her life, ML called three "treasured mentors" to her bedside to discuss the implications of her doctoral work, especially as it related to the creative arts. In addition to her DFCI and Lesley mentors, ML entreated her field-based mentor and author Shaun McNiff to join her final gathering. Fully aware that death drew nigh on that day during the last week in August, ML regally held court in her home, as ocean breezes blew in the window and water lapped on the seawall of the Atlantic coast. *She had designed the scene for her penultimate act*.

While a Rockport bedroom hardly seemed a likely location for formalizing a Lesley and DFCI partnership, no one could have dissuaded ML from her mission. She assigned places for her "guests" immediately next to the bed so that she would not have to raise her voice or exert herself unduly, and proceeded with her carefully constructed agenda. Indeed, with the presence of one of her adult children as her familial witness, ML's intense focus made those in attendance aware that this was not a meeting for social conversation or intellectual discussion, but rather for focused program planning. In an unforgettable blend of aesthetics and purpose, ML clearly reiterated her vision and beseeched the three mentors to carry forth her work. All three honored ML with a covenant, formalizing the Dana-Farber Cancer Institute Creative Arts Program.

With humor and style, and no doubt with satisfaction of the birth of her program, ML died a few days later on Labor Day, author of a dissertation completed three days before and after bidding farewell to her six children, siblings, and mother.

In her honor, the DFCI held a posthumous doctoral award ceremony, with the DFCI President, representatives of ML's medical team, members of the Lesley University academe in attendance, ML's mother, and her six children. Memorial speakers noted ML's contributions to DFCI as patient and activist, and announced the birth of the DFCI program focusing on creative arts as companion cancer therapy, with ML attributed status as founder. The three mentors who had been at her bedside, present again in the graduation audience, became the founding members of the advisory board: Susan DeCristofaro, Shaun McNiff, and Marion Nesbit.

Pioneering a patient's vision proved life transforming, not only for patients but for others involved, as well. The Creative Arts Program at DFCI is now flourishing, supported by an advisory board comprised of 8 members who share ML's values and continue to sustain and develop her ideas. The program now has a staff artist, visiting artists, volunteers, and provides student internships. Program offerings have expanded beyond poetry and visual arts to include drama, music lessons, and creative writing, and—in tribute to ML's playful wit—a HumorUs Healers clown program.

The co-authors, introduced by ML in the roles of her INDS graduate faculty and DFCI oncology nurse, have grown as colleagues into friends, united by ML's spirit that continues to pervade their work together. The Lesley University and DFCI connection increased when Shaun McNiff returned to Lesley as University Professor. Ten years of considerable efforts to form a niche in a teaching hospital have led to offerings only imagined ten years ago. The members of the advisory board believe that ML would be pleased to realize that the Jimmy Fund auditorium would see the production of WIT featuring DFCI patients, staff, and physicians as actors. She would delight in noticing the art group at the Blum Resource Center table, sharing stories of their cancer and healing experiences as they created boxes. ML would stop to listen to the melodic movement from a cellist funded by a grant and happily join a group of dancers learning line dances in a private medical conference room. Surely she would laugh out loud to see her beloved nurse, recently graduated from hospital clown training, romping in her clown get-up with both child and adult patient populations.

No doubt ML would be thrilled to see how the original 3 founders now carry the hospital and academe partnership forward in lively advisory meetings of a cross-section of DFCI medical and administrative staff intermingling with faculty representatives from 3 colleges and universities. She would recognize that the program legacy was extended through education of interns, public exposure during Arts Week, and in national and international presentations. And, she would sigh relief knowing that there is financial support through donations from grantors, art show sales, and other fundraising efforts.

Most of all, we would like to believe that ML would be touched by participants' smiles, notes of gratitude, and proud displays in the DFCI showcase of products the patients and

families exhibit proudly. She would be reassured that her Creative Arts Program is growing to the benefit of its participants and be impressed by the sustaining commitment of the partnership to take her values and ideas out into the world for the benefit of others.

End Notes

(1) ML O'Connor's comments later served as text in the Creative Arts as Companion Cancer Therapy program brochure.

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