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Integrating Art and Narrative to Enhance Quality of Life in Palliative Care

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Integrating Art and Narrative to Enhance Quality of Life in Palliative Care

Abstract

Lacie Lee Wallace, a mixed-media artist from Wheeling, West Virginia, is featured on the cover of the Fall 2018 issue of *The Open Journal of Occupational Therapy* (OJOT). The photograph depicts Lacie holding a self-portrait painted by artist CeCey Rose. Lacie's physical appearance in the photograph is strikingly different from the physical appearance of the woman featured in the painting. The portrait was created 4 years before Lacie was diagnosed with advanced stage colon cancer. In the year following the diagnosis, Lacie lost nearly 100 lbs. as a result of an aggressive treatment regimen. When the palliative care team at West Virginia University Ruby Memorial Hospital launched a clinical study on narrative medicine, Lacie was one of the first patients to participate. Throughout her illness experience, Lacie found comfort in sharing both her art and her life story. Lacie's personal narrative made it clear just how meaningful art was in her life. Narrative medicine empowered Lacie's palliative care team to improve patient care and enhance her quality of life.

Keywords

occupational therapist, occupational therapy, occupation, art, narrative, palliative care, quality of life, cancer

“We are as surrounded by narrative as we are by air. We live in narrative. We live out narrative To be human is to know, tell, and live stories” (Schell & Schell, 2008, p. 126). Stories are a part of life. A personal narrative is a description of one’s life story based on lived human experience. We often identify ourselves by describing meaningful occupations and experiences in story form. Thus, narrative plays an integral role in the formation of personal identity. Appreciation of narrative is evident in occupational therapy practice. A patient’s life story provides critical information about occupational performance throughout the evaluation and intervention process. Narrative reasoning is a form of clinical reasoning that empowers occupational therapists to better understand how an illness experience impacts the patient’s quality of life. Thinking in narrative allows the therapist to assign meaning to the patient’s individual values, concerns, and expectations. An unexpected illness or injury may have a profound impact on the trajectory of one’s life story. To provide patient-centered care, health care providers must consider the patient’s whole life story.

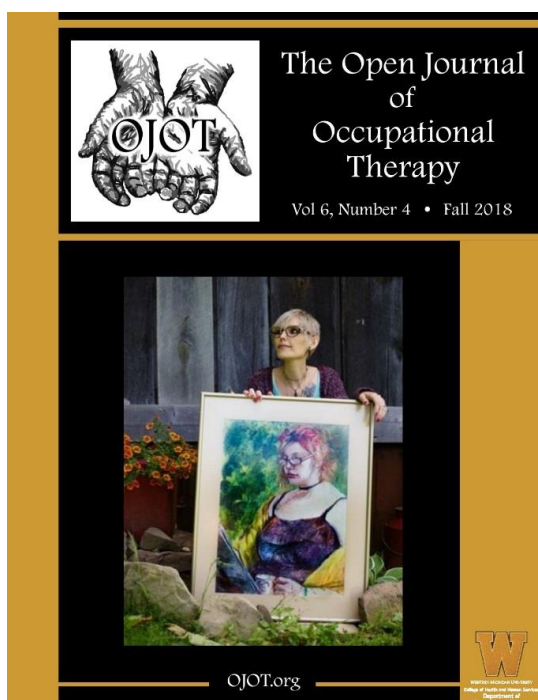


Figure 1. Fall 2018 Cover of OJOT

Lacie Lee Wallace, a mixed-media artist from Wheeling, West Virginia, is featured on the cover of the Fall 2018 issue of *The Open Journal of Occupational Therapy* (OJOT) (see Figure 1). The photograph depicts Lacie holding a self-portrait painted by artist CeCey Rose. Lacie’s physical appearance in the photograph is strikingly different from the physical appearance of the woman featured in the painting. The portrait was created 4 years before Lacie was diagnosed with advanced stage colon cancer. In the year following the diagnosis, Lacie lost nearly 100 lbs as a result of her treatment regimen. When the palliative care team at West Virginia University (WVU) Ruby Memorial Hospital launched a clinical study on narrative medicine, Lacie was one of the first patients to participate. Throughout her illness experience, Lacie found comfort in creating art and sharing her life story. Lacie’s personal narrative made it clear just how meaningful art was in her life. Narrative medicine empowered Lacie’s palliative care team to improve patient care and enhance her quality of life.

Lacie’s life story consisted of several meaningful roles, including wife, mother of two, friend, artist, and musician. She was known for writing poetry, writing and performing music with her husband and daughters, and maintaining a beautiful garden. She also put herself through school to become a teacher while working multiple jobs. For Lacie, one of her more meaningful roles was that of an artist. She enjoyed combining a variety of media and creating interactive works of art from everyday objects. At the age of 33, Lacie was diagnosed with Stage 3 colon cancer. After seeking a second and third opinion, Lacie began an aggressive treatment regimen. She endured multiple surgeries, radiation, and several combinations of drugs with debilitating side effects. During that time, she continued to work and care for her family. Unfortunately, none of the treatments worked for more than a few weeks. Less than 6 months after receiving the initial diagnosis, Lacie’s cancer progressed to Stage 4. When treatment was unable to slow the growth of Lacie’s cancer, doctors referred her to palliative care to assist with symptom management.

The presence or absence of illness can have a profound impact on quality of life. Palliative care aims to provide an additional layer of support to ease suffering in patients with serious illness. Palliative care is typically provided in addition to traditional curative treatment, which is dominated by evidence-based medicine (EBM). The practice of EBM relies on the best available research to guide decision-making and prescribe interventions in a specific circumstance. Therefore, client factors outside of the physiological function of body systems are typically not addressed in a traditional plan of care. The American Occupational Therapy Association (AOTA) defines client factors as the specific capacities, characteristics, or beliefs that reside in a person and influence participation in occupations (AOTA, 2014). The factors include body functions, body structures, values, beliefs, and spirituality. Client factors influence personal motivation to engage in occupations and give life meaning (Puchalski et al., 2009). Meaningful occupations and experiences are personal and subjective. Therefore, strong communication between the patient and the palliative care provider is key. The role of narrative medicine in palliative care is to improve patient-physician communication (Rosti, 2017). Communication is an important but often overlooked factor in health care delivery. Personal narrative is not only a way to communicate, but also a way of perceiving the world (Schell & Schell, 2008).

In 2016, WVU Medicine launched a clinical trial on narrative medicine. The study was developed by Dr. Carl Grey, a hospice and palliative care specialist, and Renee Nicholson, assistant professor of Interdisciplinary Studies at WVU. Renee served as the project's lead writer. The purpose of the study was to examine whether personal narrative could enhance quality of life and assist with care planning in patients with advanced stage cancer. Dr. Grey's primary interest was whether the inclusion of narrative in an advance directive would provide greater context to support the patient's final wishes. Additional expertise was brought to the team by Dr. Monika Holbein, M.D., hospice and palliative care specialist and professor at WVU. The team was awarded a grant that enabled them to launch a 2-year study at the WVU Cancer Institute's infusion center. Lacie was one of the first patients to participate.

The study approach drew from previous work on narrative medicine by Dr. Rita Charon, as well as Dr. James Pennebaker's work in expressive writing. During the study, researchers worked one-on-one with participants to document their personal narratives. The McGill Quality of Life Survey was administered before and after each participant's personal narrative was created. The survey was followed with questions regarding the participant's level of enjoyment while creating the narrative, and his or her understanding and level of preparedness to have a conversation about advance care planning. After the stories were collected and transcribed, qualitative analysis was performed to identify common

themes related to quality of life in palliative care. The researchers looked for correlations between quality of life ratings at the beginning and end of the study. The finished narratives would become part of the patient's permanent medical record.

Renee Nicholson's role was to document each participant's personal narrative during chemotherapy treatments. The patients were encouraged to talk about any topic that was important to them. "Lacie's story stood out to me because she spoke so much about what art meant to her," said Renee. For Lacie, art was therapy. "Cancer Body" (see Figure 2) is a 9" x 12" portrait made from mixed media. Through art, Lacie came to terms with her cancer body. Art brought Lacie comfort and provided a means to chronicle



Figure 2. "Cancer Body" by Lacie Lee Wallace, courtesy of Kara Lofton

her illness experience. Lacie perceived her cancer as a side note in her narrative, not the main chapter. Instead, she focused on memories that made her happy and what inspired her as an artist. One of her favorite memories was posing as a model for a life drawing class at the Stifel Fine Arts Center. Lacie enjoyed dressing up in styles popular in the 1920's to give the artists something interesting with which to work. "Self-reflection is the whole point," said Renee. "This is how you learn what is most important to the patient."

In 2017, Rondalyn Whitney, PhD, OTR/L, FAOTA, joined the occupational therapy program at WVU. As a clinician, clinical researcher, and content expert in therapeutic use of narrative, she was well-prepared to assist the research team. Rondalyn also serves as a member of the OJOT editorial board. "When I heard about the study, I was intrigued," she said. When Rondalyn joined the study, the research team had already identified three important themes: hobbies, vocation, and family. "These are occupations," said Rondalyn. "The team had not yet made the connection to occupation; however, they knew the variables they had identified were not providing the information they wanted." Rondalyn stepped in to assist. She introduced Dr. Grey and Dr. Holbein to the Occupational Therapy Practice Framework (OTPF). "I explained that what they were actually looking for was occupations," she said.

With help from student researchers, Lynsey Soule and Elliott Theeke, the team began qualitative analysis of the personal narratives of 24 patients. As Rondalyn coded Lacie's narrative, she began to see her as an occupational being. Although Lacie held several important roles in life, art overshadowed all of them. "Even Lacie's children coded as works of art that would ultimately be part of her legacy in the world of art," said Rondalyn. It became evident that Lacie was first and foremost an artist. Rondalyn believed Lacie's artwork provided insight into the mind of a patient in need of occupational support. "What we learned from her narrative was how art can be used as a therapeutic modality to improve patient care." The result of Rondalyn's qualitative analysis was an occupational portrait that palliative care physicians could use to identify occupational potential in their patients. Rondalyn presented the idea to Dr. Grey. "He understood it completely," she said. "Physicians call it adaptive coping. Occupational therapy is the ticket to enabling it."

Occupational therapy can play an important role in enhancing quality of life for patients living with a terminal illness. Russell and Bahle-Lampe (2016) presented a historical analysis of occupational therapy's involvement in palliative and hospice care. According to the authors, it was not until 1986 that AOTA published a position paper acknowledging occupational therapy's role in hospice care. The paper affirmed that terminally ill patients can lead productive and meaningful lives and that occupational therapy can provide an essential service during this process (AOTA, 1986). When providing end-of-life care, an occupational therapist can obtain the patient's occupational history, which includes identifying meaningful life roles, routines, and activities of daily living. An occupational therapist is also concerned with optimizing the patient's functional abilities. This requires maintaining the patient's autonomy and independence, despite limitations, while in alignment with the patient's treatment goals (Russell & Bahle-Lampe, 2016). Although the role of occupational therapy in end-of-life care has yet to be clearly defined, the primary objective is to empower patients with terminal illness to live life to the fullest. This goal is achieved by facilitating participation in meaningful occupations, such as art.

On October 10, 2017, Lacie's life and art were honored with a reception that was held at the WVU Health Sciences Library. Her exhibition, entitled "Bodies of Truth: An Artist's Creative Exploration Through Cancer," was scheduled to open the next day. Original paintings were paired with personal narratives written by Lacie and others who were close to her. The exhibition shared Lacie's

illness experience in a way that only she could. “Showcasing Lacie’s art and story together provided the opportunity to move beyond a theoretical understanding of narrative medicine,” said Renee. “Her artwork in particular made the theory tangible.” Lacie’s art allowed the physicians, faculty, clinicians, and others from WVU Medicine to see the value in art-based interventions. Cancer treatment programs all over the United States have been incorporating art therapy for years. For example, the University of Michigan Medicine Comprehensive Cancer Center offers art therapy workshops at no cost to patients and their loved ones. The workshops aim to decrease feelings of anxiety and isolation while enhancing coping skills and quality of life. Because of Lacie’s story, Dr. Holbein raised money to purchase three fully stocked art carts for patients receiving cancer treatments. The research team considers the art carts to be a tribute to Lacie’s work.

Lacie Lee Wallace’s life story includes meaningful roles as a wife, mother, friend, musician, and artist. Lacie enjoyed creating interactive works of art from everyday objects. Ultimately, Lacie perceived everything in life as an extension of her art. When a serious diagnosis changed the trajectory of Lacie’s life story, art and narrative enhanced her quality of life. Sadly, Lacie Lee Wallace passed away on October 14, 2017. Her death came just days after the opening of her art exhibition. Before her passing, Lacie shared some reflections on narrative medicine during a radio interview with Kara Lofton, Appalachia Health News Coordinator at West Virginia Public Broadcasting. “We want to feel like we are important,” she said. “We want someone to hear our story. I think art is therapy in that way. I think it’s the same with storytelling. You know, it builds us up. Even if it’s just for one day, or one minute, or one hour. You feel empowered because someone is listening and actually cares about your story.”

Visit the OJOT Gallery to view more of Lacie’s art:

https://scholarworks.wmich.edu/ojot_occupationandartist/24/

To make a donation to Lacie’s Legacy call Information Helpline at (304)233-6300

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