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Creating a New Normal Through Engagement in Meaningful Occupation

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Creating a New Normal Through Engagement in Meaningful Occupation

Abstract

Katie Edick, an occupational therapist and artist based in Portland, Michigan, provided the cover art for the Winter 2021 edition of *The Open Journal of Occupational Therapy* (OJOT). "Katie Bird" is a 4" x 6" watercolor painting. After receiving a diagnosis of metastatic breast cancer (MBC), Katie set out to find a new purpose and leave a legacy. She made the decision to live with intention and choose life experiences that create joy. Through engagement in meaningful occupations, such as painting and patient advocacy, Katie is creating a new normal.

Keywords

occupation, occupational therapy, art, painting, metastatic breast cancer, Katie Edick

Credentials Display

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What makes life worth living? In the book *Finding Flow*, author Mihaly Csikszentmihalyi proposes the answer lies in experience. “To live means to experience – through doing, feeling, thinking” (Csikszentmihalyi, 1997, p. 8). There are limits to what we can do and feel. For example, experience takes place in time, which is the ultimate scarce resource in life. To a certain extent, we have control over how time is spent.

What our life is consists in experiences related to work, to keeping things we already have from falling apart, and to whatever else we do in our free time. It is within these parameters that life unfolds, and it is how we choose what we do, and how we approach it, that will determine whether the sum of our days adds up to a formless blur, or to something resembling a work of art. (Csikszentmihalyi, 1997, p. 13)

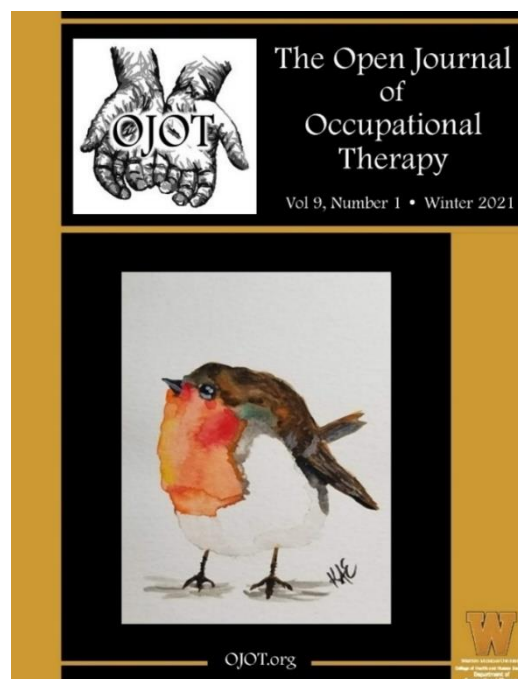
What happens when terminal illness determines how time is allocated? After receiving a diagnosis of metastatic breast cancer (MBC), Katie Edick choose to engage in experiences that create joy. An occupational therapist and artist based in Portland, MI, Katie provided the cover art for the Winter 2021 edition of *The Open Journal of Occupational Therapy* (OJOT). “Katie Bird” is a 4” x 6” watercolor painting (see Figure 1). Katie set out to find a new purpose and leave a legacy. She made the decision to live with intention and choose life experiences that create joy. Through engagement in meaningful occupations, such as painting and patient advocacy, Katie is creating a new normal.

Katie grew up in Grand Ledge, MI. As a child, she liked to make things with her hands but never thought of herself as an artist. Katie and her siblings, David and Laura, grew up surrounded by creativity. Their mother, Kathe, is a talented oil painter, singer, and seamstress. A self-described perfectionist, Katie did not enjoy sewing. Her work had to be precise. “I could not use sewing as a release,” she said. One area Katie is passionate about is helping people, especially children. “It is in my blood to help those in need,” she said. “It speaks to my soul.” In the eighth grade, Katie watched a video about a physical therapist who helped a child learn to walk using a prosthetic limb. “I knew that was what I wanted to do,” she said.

After graduating from high school, Katie enrolled at Grand Valley State University (GVSU) to pursue a career in pediatric physical therapy. “Thankfully, I had a wonderful advisor, Theresa Bacon-Baguley, who told me I was better suited for occupational therapy,” said Katie. After job shadowing, Katie made the commitment. “Theresa was right,” she said. “I needed the creativity and meaningful purpose of occupation behind the why of it all.”

After completing her undergraduate degree, Katie was accepted into the Occupational Therapy Program at GVSU. Katie credits professor Denise Meier for expanding her passion for working with children. “Denise was so amazing and knowledgeable,” she said. In 2000, Katie graduated with a master’s degree in occupational therapy. Katie looked forward to attending the annual alumni events and

Figure 1
Cover Art for OJOT Vol 9, No 1, Winter 2021



reconnecting with Denise. “She always showed genuine interest in me and wanted to hear about my life as an occupational therapist,” said Katie.

After graduation, Katie’s first job was in pediatric rehabilitation at Sparrow Hospital in Lansing, MI. She was initially offered the job after a Level II fieldwork placement. Katie worked with children from birth to 18 years of age in both inpatient and outpatient settings. She gained experience in the neonatal intensive care unit, pediatric intensive care unit, and wound clinic. “It was my dream job. I learned so much,” said Katie. In 2005, Katie transitioned to a new role in early intervention with the Ionia County Intermediate School District. She provides family-centered occupational therapy services to young children birth to 3 years of age and their families. “I empower families to take care of their child,” said Katie. “This helps them to recognize how powerful they are as advocates.” Katie continues to enjoy working in this role today.

In addition to her passion for helping children and families, Katie loves to instill excitement in occupational therapy students. In 2011, Katie accepted the role of part-time clinical affiliate professor in the Occupational Science and Therapy Program at GVSU. It was Denise who recruited Katie during an alumni event. “Denise mentioned GVSU was launching a hybrid program and she wondered if I would be interested in teaching the pediatric content,” said Katie. As a new professor, Katie began to experience impostor syndrome. “I did not believe that I was smart enough to teach at the graduate level,” said Katie. “Once again, Denise taught me everything I needed to know.” Sadly, in 2014, Denise was diagnosed with colon cancer. She fought bravely for just over 1 year. To Katie, Denise was more than a colleague. “She was my professor, mentor, and friend,” said Katie. “I love and miss her every day.” Katie maintained her roles as an occupational therapist and professor for several years. Although life was chaotic, she enjoyed sharing her expertise and passion for pediatrics with occupational therapy students. “Regardless of whether students want to work with children or adults, I enjoy laying the groundwork for becoming brilliant occupational therapy practitioners.”

In August of 2016, Katie and her husband Brent traveled to New York City to celebrate her fortieth birthday. During the trip, Katie noticed pain in her right breast and shoulder, which she attributed to increased anxiety and stress. With her annual physical coming in September, Katie decided to wait to address the issue. During this appointment, she scheduled her first mammogram. Because of Katie’s pain, the doctor ordered an additional ultrasound to take place immediately after the mammogram. On entering the ultrasound room, the technician informed Katie that a radiologist would be there soon to perform her biopsy. “My heart fell to my feet,” said Katie. “I was so confused.” Katie tried to explain that she was only there for an ultrasound. The radiologist confirmed the biopsy was necessary because of abnormal cells detected in the mammogram. The results of the biopsy confirmed that Katie had breast cancer. More specifically, invasive ductal carcinoma of the right breast Stage 2B. The stage of breast cancer is based on the size and location of the primary tumor, the spread of cancer cells to nearby lymph nodes or other parts of the body, tumor grade, and whether certain biomarkers are present (National Cancer Institute, 2020). Katie’s diagnosis was contingent on a positron emission tomography (PET) scan that would determine whether the cancer cells had spread to other parts of the body.

Katie understood that cancer detected in the early stages can often be cured. She breathed a sigh of relief. And then Katie remembered the pain in her shoulder. The PET scan found the breast cancer had spread to Katie’s spine and liver. Her diagnosis was advanced to Stage 4 MBC. The Susan G. Komen Foundation (2020) describes MBC as breast cancer that has spread to other parts of the body, such as the

bones, lungs, liver, or brain. After receiving the news, Katie remembers sitting in her oncologist's office. She watched the doctor draw a line through the word "cure" on the piece of paper held in her hands. The doctor informed Katie there is no cure for MBC; however, it could be managed like a chronic health condition, such as diabetes. This experience was ironic for Katie considering Denise, who recently passed away, received the same information after her diagnosis.

Katie's diagnosis came at a chaotic time in her life. "Then, to find out I was Stage 4 and terminal," she said. "I did not want to give anything up." Katie's new normal was soon framed by a demanding treatment regimen. Every 3 weeks, she receives chemotherapy infusions. The side effects include extreme fatigue, joint pain, gastrointestinal issues, and peripheral neuropathy. After treatment, Katie often struggles with mental stamina and word recall. "Chemo brain is real," she said. At first, the side effects were mild and manageable. Katie was able to continue working as an occupational therapist on week days. Over time, the side effects grew more debilitating. Today, short-term memory and word recall are challenging for Katie. "In occupational therapy, we teach our clients compensation and adaptation," she said. "I am not going to use this as an excuse." Katie's treatment plan will require regular infusions and oral medications for the rest of her life. In addition to chemotherapy, Katie has a PET scan every 4 to 6 months. The purpose of the scan is to detect abnormal cell activity and determine the effectiveness of treatment. For Katie, scan time brings a heightened sense of anxiety and mortality. "What if the cancer progressed, or spread to a new area?" asks Katie. Waiting for the results brings a strong rush of emotions that wash over her like a wave.

As Katie sought strategies to cope with her feelings, she made the decision to focus on faith, not fear. The first year after the diagnosis, Katie envisioned herself sleeping in God's hands surrounded in white light. "This helped me to sleep soundly," she said. When Katie is fearful or anxious, she takes a step back to breathe. "Fear does not get you anywhere. It just sucks up the space in your heart where faith lives," she said. Katie makes a conscious effort to remain present with her feelings. "You have to let the feelings come. Honor them. Accept how you are feeling and then let it go," she said. "Experience it all, the good and the bad. There is no right or wrong. When you feel it all, still try to choose joy." Katie chooses to find the joy in her new normal. She admits that sometimes it can be difficult to wake up happy or not to be sad. Especially in the current climate. "You can always find something good in every day," she said. "Sometimes it is small, but you can still choose joy. It really is a choice."

Katie is intentional about how she spends her time and energy. "Everything I do must create joy," she said. Katie feels blessed that she has time to prepare to leave a legacy for her children, Drew and Anna. "Preparedness is peaceful," she said. "It makes me feel less anxious about the future." Katie likens her efforts to preparing a fallout shelter for Drew and Anna. Some of the items in her shelter include scrapbooks, greeting cards for big occasions (i.e., graduation, marriage, and babies), and personal letters Katie writes during each chemotherapy infusion. "I plan to give them their notebooks when they graduate from high school," she said. Katie is mindful that she is in an unusual situation. "Others who pass away unexpectedly are not given the same opportunity," she said.

In 2017, Katie shared her story with the world. "A friend sent me a link to a program called Crowns of Courage," said Katie. Henna tattoo artist Amanda Gilbert started the program to help women battling cancer to feel empowered and beautiful and to share their stories. Each henna design is unique and personal, just like the woman who wears it. Amanda's goal is to bring happiness and healing through her art. Twenty-two women were "crowned" with intricate henna tattoos on their heads, shoulders, and arms.

Katie was one of the participants (see Figure 2). In collaboration with makeup artists and a photographer, *Crowns of Courage* became an official entry in ArtPrize 2017, an international arts festival located in Grand Rapids, MI. “It was difficult to put myself out there, to have pictures taken and to share my story,” said Katie. For Katie, the experience provided an unexpected outlet for self-expression and stress relief. “I found it to be powerful and cathartic,” she said. “I did not realize how much I needed it.”

The ArtPrize exhibition brought much needed joy to Katie’s life, so she continued on a journey of creative self-expression. Katie started writing an online blog to chronicle how her new normal was affecting her. She and Laura started taking “sister adventures” together. “Peace on Isle Royale” is a 5” x 7” watercolor painting inspired by a trip to Isle Royale National Park (see Figure 3). One adventure took place at a mineral spa near Santa Fe, New Mexico. At the time, Katie was managing a family, job, and terminal illness. Her life felt anxious and muddy. “Trying to find a new normal is hard,” she said. At the spa, Katie noticed a woman creating beautiful watercolor paintings on small paper tiles. She stopped to admire the paintings and compliment the artist on her work. A few hours later, the artist approached Katie and offered her a painting. She selected one with the words “Hope Radically.” During conversation, Katie learned the artist was living with Stage 4 thyroid cancer. “Spending the day at the spa was a wonderful way to cleanse my soul and reflect on where I was, and where I wanted to go,” said Katie.

Upon returning home, Katie started watercolor painting in the evenings as a means to relieve stress. “Watercolor is free flowing and adaptable, which is perfect,” she said. Katie enjoys giving her paintings to family and friends. “Everything I paint has meaning and brings joy to my life,” she said. For example, Katie paints birds for her parents, Pete and Kathe. She paints classic cars for David and scenes from nature for Laura. “Dreaming of Northern Lights” is a 5” x 7” watercolor painting (see Figure 4). “The night sky is one of my favorite things to paint,” said Katie. “It is very forgiving and there are no rules.” Katie also loves to paint flowers. After the diagnosis, Katie found sunflowers to be bright and cheerful. She relates to them. “Even though I am going through dark times, I can stand tall,” she said. “Sunflowers have deep roots. They are grounded and turn to follow the sun.” This year, Katie is making hand-painted bookmarks to give as Christmas gifts. She refers to them as “small pictures of joy.” Katie includes an encouraging

Figure 2
Katie Edick in Crowns of Courage (2017)

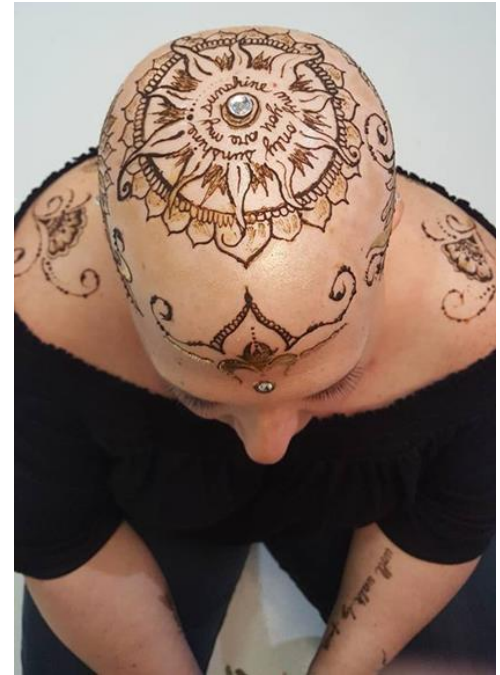


Figure 3
“Peace on Isle Royale” (2019) by Katie Edick



personal message on the back of each painting she gives away. “For me, it’s therapeutic,” she said. Through watercolor painting, Katie has found her flow.

According to Csikszentmihalyi (1997), flow describes the effortless action people feel in moments that stand out as the best in their lives. During moments of flow, “what we feel, what we wish, and what we think are in harmony” (p. 29). “When you are in flow you lose track of time,” said Katie. “That is what watercolor painting does; it puts me in my flow.” Katie says being diagnosed with a terminal illness and living from scan to scan was forcing her brain to overthink. She needed an outlet that did not have to do with cancer. “Writing my blog was cathartic, but it was still about my feelings and living with cancer,” she said. “When I am painting, I do not think about cancer. I can just create and find joy in that space” (see Figure 5).

As an occupational therapist, Katie encourages the families she serves to become advocates for their child. “I always tell my families they can do hard things,” she said. “Now I have to tell myself the same thing.” After her diagnosis, Katie had to learn how to advocate for herself. As an occupational therapist, she had the skills to research what was happening to her in order to ask informed questions. “I wanted to better understand the science behind breast cancer so I could engage in meaningful conversations with researchers and doctors,” she said. Katie began to search for continuing education opportunities she could attend as both a consumer and MBC advocate. Katie gained knowledge and understanding of topics such as genetic testing, immunotherapy, and resources for patients seeking clinical trials. “I learned from clinical researchers and oncologists,” she said. “I learned so much that my brain hurt, but my soul was on fire to do more for breast cancer research.”

After living with MBC for 2 years, Katie became a patient advocate. Her goal was to help other patients who do not have the knowledge, expertise, and energy to advocate for themselves. As a patient advocate, Katie has a seat at the table with doctors and researchers. “I always have my occupational therapist hat on,” she said. “This has been helpful to make informed decisions.” Katie also serves on two patient advocacy committees. Her focus includes bringing awareness to MBC, advocating for women of color and those who do not have readily available access to health care and support groups because they live in rural areas. In addition, Katie has partnered with Imerman Angels, a non-profit organization that provides cancer support by matching newly diagnosed women with a mentor who has been living with MBC.

Figure 4
“Dreaming of Northern Lights” (2019) by
Katie Edick



Figure 5
Photo of Katie Edick, Courtesy of
Christina Baker Photography (2020)



In January of 2020, Katie took her advocacy one step further by testifying at a Senate Health Policy Committee Hearing in support of Bill 612 (Michigan Legislature, 2019). Katie spoke on behalf of the Health Can't Wait coalition, a collaborative of patients, health care providers, and associations dedicated to ending delays in access to health care (Health Can't Wait, 2020). Katie shared her story and asked Congress to limit health care delays for patients with MBC so they have access to needed medications without having to wait. Katie also worked in support of the Cancer Drug Parody Act and the Metastatic Breast Cancer Access to Care Act. "I just want to help people as much as I can in this moment," she said. Katie hopes to increase awareness of MBC and raise funding for research. "On average, the survival rate is two to three years after diagnosis. Each day, 113 men and women die from MBC," she said. "We need research, not ribbons."

According to Wood (1995), an underlying philosophical belief in the occupational therapy profession asks that therapists offer therapeutic occupations that are meaningful threads capable of weaving together the past, present, and future. Katie envisions her life as a quilt where everything is connected. "Denise is one example of a full circle connection," said Katie. "She is part of my quilt." Another connection occurred when Katie was required to attend a breast cancer clinic. She met an occupational therapist providing education on wound care and lymphedema. "I don't know how it came about, but she told me that years ago I worked with her daughter and the work we did inspired her to go back to school to be an occupational therapist," said Katie. "If this didn't happen to me, these events would not have merged. I am where I am supposed to be, doing what I am supposed to do."

What makes life worth living? For Katie Edick, the answer involves helping others in need and leaving a legacy. After receiving a terminal diagnosis, she made the decision to focus on faith, not fear. Katie lives with intention and seeks life experiences that create joy. Engagement in meaningful occupations, such as watercolor painting and patient advocacy, are helping Katie find a new purpose and leave a legacy. Painting provides moments of flow where Katie does not have to think about cancer. Everything she paints has meaning and brings joy to her life. Katie shares her story to help others. As a patient advocate, she empowers others to make informed health-related decisions. Not only does Katie choose to create joy in her new normal, she also spreads joy to everyone she meets.

View more of Katie's art work in the OJOT gallery:

https://scholarworks.wmich.edu/ojot_occupationandartist/33/

Visit Katie's Website: Terminally Joyful: My Life, Living with Metastatic Breast Cancer

<https://www.terminallyjoyful.com/>

Watch the Video Crowns of Courage: 22 Courageous Women: <https://vimeo.com/227986233>

Listen to Katie's testimony on Senate Bill 612: <https://vimeo.com/390050820>

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