Mosaic of Cancer

Sarah Mullen

University of Iowa
THE MOSAIC OF CANCER
An outreach project designed by Sarah Mullen as part of the Latham Science Engagement and Outreach Fellowship Program 2017-2018 at the University of Iowa

Inspiration
The Mosaic of Cancer was inspired by a conversation with a friend. Her grandfather had died of cancer in fall of 2016, within a week of his diagnosis. Frustrated that some disease she did not understand took her grandfather’s life, she asked me a simple question: “What does cancer look like?” The question echoed in my head. I study cancer as a cancer biology lab assistant and have seen cancer cells under a microscope. I worked as an autopsy assistant in the University of Iowa Hospital’s morgue and saw cancerous tumors postmortem. I have over 40 hours of clinical experience shadowing oncologists and have seen cancer on patients’ exterior or on their imaging scans. I have family and friends who are currently living with cancer. Despite my experiences, I could not answer her question. Cancer is multifaceted and understood or experienced uniquely by each person. Thus, I created The Mosaic of Cancer to combine many people’s idea of “what cancer looks like,” thinking this could be a start to an answer to my friend’s question.

Purpose
Cancer is both scientific and human. I sit in lab meetings each Friday listening to how researchers are studying cancer through genetics, molecular biology, pharmacology and more; but, this is not how cancer is experienced. Cancer is inside living people who have emotions, relationships and dreams. My biggest struggle in designing The Mosaic was figuring out how to discuss the scientific aspect of cancer without losing context of its human impact. I decided to ask medical specialists, researchers, patients and loved ones to participate by submitting one or more hand-drawn or digital images of how they see cancer. Scientific terminology inhibits many from understanding cancer biology, so visual illustration of cancer seemed most appropriate to create accessibility to the widest audience. The prompt was open ended, for example: “How do you see cancer?” “How does cancer impact you?” “How do you understand cancer?” I designed The Mosaic with the goal of educating and increasing understanding. For patients, confusion often surrounds the cause of their cancer, what the disease is and how it can be treated. Confusion increases anxiety on top of the physical and emotional burden of cancer. I hypothesized that by increasing understanding of cancer biology and treatment, The Mosaic could alleviate some of patients’ anxiety and confusion. For loved ones, the struggle to understand how a patient is feeling and how to best help that person makes the pain of watching a loved one suffer that much worse. By showing patients’ perspectives, The Mosaic helps loved ones address these struggles. For medical specialists and researchers, The Mosaic
displays the human aspect of the science they study and motivates them to continue pushing towards better treatment and knowledge. The Mosaic increases awareness of the impact of cancer for those who have not been affected by the disease.

**Design**

I began gathering participants through emails and phone calls to people I knew who work with or have been affected by cancer. I created a release form, titled “Dear Participant,” to explain the project goal and prompt and to gather consent to use people’s submitted images in the display.

I created a Facebook page titled “Mosaic of Cancer” ([https://www.facebook.com/groups/14047106666555](https://www.facebook.com/groups/14047106666555)) to invite participants and create a central place that housed the release form and all information so anyone could participate. I posted submitted images and their accompanying stories to the Facebook page every so often to remind the page’s 83 members to submit or suggest people they know to submit. I created participation packets to deliver in person including the release form and 8 inch by 11 inch paper for people to draw on. The project spread through social circles, and multiple people I have never met reached out to submit to The Mosaic. I personally interacted with each participant and received over 50 images in less than two months.

Stained-glass inspired the design of The Mosaic to be a colorful, bright display. I created six unique “stained-glass panes” using Adobe InDesign and an image of stained-glass to guide the combination of shapes. I pieced together each pane on Adobe PowerPoint slides and added an approximately equal number of scientific and human submitted images on each pane. I created a project description slide because I knew I would not always be there to explain the background of The Mosaic to viewers. The slides were printed by the University of Iowa Biology Department as seven 22 inch by 36 inch colored posters. Designing The Mosaic was the most time consuming part of the project, and printing the posters took up most of my $200 budget.

**Display**

The first venue for display was the University of Iowa Hospitals and Clinics’s “Mini Medical School” from February 6-20, 2018. The Mini Medical School is a yearly event open to anyone eager to learn about the topic chosen for that year. Fittingly, the 2018 theme was “Targeting Cancer with Personalized Precision Care.” During this three-week long program, I presented each Tuesday night for varying lengths of time about my undergraduate research project with melanoma (Week 1), The Mosaic in open table format (Week 2), and The
Mosaic in 30-minute presentation format (Week 3). During the open table event, I set out participation packets and colors for attendees to participate in The Mosaic; however, no one drew an image during the event and only a few took a packet. During the preprogram talk, I explained how three types of cancer treatment, chemotherapy, radiation therapy, and immunotherapy, kill cancer. I also discussed the inspiration, creation and purpose of The Mosaic. The Mini Medical School had 213 attendees ranging in age from high school to senior citizen. This audience fit my target group because each attendee had an interest in understanding cancer and many told me they have been personally impacted by the disease.

The next venue for The Mosaic was University of Iowa Blank Honor’s Center in the student commons area. I contacted a few university buildings to ask if I could display the project, but many did not have the space to fit it. Blank Honor’s Center was ideal because I could hang the posters in two rows, as I originally intended them to piece together like real stained-glass.

Two events I presented at were held in the atrium of this building. I shared The Mosaic with underrepresented high school students interested in pursuing science during the “Possibilities in Science: Knowledge for the Future Conference” held in Biology Building East on April 14th. The final showcase event held by the Latham Fellows Program was in this building for donors and anyone interested in hearing about the Fellows’ group and individual projects. In total, The Mosaic hung in 3 different locations and was presented to a variety of audiences.

**Impact and Future**

The Mosaic touched the 42 participants who submitted images, 83 members on the Facebook page, 213 attendees at the Mini Medical School, 15 young adults at the Possibilities in Science: Knowledge for the Future Conference, and anyone who walked past the display in either building it hung in. Qualitatively, The Mosaic’s impact can be described by a few responses I got to the project. At least five participants thanked me for raising awareness for this cause. A friend’s mom who
participated cried when she saw the final product. I received positive feedback from many at the Mini Medical School presentations, such as “this was a great idea,” “I learned something from this, thank you,” and “it is amazing to see someone young and passionate about this cause.” After my preprogram speech for the last Mini Medical School event, a woman approached me and told me she agreed with my message that it is hard to know what to say to your loved one with cancer. She began to cry, and thanked me for helping her reflect on the disease before she walked away. Based on viewers’ feedback, I believe The Mosaic was successful in its goals of increasing understanding, community and awareness.

The project design’s main limitation is that The Mosaic has the greatest impact if I or someone who knows each image’s story is present to explain The Mosaic. I considered writing descriptions for some or all images in The Mosaic but felt these captions would subtract from the beauty of the display and clutter the images. Ideally, I will find an online format to house the images and accompanying stories permanently. Facebook was useful to increase awareness and spread the project idea, but I often felt that social media was too impersonal to share such personal stories. In the beginning of my research, I found an online project by the American Cancer Society titled “Mosaic.” I had already named my project Mosaic of Cancer, so the similarity in naming is coincidental, but I do think that site may be a potential spot to submit and store The Mosaic stories. I would have to get permission from participants to post their story there, of course. Some participants filled out the release form I sent out, but others gave me written permission and did not fill out the form. If this project was to be recreated in the future, a simpler way to give permission would likely increase participation. I tried to make the submission requirements as open-ended and easy as possible so as to encourage maximum participation, but still some people I contacted to participate did not submit because they did not have enough time. For the future, I have all of the stained-glass templates saved and could easily create more posters if I got more submissions. The time and emotional effort required to gather submissions is a barrier to my continuing this project. Especially for patient and loved one submissions, I prefer to give each person my full time and attention, ideally in person. People will tell you their story if you take the time to listen. However, some participants got quite emotional when discussing their story, which is something I appreciated but felt at times inadequately equipped to respond to. Overall, I hope The Mosaic sparks more conversations about cancer between patients, patients and their loved ones, and anyone who seeks to better understand the disease and its human impact. Cancer is sometimes an avoided topic due to the emotions and personal impact involved, but I hope to see this change. Many people I talked to had a smile on their face by the end of our conversation, suggesting that discussing cancer helps people to share their emotions and thoughts in a helpful and relieving way. No one should carry the burden of cancer alone. The Mosaic should be utilized to spark conversation. Even if you do not know what to say, simply asking, “How has cancer affected you today?” is a good place to start. I was worried about sounding too objective while trying to blend the scientific and human aspects of cancer. I found that as long as I spoke respectfully, listened to others and kept calm to emotions, my message was well received. The Mosaic of Cancer for me was a lesson in science communication and an emotional experience. I encourage anyone who is passionate about a topic to design an outreach project like this and turn your negative reactions to pain and suffering into a positive action.
Acknowledgements

Drs. Sue and Bob Latham, donors for the Latham Fellows Program
Lori Adams and Brinda Shetty, Latham Fellows Program instructors
Denice Ackerman, my best friend who inspired this project
Chris Stipp, PhD., whose lab I work in and who helped connect me with researchers and doctors
Jayne Crawford, University of Iowa Hospitals and Clinics Outreach and Engagement Specialist,
Mini Medical School contact
Andrew Willard, Director of Experiential Learning for Blank Honors Center, contact
Steve Kehoe, Administrative Services Coordinator (poster printer) and Biology Building East contact

All participants who submitted images and shared their stories: Adam Dupuy, PhD, Al Klingelhutz PhD, Brad McCabe PhD, Brittany Durham, Carol Mullen, Christopher Stipp, PhD, Dale Anne, Dani Vieni, Daniel Golden MD MHPE, David Price PhD, Dawn Quelle PhD, Debbie Hull, Denice Ackerman, David Gordon MD PhD, Gianna Hansen, Hannah Hildahl, Jeremy Bobera, Joanne Harrison, John Hewitt, Lauren Hewitt, Julia Barcia, Alex Barcia, Karen Van Dyke, Kathleen Pallesen, Katie Pallesen, Kris McArdle, Laura Cohen, LesLee Hacker, Maria Spies PhD, Mary Tracy, Maureen McGargill PhD, Michael Henry PhD, Mohammad Milhelm MD, Nicholas Mullen, Patricia Kiscoan, Rochelle Mullen, Rosie Damien, Shelly Fleck, Susie Rotert Dotson, Timothy Yahr PhD, Amy Yager DNP APRN-NP FNP, Anonymous