

Moments Held

"Moments Held" photography is a part of a larger project, "Legacy, Life and Courage," a collaboration with the University of Michigan Comprehensive Cancer Center's Grief and Loss Program and Complementary Therapies Program. The intent of the pilot project was to support and enhance coping for patients and their families living with a diagnosis of cancer through the use of legacy-making materials. Two patients, Mary and Bob were selected as participants for the project. Both had significant diagnoses and were actively being treated in the hospital (one inpatient and the other outpatient). I believed that the documentary approach was appropriate for this project. The project also includes an accompanying video documentary. While I typically tell patients' stories through photographs, I considered going into this that I'd also ask, after a few days with them, if these two patients would consider talking with me with a video camera rolling. Both agreed. With but a small amount of structure in mind, I hoped to be open and present to what might occur in the four days I had to spend with Mary and Bob. I understood that this short time period during their illnesses was but a slice of each of their very full lives, literally and figuratively. Yet, what came through for me was a deep sense of who they are and their relationships to their families, friends, caregivers and their illness.

Through the challenging experience of illness, our essence is somehow made more available to others and to ourselves. It's as if the veil falls in order to cope with a life-threatening illness, allowing us to connect with what matters most in our lives - those things often obscured by the myriad details of modern life. And of course, for any individual, though potentially rewarding, these intimate revelations pertaining to self may be difficult to hold. I was surprised how easily Mary and Bob engaged with the documentary process. It seemed that the cameras and my presence actually offered an invitation to them to share much more of themselves than they had expected to. The opportunity to tell one's story, with no agenda beyond the telling, is one potential compelling reason for their openness. Bob said, "We've all been given journals to write in... the pages are blank... we wouldn't have done this on our own." As we talked, I was transfixed as Mary and Bob shared intimate thoughts and feelings about their diseases, treatments, families, and deaths, prompted by only a handful of open-ended questions.

Mary is a 52 year old, married with children, and grand children living in Grand Rapids. Her diagnosis was non-hodgkins lymphoma and was about to undergo her third stem cell transplant. Her brother Jack was a 100% match and was her donor. I arrived the day Jack's cells were being harvested. Mary was courteous, jovial and yet, a bit shy. Also a friendly engaging man, her brother described his disapproval of Mary going this route of treatment and yet selflessly gave his time and blood for her, saying he couldn't do anything else but help. Harvesting was a several hour procedure, he was calm and talked and joked with nurses, techs and myself telling stories about sailing and saving a child's life a few years earlier. Harvesting was a 4 hour ordeal and yet Mary's infusion took just 20 minutes. They were both pretty astonished at that. She was discharged doing well at day 66 post transplant and went home. Though her transplant was successful she suffered several setbacks since due to infection requiring subsequent hospitalizations. Sadly, after a prolonged stay, Mary died this past Nov. 16, nine months after her transplant.

Bob is a 46 year old married man with two adopted children, ages 14 and 11. His diagnosis is metastatic squamous cell carcinoma of the head and neck, and now has tumors in his lungs. Bob is a devoted husband and father. He formerly worked for Ford as a full-scale model builder. He is a very thoughtful, creative and inquisitive man, and a gentle spirit. His relationships with his wife and children are very honest and loving. I was with him on a chemotherapy day and spent much time with him and his family, at home and with in his community. He was in cycle #4 of his chemotherapy treatments and doing well.

Both patients spoke of having a strong faith and support from their family that buoyed them through their struggles.

I presented this work at a full day retreat for the Cancer Center in May 2006. In July 2006, an exhibit of this work opened at the Voices Art Gallery at the University Medical Center. The response from the patients and families engaged in the project has been overwhelmingly positive. Mary, Bob and their families were present at the show opening and were the stars of the evening, though Mary had been recently re-hospitalized and stayed through the program only. A sense of love, understanding and community flourished in the gallery that evening with family and friends drawing ever closer to Bob and Mary. Hospital staff who viewed the work in either venue reported leaving with an understanding of the 'experience of illness' beyond what they knew from their clinical work. One nurse shared with me, "I now get them as the people they are... sometimes it makes it harder to work, but it's important to be reminded {of this}."

I am honored to have known Bob and Mary and thank them, their families and friends for their trust and generosity in allowing me into their lives.