

Case Report

Humanizing Care with Compassion and Empathy

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The case report explores the benefits of reflecting on a physically and mentally painful 10-week hospitalization from the patient and clinician-family member perspectives. My husband felt stripped of everything in his life. We were in the sick world, both of us. He felt dehumanized, it all seemed so hopeless. Yet it was the simple acts of kindness shown by some clinicians that made a difference. When a clinician connected with him by truly being present and showing compassion and empathy for what he was going through provided hope. The reflections demonstrate resilience, while attempting to maintain an attitude of hopefulness to return to our well-world path. Included in the case report is a painting created to enhance the emotions and feelings experienced. What mattered most to us was the connectiveness and the compassion and empathy demonstrated by clinicians.

Keywords: Narrative medicine; Patient-centered care; Compassion; Empathy; Connectiveness

Case Report Reflections from the Patient and A Clinician-Family Member

Patient Reflection

My entire hospitalization in 1976 lasted 10 weeks and involved two hospitals, first a community hospital and then later an academic-affiliated teaching hospital. At the first hospital, I experienced more amenities and a personal approach than the second hospital. However, three weeks into my hospitalization my clinical status continued to get worse with ongoing weight loss and relentless disease symptoms. The pain was excruciating; it was out of control. The physician projected I would need to stay in the hospital an additional 2-3 more months. My wife and I decided a different clinician perspective was needed to understand and treat my disease process, thus requiring a transfer to the second hospital. We discussed our decision with the physician and plans were made for the transfer that very day. No ambulance or transport system was provided, my wife had to drive me, sitting on bed pan, to the next hospital. We had to go through seven hours in the admission process to the academic-affiliated teaching hospital before I could lie down in a bed. I was completely exhausted, both physically and mentally. For this paper, I was asked to write about my feelings as a patient, after viewing pictures of myself taken during the hospitalization. My first response was the I had erased those memories from my mind; they were too painful. It is hard to think about this period in my life. Later I took time to remember. These are the first words that came to me after reflecting on my experience, most of these I remember occurring in the second hospital. At first, I only wrote the words, but later added additional content.

- Confused — about the level of care and experience with my condition by the clinicians.
- Sick — lack of definitive diagnosis, everything seemed experimental.
- Not in control — isolated, spotty support.
- Trapped — at the teaching hospital coming from a setting where there was constant care, this new environment felt like being warehoused, never felt comfortable what was being accomplished or did I make a mistake transferring.
- Alone — No one seemed to be monitoring my care.
- Weak — not able to do more than just get through whatever happened each day, very much not in control.
- Abandoned — I was misplaced in the hospital in a wheel chair, while going for a procedure in another building, hours passed, no one was looking for me, until my wife came from work later that afternoon and found me.
- Frustrated — what was going to be the solution?

I am hard pressed to remember any positive words about my experience. My wife did not want to alter my perspective on the hospitalization; therefore, I have not yet seen what she wrote on her perspective. She did remind me of some positive clinician interactions that helped me at the time, which are included below:

- Relief — when a clinician took some extra time to help draw blood from my collapsed veins or provided vital education of



Figure 1: Painting entitled: Viewing an Illness from a Well-World Perspective.

a process that I needed to be able to do. Those clinicians cared a little more for me than I had been experiencing.

- Compassion — making me more comfortable with a procedure.

As a specific example, an incident where I felt compassion by the clinician involved changing the intravenous (IV) line. Two clinicians were talking about the need to do a venous cutdown for the IV change, due to multiple failed attempts at gaining access. One of the nurses said that before we do a venous cutdown, let me wrap his arm with a wash cloth soaked in warm water. Fortunately, that was applied and left on for several minutes. The IV line was able to be changed with only one attempt at sticking me. I felt relief, compassion, and empathy that night. I slept because I was just too exhausted to do anything else.

Clinician-Family Member Reflection

As a clinician and wife of the patient, I realized how my early career attitude shaped my compassion and empathy for the patient's perspective and what I call the *well world* and the *sick world*. Prior to my dietetic internship at an academic-affiliated research and teaching hospital, I felt I was predominately in the well world. My well world included family members, friends, and a faith community. The sick world to me was only an abstract concept that I studied in my undergraduate education. I reflected on why and how so many individuals lived in the sick world during my internship and at the start of my over 50-year dietetics career, which included 43 years in the hospital setting. Only a few months into our marriage my husband's symptoms first appeared and rapidly started moving us into the sick world. There were numerous physicians trying to determine a diagnosis, provide treatments, and perform procedures, but there was no resolution of the underlying symptoms. My husband was hospitalized for one week earlier in the year, a few weeks later we had no idea that the next hospitalization would last 10 weeks and result in severe malnutrition. I felt my husband was sicker than any intensive care patient I was responsible for at my hospital during the darkest days of his hospitalization. At the time, these events felt like enormous mountains for us to climb, but now they are only small hills in our

overall lives. In reflection on our narratives and integrating the health issues into our story, we determined that what helped us the most was our faith, attitude of thankfulness for the joy of every day, and our resilience, our sheer willingness to survive against all odds.

My attitude then and throughout our lives together with the various illnesses and hospitalizations is that we are not staying in the sick world. We need to move as fast as we can to get out of the sick world, doing whatever it takes to return to the well world, both physically and mentally. During the hospitalization, we needed to be fully informed of the treatment options involving the benefits versus burdens and risks to be at the forefront of every decision made with the clinical team. We would not let the illness define us. We were not victims of our circumstances. I was not going to let my husband die on my watch. We were a team; we would get back to our normal lives on *our path*, thankfully enjoying life. This provided the hope for the future we desperately needed.

A sense of hopelessness had started to set in for my husband, after the second week of his hospitalization. He stopped shaving, which he always did every day. It was a sign of giving up. I told him I would shave him, which I did that one day; thereafter, he decided to shave every day. I knew that whatever mental cues, including his shaven face when looking in a mirror, were needed to keep my husband feel connected to the well world. The situation appeared dire to combat the weight loss and the illness; therefore, maintaining a positive attitude was essential. Perhaps we did have control of something during this illness and hospitalization, which was our attitude, our resolve to get to the other side, back to our path, our lives.

There were two periods in my husband's long hospitalization that I felt the healthcare team trusted us involved taking him home. At the second hospital I asked the healthcare team if I could take my husband home for the weekend, before the scheduled surgery the next week. I had never heard of a patient being able to leave during a hospitalization and then return. This was nearly five weeks into his hospitalization. The window of opportunity for a successful surgical outcome was narrowing between the ensuing malnutrition and the need to end the medical management approach to the disease.

This was in the era before parenteral nutrition, delivery of nutrients intravenously, which was not a viable medical therapy in most hospitals. The nutrition support field was in its early stages in 1976. My husband's illness occurred too early before the guidelines, protocols, solutions, formulas, equipment, trained healthcare clinicians, and safety issues were yet to evolve. My healthcare career was spent in the nutrition support field due to the experiences with my husband's illness and hospitalization. Surprisingly, the team agreed to my request that afternoon, trusting that I could take care of my husband and keep him on the appropriate diet preoperatively. We felt as if we had escaped that day, as we drove away from the hospital with my husband on a bed pan in the passenger seat. We were free, we were in control! He had to pull himself up with both hands on the railing to walk up each step to our apartment on the second story. That was the only way he could reach our home, but he did it! Saturday, his long-time barber came to our apartment to cut his hair; he was too weak to go to the barber shop. Easter Sunday, we went to our church service. His clothing did not fit, but just hung on his emaciated body, the hospital band was still on his tiny wrist. I could

hold his wrist between my thumb and my index finger with one hand. What a glorious weekend to prepare us for the upcoming surgery and remaining five more long weeks of hospitalization. However, we did not know it at the time that his hospitalization was only half over, even after having surgery. He now had something to look forward to, he needed a sense of hope, the will to survive, to endure.

I took off work the day before the surgery to be able to meet with all the services that would be required the next day. My husband was too weak to walk to the locations throughout the hospital. The malnutrition and inability to ambulate had overpowered his once strong, muscular body. He was now being hydrated with intravenous (IV) fluids; however, the wheel chair did not have a pole attached for the IV. With one hand I elevated the IV and the other hand pushed his wheel chair. Later in the day, the surgeon sat by my husband's bedside and meticulously went over the surgery consent form with us. He described every possible complication that could occur. As we listened intently to the complication descriptions, we declared after each one that we did not want that to happen. Then the surgeon came to the last complication on the list, he could die. The surgeon informed us that my husband had a 50% chance of dying during the surgery, due to his clinical status. My husband and I told him that was the only complication the surgeon needed to focus on avoiding. The surgeon told us that he was going to study the procedure that evening using his surgical text book. I asked the surgeon if I could view the surgery from the observation room and that I had seen surgeries in my internship. He said no, that it would make him too nervous. However, a few days later after the surgery he brought in his surgical text book to show us exactly what he had done. This is an example of compassion, empathy, and a clinician connecting with the patient and family. We felt with this clinician we were truly *seen* as human beings with a life beyond the hospital.

At the end of the next five weeks of the hospitalization, I asked the healthcare team if I could take my husband home. His discharge had not yet even been discussed. Surprisingly, the team agreed to release him that day. We got ready to leave as soon as we could, we did not want them to change their minds. The team trusted us in our ability, resilience, and determination to resolve the remaining medical issues: full return of the gastrointestinal tract function and the refeeding process to recover from severe malnutrition. He had sustained a 22.7 kg (31%) weight loss in the first five weeks of the hospitalization. My dad helped put this hospitalization in perspective for us. He said, "It is the bad times, that make the good times look even better." Being in the well world is not to be taken for granted, it can also be a state of mind; and that sense of well-being can be an attitude, a choice. Getting back to our home was going to help regain this perspective in our lives.

This hospitalization took away my husband's feeling of being in control, uncertainty abounded for him and me. He was no longer in control of many aspects of his life, including control of his body and how it functions; control of his illness; control of his situation; control of his environment; and control of our lives. Essentially our whole world was out of control. We needed a patient-centered approach with shared decision-making to get a sense of trust and hope. In writing this paper and creating the painting, I feel what would help patients is to feel a sense of control, structure, trust, hope, compassion, empathy, and a connection with the clinician to their normal life.

I knew during this hospitalization my husband felt stripped of everything in his life. His independence, his strength, his privacy, his quality of life, and his ability to perform normal body functions, all were gone from his life. We were in the sick world, both of us. He felt dehumanized due to the circumstances of his failing body, it all seemed so hopeless. Yet it was the simple acts of kindness shown by some clinicians that made a difference. When a clinician connected with him by truly being present and showing compassion and empathy for what he was going through helped during this long hospitalization.

Forty-eight years later I was able to locate the surgeon in another area of the country who performed the life-saving surgery in 1976, to thank him for all these years. We shared our life story and family pictures with the retired surgeon and he shared his life story and pictures with us. We reconnected and it felt good for the three of us.

I feel it would be helpful for hospitals to design a new process to enhance clinician-patient connection, after writing my reflection. Clinicians might consider developing a tool to be used for patients hospitalized one week or more, a narrative medicine approach in real-time. The process would involve a member of the healthcare team who has developed a personal connection with the patient. This clinician would explain to the patient, while sitting down in the patient's quiet room, that the healthcare team would like to know how the patient is feeling about what is happening to them and what clinicians could do to improve their feelings. The sensitive information from the conversation would then be relayed to the other healthcare team members and hopefully resolve any issues for the individual that could make a difference in the patient's perspective of the care provided by the team.

A painting (Figure 1) was created for this reflective article to illustrate how we see our narrative story. We feel a sense of favored grace through the years as we recently reflected on celebrating our 50th wedding anniversary with family and friends. The painting distinguishes between the well world, with a feeling of peace and life, compared to the sick world, with a sense of darkness all around, hopelessness, and despair, engulfing our whole life. There is only a thin line between the two worlds, essentially a crack in the path. We are seen walking on the path through life events with marriage, the joy of a child, and reaching a 50th wedding anniversary. The four miniature black and white vignettes in the sick world represent some of the hospitalizations, especially the longer ones. All four vignettes were created from pictures taken during the 10-week and 4-week hospitalizations early in the path. The image created implies that the hospitalizations were not the main component of our forward moving lives, but only brief interruptions.

I asked my husband what helped him the most between the written content of this article or the painting in reflecting on his hospitalization. He responded, "I could not argue with the reality of the painting that it was only as small part of my journey. The painting *pierced the veil* of doubt and despair by showing that a major part of the journey was in the well world. The painting forced me to reflect on the well world versus the sick world."

Clinician-Family Member Reflection on Learning from the Case Report

Narrative medicine could be integrated into clinical care in the

hospital setting. A starting point would be to focus on the perception of the hospitalization from the patient and family's perspective. This did not occur for us during the 10-week hospitalization. Two questions that could be addressed to the patient are:

1. How is this period in your life altering how you feel from an emotional perspective?
2. How can the clinician participate in responding to this question and improving the situation for you?

This might involve therapeutic listening and creative ways such as poetry, visual arts, music, reflective storytelling to enable the connection between the patient, family members, and clinicians. From a patient and family perspective the goal is to reduce anxiety, the sense of isolation, and stress. By exploring what matters most to the patient and family in a deep and meaningful way the clinician may also experience increased empathy and personal-well-being.

Conclusion

The case report demonstrated the benefits of the patient and clinician-family member providing their perspectives on a physically and mentally painful hospitalization. The narratives validated our resilience, while attempting to maintain a hopefulness attitude and a return to their well-world life path. The actual events in the reflections indicate the need for clinicians to understand how to incorporate patient-centered care by exhibiting compassion and empathy into clinical practice and the importance of building the clinician-patient relationship by humanizing care and developing mutual trust. The painting created for the case report provides a visual for viewing an illness from a well-world perspective. Apparent in the reflections is discovering what matters most to the patient and family member is the importance of connectiveness and the compassion and empathy demonstrated by clinicians.