

Online Only Supplement

Engagement of Families in Cardiovascular Care - The Patient's Viewpoint

On June 8, 2000, I experienced a heart attack at work, diagnosed as a sudden MI, and diagnosed ten years later as “Broken Heart Syndrome”. Although I needed no stents or open-heart surgery, I spent a frightful week hospitalized for diagnostic testing, regulation of arrhythmias, and getting accustomed to taking daily medications. Despite having been a nurse for many years, I was totally unprepared to find myself in the “patient” role. As a single woman and a recent ‘empty-nester’, this had a huge impact on me and my family.

While hospitalized, the medical team offered no ready explanation other than “you’re having a heart attack” and very little support or education was provided. At discharge, I was given a list of medications and a return appointment to see the cardiologist assigned to me. Since my own mother had died from heart disease at age 42, I was very fearful and even recall contacting the hospital on my ride home to ask if I needed a prescription for nitroglycerin in case the chest pain returned. I was clearly unprepared.

My family visited me regularly in the hospital, which was certainly appreciated, but I felt the need to hide my fears to make them feel less anxious--a very common behavior I have since observed, especially by wives and mothers. My son remained stoic and supportive; he drove me back from the hospital but burst into tears of relief when I finally was back safe at home. My daughter was dealing with her own newly diagnosed health issue, and the stress on her was especially painful to us both. I remember feeling guilty that the attention was diverted to me and experienced feelings of blame and guilt I now recognize as common after a cardiac event. I am sure we could all have benefited by some education and support from the care team prior to discharge!

Things markedly improved when I reached out and found a recommended cardiologist, away from the large teaching hospital where I had been cared for, and then discovered my two best recuperative tools--cardiac rehabilitation and WomenHeart, The National Coalition for Women with Heart Disease. The impact they had on me personally, and my family as a result, was life changing.

This month, I am fortunate to be celebrating 21 healthy years since my “event”. I continued my nursing career for many more years, switching to the field of cardiology soon after my initial diagnosis. Through my extensive network with Heartsisters (survivors) and friends, I have met many patients and families impacted by this number one cause of death in America. While my own recovery was fairly straightforward and uncomplicated, this has often not been the case with others. I hope that by offering a synopsis of what I have heard and observed, rather than just my story alone, a wider patient viewpoint can be appreciated. Their stories are all as unique and personal as mine; their recoveries and experiences equally important and valued.

I am honored to share below some of the more common experiences voiced that illustrate the value and importance of engaging families in cardiovascular care.

“I felt blindsided by the event/diagnosis and really needed family support”

“It would have really helped if my family could have been involved in the education and discharge plans. I was still in my own state of shock and denial and could not really remember anything and honestly didn’t even know what to ask.”

“I wish the doctor/medical provider had asked about my home life/family support and involved them from the beginning. A family meeting to explain my condition and answer their questions would have been so helpful.”

Questions and comments around activity progression, dietary restrictions, healing, returning to work, “when to call the doctor”, medication compliance/side effects, self-image, intimate life, etc. are all topics brought forward by the patients with whom I have spoken. These areas were felt to be important for family engagement and integral to setting realistic expectations. When these points are not addressed, it is an opportunity for problems leading to conflict within the family and an extra burden on physical and emotional recovery. It may even have a societal and financial impact if return to the workplace is hindered due to a prolonged, non-supported patient recovery and return to their place in the society and within the family unit.

I heard many comments from the patients and their families after their hospital discharge, especially from my Heartsisters and the patients in cardiac rehabilitation. Some are listed below in italicized text. Following the statement are ideas about how they felt attention to family engagement could have benefitted their experience or outcome.

“The family would NOT let me drive for so long that I felt infantilized and useless.”

Explanation of criteria and expected time to return to driving would have done a lot to make this easier. The fear of loss of future independence is widespread.

“It turns out that one of my meds made me so tired that I felt guilty not being able to return to my regular active role in the family”.

It is important to give information about common side effects of the newly prescribed medications (especially voiced by many on beta-blockers for the first time). I recall an incident, fairly soon after my own event, when I decided that going out to the movies with friends would be low stress and a chance to get back to ‘normal’. I became so exhausted just walking from the car to the entrance in the mall, a walk I had made multiple times before, that I had to sit on a bench to catch my breath. I burst into tears thinking, “I will never be the same”. At that moment it hit me, and I felt old and helpless! After getting used to the meds, in combination with cardiac rehab, I was back going to the movies and socializing again. A major milestone and emotional shot in the arm for my recovery! If I had only known about those side effects!

“My family were like sergeants and watched every bite of food I put in my mouth. I felt like they blamed my prior eating habits on my condition which made me feel guilty and depressed.”

A favorite outspoken Heartsister told me that upon getting home, her daughters went grocery shopping and came home, per her account: “carrying bags of expensive ‘heart healthy’ items. After trying a dry, low fat turkey sandwich on low salt bread (that tasted like cardboard), I yelled

at them to take it all back, I wasn't eating ANY of it!" A visit by a dietician or referral to one, can positively impact patient compliance through understanding of individual preferences and set realistic goals for adaptation and success as needed. In this instance, it might have prevented both family and patient distress.

"On one hand, my family was always insisting that I take it easy but acted upset if I said I could not do something or needed to take a nap. They wanted to protect me but also wanted the 'old Mom' back! Couldn't they see that I also, wanted my 'old self' back?"

This is another opportunity for understanding and support by professional engagement with the family and patient as a unit. In reality, everyone mourns the 'old Mom, the old self,' after a cardiac event. Validating and talking about these feelings is critical to compassionate care, understanding and recovery.

"I had to have a defibrillator implanted and have since had to have a new one. Everybody talks about 'moving on' after a cardiac event but I wish they could know that every time I look at my body when I shower, or look at the bedside device monitor, or worry about if it might activate, I am reminded that I am always a 'heart patient'. I know my friends with open heart surgery feel the same seeing their scars."

This common statement speaks to the need for compassionate understanding by those engaged in our care. Statements related to me such as: "don't worry - you are 'fixed', you need to move forward and get on with your life", "you just need to accept this, you are fine now" are actually not comforting at all and only reinforce shame or halt open communication with the caregiver or family.

"I had a call from an old friend after discharge. She was a medical professional and asked me if I was going to cardiac rehab? I had never heard of it, no one mentioned it to me in the hospital. I called and was told I qualified but needed a referral from my cardiologist. At my next visit I mentioned it he said, "well, not sure you need it, but you can go if you want to." This took me by surprise but I got the referral! Because of the demand, I had to wait weeks before an available appointment to start; when I joined, there was only one other woman - it was awkward! Thankfully, the staff was great, and I benefitted tremendously by attending".

This is one instance where caregivers can actively engage patient and family to take advantage of this proven therapeutic tool for improved recovery. The long delay of access to care can be shortened with timely referral. Patients voiced that they felt most receptive to acceptance of their new diagnosis and adherence to healthy behavior changes the closer they occurred to the time of their event. It was equally important to hear examples of things that DID work through good family and caregiver engagement, intervention, understanding, and communication. Some comments are listed below.

"My daughters were attuned to my vanity and my need to not look 'sick'. They made sure I could be prepared for visitors and controlled their number, helped with my hygiene when needed, protected my privacy in the hospital, and prepared my home for discharge. They knew I would be so happy to see they had kept the house clean and organized and had arranged for friends to help with meals."

"Meeting with the cardiac rehab professional at discharge was so helpful as they included my

family and they gave suggestions about a shower chair, activity progression, diet, medications, future appointments, etc. My family felt vested in the idea that I could have professional guidance and monitoring of my recovery. They supported my attendance and adherence to completing the program. Upon graduation we all felt much more secure to go forward into this new life--they practiced less hovering, and I recovered my independence.”

“I felt so hopeful after a visit in the hospital from a woman on their WomenHeart team. Actually SEEING someone who survived and was now thriving meant more to me than any assurances from the doctors. She offered to stay in touch as needed and provided information about their support and educational meetings. I attended my first one the month after discharge and continue to gather with my newfound “Heartsisters”. I am forever grateful for their impact on my continued physical and emotional recovery.

In conclusion, I hope I have provided a glimpse into the Patient Experience following entry into the world of heart disease. I endeavored to bring voices forward in the hope of illustrating common themes, their effects, and opportunities for better outcomes in the future. It should be recognized that patients and their families overall expressed sincere gratitude and appreciation for the caregivers they encountered, as do I.

Behind the universal statement that ‘my cardiology team saved my HEART’, it is important to uncover and explore areas where our precious LIFE going forward can ALSO be ‘saved’ and enriched. I believe that through sharing of experiences, thoughtful consideration of ideas, and our common goal of improving and enriching this journey we share together, that this result can be achieved.

Thank you for this opportunity to share my observations and personal experience.

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