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CHAPTER 10: BY THE NUMBERS Michelle

Family Summer Vacation August 2008 Pentwater, Michigan: Our extended family had been vacationing for a week in a cottage at Pentwater, Michigan. It had been almost a decade since our entire family, (my husband and son, joined by both my parents, and 2 sisters with their husbands), have taken an entire week vacation trip. It was picture perfect. The weather was nice each day we walked down to the sandy shore. My mom, who brought along her pots and pans to this rental cottage, along with her Filipino spices and magical mystery ingredients, would wake us up to traditional breakfasts, and serve us delectable lunches and dinners for the entire week. My dad brought along his fishing poles, binoculars, goggles & flippers, to enjoy the sandy beaches of Lake Michigan.

My parents, Alvaro (then 65) and Christina (then 60), born and raised in the Philippines, immigrated here in the United States in 1992. They were raised from a time and culture that didn't complain much, and was happy and content with the simple joys in life. They brush off little aches and pains here and there, thinking that it comes with age, and that it will somehow go away with rest and sleep.

On one of the afternoons during this vacation, we all took a stroll down to the beach. There was a lighthouse at the end. We also found a trail that turns into flights of wooden steps that leads up to a high perch overlooking Lake Michigan with its gorgeous sunset viewing area.

As we headed down the trail, my dad paused midway through the flat sandy path, and told us he felt "too tired" and wouldn't be able to catch up with us on this activity. He told us he just wanted to relax, wanted for us to go on. We have all been pretty active throughout this vacation, exploring the town and walking down to the beach every day. So, we really didn't think too much of this hesitation on his part. But my husband and I (both nurses at U of M), did take a little pause at that fact, and stored that mental image in the back of minds. I say this, because this will eventually play a role in putting pieces of the puzzle that will unfold later. Even to this day, that moment rings clear in our memory.

Christmas season came. At the end of our family dinner, my dad sat on the couch and started tapping his arms. I took notice and asked him why he was doing that. He said both arms just feel tired and a little numb. My mom said she also saw my dad looked like he was short of breath just with getting ready to go out and putting on his coat and stuff. That then cued me to know that something was wrong. I called for the next available clinic appointment to get him seen by his doctor.

I accompanied him to his primary doctor to get him checked. In the exam room, I related to his doctor, the signs and symptoms I had noticed, even recalling his comment of "feeling tired" from walking on the sandy beach of Pentwater, Michigan. His doctor orders an EKG to be done right then and there. Needless to say, after he saw the print out from the machine, we didn't end up going home that day, but instead going to the emergency room. He was then admitted to the University of Michigan ER, where he was ordered for a stat Echocardiogram at the bedside.

Here were his revealing results from that study:

Echo Report Case Date: 10/24/2008 Report Date: 10/24/2008 University of Michigan Health System / Cardiovascular Center Adult Echocardiography Laboratory Portable Transthoracic Echo -- Acquired Referring Location: Emergency Department Indications: Chest Pain, Unspecified (2D, SE), Abnormal EKG (2D, SE) PROCEDURE INFORMATION Performing Location: Emergency Department Sonographer Priority: Stat Status: Emergency Department Modalities: -- Color Doppler -- Spectral Doppler MEASUREMENTS LVIDd: 60 mm LVIDs: 55 mm IVSd: 12 mm LVPWd: 12 mm LA: 38 mm LV EF: 20/ Estimated VALVES AORTIC VALVE Focally thickened, without stenosis Anatomy: Regurgitation: Minimal MITRAL VALVE Anatomy: Restricted mitral valve leaflets. Regurgitation: Mild to moderate TRICUSPID VALVE Anatomically normal Anatomy: Regurgitation: Minimal, may be within normal limits Estimated RV Systolic pressure of 36 mmHg based on estimated RA pressure of 5 mmHg. PULMONIC VALVE Anatomy: Grossly normal Regurgitation: CHAMBERS AND FUNCTION NOTES: Left ventricular hypertrophy. Left ventricular enlargement Abnormal septal motion consistent with post--operative state and bundle branch block.

Severely decreased left ventricular systolic function. Normal overall right ventricular systolic function. Inferior wall akinetic.

AORTA Grossly normal as seen

PERICARDIUM Pericardial Effusion: None

CONCLUSIONS Severely decreased left ventricular systolic function (Full--thickness myocardium) Mild--to--moderate mitral regurgitation. Needless to say, after seeing all these, and consulting with the doctor in the ER, it looked pretty shocking and grim. My dad went from being able to witness the birth of his first grandchild (Lance, then 4 years old), and looking forward to years of sharing Lance's childhood and more with him, to maybe looking at shortening that span to about a year. My husband, who also worked as a nurse in the electrophysiology lab back then, painted a grim but realistic future to our family members.

Looking at the labs and test results, it didn't bode well for my dad. I understood what the numbers meant and could translate them to the saddening fact that we may not have my dad for long in our lives. He is now looking at heart failure with an ejection fraction of 20.

Looking back in August of 2008 at our Pentwater family vacation and fast forward that to 4 months, and having the following findings...

-coronary heart disease

-dilated cardiomyopathy

-severely depressed left ventricular systolic function

-estimated ejection fraction of 20-25%

-New York Heart Association class 2-3 Heart Failure symptoms

The one blessing about this was being at the University of Michigan Hospital, Cardiovascular Center. It is a facility that has all the resources you could think of, and all are there available to you as a patient and as a family member. The staff is all knowledgeable and well versed in their fields of expertise. My dad's admission in the emergency room, and the number of cardiac diagnoses he obtained triggered the systematic array of collaboration that was immediately set up, as part of being under the system of health care management at U of M. There would be the integration and coordination between his primary doctor (with Dr. McMaster), the electrophysiology department (with Dr. Good), and the introduction and management of the Heart Failure Clinic (with Dr. Koelling), to comprise his entire cardiac care team. My dad and mom would also eventually develop a good relationship as well, with the device nurses and staff at the clinic for his follow up and checks. This was such a tremendous benefit being at this facility. The communication, expert skills, and dedication from each of these services were outstanding.

Part of my dad's cardiac care involved being placed and managed by the heart failure clinic. He was put on a number of medications, each controlled and monitored by their skilled staff. Each and every medication was explained as far as what they do, and what lab values they can look at that would let them know how effective it was working and helping his heart function.

I could remember my dad noting one of the medication he identifies as the pill that "helps his heart muscle get that extra squeeze" at end of every pulse. Things the staff help explain it like that, help the non-medical person understand what the meds they are taking and why.

For the scientifically minded reader out there, this type of medical management aided in providing an outstanding improvement of my dad's heart failure status. One evidence is from his BNP results, which the heart failure clinic monitored every time. Keep in mind his starting BNP on admission was 368. I will reveal his latest numbers towards the end, along with the other empirical data.

B-type natriuretic peptide (BNP) is a cardiac neurohormone secreted from membrane granules in the cardiac ventricles as a response to ventricular volume expansion and pressure overload.

Levels of atrial natriuretic peptide (ANP) and BNP are elevated in cardiac disease states associated with increased ventricular stretch. Levels above 200 pg/ml, however, would almost always indicate left heart failure.

March 2009, University of Michigan Cardiovascular Center: Under the skilled and expert care of Dr. Good, my dad would receive a Dual Chamber Biventricular ICD.

A special kind of pacemaker, called a biventricular pacemaker, is designed to treat the delay in heart ventricle contractions. It keeps the right and left ventricles pumping together by sending small electrical impulses through the leads. This therapy, also called resynchronization therapy, has been shown to improve the symptoms of heart failure and the person's overall quality of life. Re synchronization therapy is one part of a comprehensive heart failure management program. Medications, diet, lifestyle change, and close follow-up with a heart failure specialist, combined with device and/or surgical therapy, will help reduce symptoms and allow the patient to live a more active life.

During the time of my dad's implantation procedure, while waiting, my mom and I took a stroll through the small library that was on the 1st floor of the Cardiovascular Center (CVC). It's called "the Friends with a heart gift shop." We found so much materials and resources, that were available to the patients and their families, all jam packed into such a small space. They even had models and pictures of the heart and its anatomy, and samples of different pacemakers and defibrillators for the public to view and touch. Books lined the shelves. Pamphlets abound the walls for all the different heart problems and all other information one might need to avail of. I could even remember the volunteer worker in that shop asking me that time, if I needed anything, and that if I couldn't find a book or material I wanted, she could obtain and borrow it from the other university libraries around the campus. I thought to myself, even I, a nurse who had worked there for more than a decade and a half, am truly impressed being on the receiving end of the care we strive to always provide to our patients.

My dad's procedure and recovery went well. With the system in place at the CVC, follow ups and everything were set up for him at discharge. It included clinic appointments with the heart failure department, his primary physician, and now, with the Device clinic.

A few weeks after my dad's procedure, I could tell by his non-verbal cues, that he was still adjusting to having the bi-V ICD implant. It felt to him as if something "foreign" was now residing inside his body. His device was also implanted sub- muscularly, meaning, it stuck out a bit from his upper chest. We could see slightly, the edges of the little "generator outline" protruding under his skin. For my dad, it wasn't only knowing the fact that a "foreign body" was inside of him now, but he could also see it in the mirror, and feel it with his hand. For quite a while, I could see him massage his upper left chest where the device generator was. Maybe it was to coax it and have it in his mind, that "it" was now part of him. This adjustment did take a while to overcome. What helped him tremendously was knowing that he was not alone in this venture. With the system in place at the Cardiovascular Center, they are not only concerned with the surgical and medical part of the diagnoses and schematics. They are also concerned with the psychological aspect and the impact of having a cardiac device implanted. Within their device clinic, they have built and structured a number of organized support systems. They introduced not only my dad, but my mom and the entire family, to the ICD support group.

My mom and dad attend these sessions held throughout the year. The Device clinic pools in resources, invites knowledgeable speakers, and collaborates with other patients and their family members to join, comfort, and encourage one another, as they go through living life with an implantable device. Then there's the big annual June Device picnic that my parents always look forward to. My mom always makes sure she has that day off. My dad and mom are able to talk to other patients/families who share the same path. That is how much they look forward to these events. Believe me when I say, it DOES really help, to know you have support out there. I know it has helped my parents. The clinic also has a support group that targets young patients who have received their device at an early age. I have been invited to volunteer along with my husband at one of the events they sponsor for the kids. They call this annual event "Young ICD Connection." Being around these kids, I witnessed how they all develop a sense of comradeship with each other, and the way the entire device clinic provides support to their families. It really proved and showed their commitment to their "device support program, kids and grown-ups alike."

I would like to start closing this chapter with the Ex post facto test results revealing how well my dad recovered and benefited from being under the care of the heart failure clinic and the Device clinic. The Bi-Ventricular device, coupled with the excellent care he obtained from the heart failure clinic, have returned years of life that my dad would've lost, knowing the condition we were presented with in the Emergency room. We were staring at heart failure and a complete halt of his golden years, to being given back time and years with his grandson Lance.

As of now, my dad is only seen at the heart failure clinic once a year, since his heart has responded remarkably and recovered well. I remember about 2 years ago, Dr. Koelling saying to my dad at the last visit I accompanied him with, "well looking at your numbers, I only need to see you once a year now..."

By the way, his BNP lab result from"368" at the emergency room admission in 2008, to now "15" at best !!! (Can we get a "whoa" here?)

Here are his post Device Echo studies/results:

Other Results Text --? Test Name: Echo Report Case Date: 11/17/2009 Report Date: 11/19/2009 University of Michigan Health System / Cardiovascular Center Adult Echocardiography Laboratory TTE -- Acquired Referring Location: 150 -- Cardiovascular Medicine Indications: Cardiomyopathy (2D, SE, TEE) PROCEDURE INFORMATION Performing Location: Canton Health Center Priority: Routine Status: Outpatient Equipment: Acuson Sequoia Modalities: -- Color Doppler -- Spectral Doppler Quality of Study: Adequate **MEASUREMENTS** LVIDd: 46 mm LVIDs: 25 mm LVPWd: 13 mm IVSd: 12 mm LA area: 13.4 cm2 LA: 35 mm LV EF: 65 / Estimated (here lies the proof in the pudding !!!) AORTA Annulus: Sinus: 31 mm SinoTubular: Tubular: Arch: VALVES AORTIC VALVE Anatomy: Thickened aortic valve without stenosis Regurgitation: No evidence of aortic regurgitation Peak gradient: 6 mmHg MITRAL VALVE Anatomy: Calcified mitral annulus Regurgitation: Minimal, may be within normal limits E/A ratio: 0.7 Decel time: 143 msec

TRICUSPID VALVE Anatomically normal Anatomy: Regurgitation: Mild Estimated RV Systolic pressure of 34 mmHg based on estimated RA pressure of 5 mmHg. PULMONIC VALVE Anatomy: Grossly normal Regurgitation: No evidence of pulmonic insufficiency CHAMBERS AND FUNCTION Left Atrium: Normal Size Right Atrium: Normal Size Left Ventricle: Normal Size LV Hypertrophy: Mild, concentric Right Ventricle: Normal Size NOTES: Normal overall left ventricular systolic function. Normal overall right ventricular systolic function. Normal wall motion.

AORTA

Anatomically normal PERICARDIUM Pericardial Effusion: None MISCELLANEOUS Pacemaker lead in the right atrium and right ventricle. CONCLUSIONS Normal left ventricular systolic function.

Interpreted Date: 11/17/2009

My dad, our entire family, and especially his grandson Lance, would like to express our appreciation for the excellent care the University of Michigan Cardiovascular Center has provided. I being an empirical person, the year 2008 had my dad staring at the reality and repercussions of having an ejection fraction of 20-25 %, and heart failure. Now, he is thriving with a staggering EF of 65 % and THAT translates to years given back, to be spent fishing, vacationing, and playing chess with his grandson, Lance.