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VIEWPOINT

VOICES IN CARDIOLOGY

Both Sides of a Coin

Having Open Heart Surgery While Researching in Cardiology

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As a PhD researcher in cardiovascular physiology, the process of developing and publishing research with clinical relevance to disease and mortality risk is routine. Alike many other researchers, the statistical outcomes of these journal articles bare minimum emotional relevance to oneself, often representing little more than a successful publication and data nicely presented on a PDF file that will hopefully improve clinical decision making for those patients unfortunate enough to have been burdened with the investigated pathology. When I was informed of my need for open-heart surgery due to a structurally abnormal mitral valve with a resulting decline in left ventricular function, this very data suddenly became rather personal. Being fortunate enough to work under a highly expert mentor in echocardiography, I became very familiar with the current literature on how parameters such as left ventricular ejection fraction, global longitudinal strain, and left atrial diameter are associated with the risk of mortality. However, my personal concern for this information was absent until my recent journey as a cardiac patient exposed me to life on the other side of the dataset. A year later, with a repaired mitral valve and an impressive sternotomy scar, I wanted to write this piece to tell my story as an individual working within the field of cardiology and as a concurrent cardiac patient.

Born in 1998, I was diagnosed with congenital muscular torticollis where my head remained in a tilted and rotated angle constantly. While my mum tells me how she would blindly deny anything was wrong with her baby, I eventually required invasive corrective surgery when I was 3 years old at Great Ormond Street Hospital. I was also born with a bifid uvula, some mild craniofacial features, and later recognized significant hypermobility as well as rather elastic and translucent skin. Furthermore, I am one of three brothers all above a height of 6 feet, 5 inches (~196 cm), birthed from a 5-foot-tall mother with a 5-foot, 10-inches-tall father. Thanks to the expertise and detective skills of some excellent medical professionals over my early life (via the cleft palate clinic), these random personal characteristics were in fact the early diagnostic clues as to my appropriate management. I was subsequently screened for Marfan syndrome and eventually diagnosed with clinically suspected Loeys-Dietz syndrome. My first surveillance echocardiogram in 2018 was generally normal except for revealing some mild mitral regurgitation.

Fast forward to 2021, the situation had changed with the findings of my next echocardiogram. In conversation with the skilled sonographer during the scan, he disclosed to me what he believed to be the problem: mitral annular disjunction. This was a novel term for me that I couldn't accurately understand as a relatively new entity with a lot of zebra zones. This added frustration and a feeling of an extra duty that I had to study about my health issue. The regurgitation had also progressed to moderate to severe, my left atrium was dilated and left ventricular function was now impaired. Not only was the speed of this decline concerning, but I was also now overthinking the risk of sudden cardiac death, reading the latest data on the relative risk of such an event and wondering about the suitability of a preventative implantable cardioverter-defibrillator just for my own peace of mind. While I would frequently get bigeminy ectopy, on rare occasions I would go into a much faster rhythm that felt more sinister, which was always alarming. Sometimes I wondered if it would be easier

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to not be knowledgeable about what was happening inside of me, and what purposes the data I was reading really provided other than to scare me. Following some more testing, including a stress echocardiogram that demonstrated the absence of any contractile reserve, the situation was becoming clear. As a healthy, physically active 23-year-old, the proposition of open-heart surgery is a rather difficult pill to swallow. I was completely asymptomatic and lived a normal life, and therefore, agreeing to this procedure would have been very challenging had I not been familiar with the prognostic importance of this from my line of work. Despite this, I still vividly remember my initial worries about the repair attempt failing and then having a metallic valve for the remainder for my life. Again, these worries were largely driven by reading external data (albeit, largely inapplicable data to a 23-year-old) on re-thoracotomy rates, stroke, bleeding risk, and most importantly, life expectancy.

Some months after being informed of the procedure, while shopping for ornaments for the new apartment I had just moved into with my partner Molly, I received a phone call regarding my surgery date which marked a time in which the situation suddenly started to feel very real. The next 4 weeks of preparation were stressful and anxiety-producing, but I ignorantly blocked it from my mind by forcing myself to stay incredibly busy with work every day as a defense mechanism. I remember relentlessly working on a research paper for 12 to 16 hours a day all the way up to my admission, where just minutes before leaving to travel to the hospital, I sent the final draft to my supervisor. This distraction tactic was certainly effective in offsetting the anxiety until my admission to the hospital where I said a very emotional goodbye to Molly. Waking on the day of the surgery, with my procedure scheduled for 2PM, I spent the entire morning pacing around my room crippled with apprehension and worry, watching the clock tick very slowly in what felt like the longest morning of my life until I was finally called to the operating room at around 3PM. A brilliant nurse and anesthetist kept me occupied with aimless but necessary conversation while waiting for the prior patient to leave until eventually the general anesthetic was administered.

I vaguely remember waking up in the intensive care unit not too long after my surgery while still intubated in what felt like a dream. According to Molly, who happened to be phoning in at the time to check on me, the nurses were extremely panicked by this, which in a domino effect scared Molly who could do nothing but listen to the commotion on the other end of the line. Around 10AM the next morning I was properly woken up. I remember first asking "Was the valve repaired?" A nurse replied, "Yes, I believe it all went fine." I then immediately asked to ring Molly, and was thrilled to hear the happiness in her voice knowing how difficult the last 24 hours must have been for her. My overall feelings were pure relief. Although the physical pain and road to recovery was only beginning, the worry and anxiety was over.

The next 3 days were physically the most difficult of my life. The systemic pain, tiredness, and sickness could be overwhelming at times. While the thought of sternotomy is more painful than the reality, the same cannot be said for the removal of chest drains, which remains the worst experience of the entire journey. On a more comical note, during the second night of my stay, my bed deflated, and I was laying on the metal base, requiring an emergency mattress swap at 3AM. On the topic of hospital beds, they are certainly not designed with tall people in mind—some of us need some leg room! Furthermore, the bed adjustment buttons are rather inconveniently placed for those who have had sternotomy and they can also get very hot at times. I strongly advise anyone going for a similar procedure, particularly if it is summertime, to ensure you have a desktop fan at your disposal. On day 4, I was starting to feel like myself again, walking to the toilet produced a great feeling of once again being independent. On the advice of my nurse, I then began wearing my own clothes, rather than the hospital gown. I cannot describe the momentous feeling of being in my own T-shirt and shorts again. This simple change of clothing was a landmark in my journey, in some indescribable, deeply intrinsic way, it signified recovery to me. It felt like I had been handed a trophy, I was ecstatic.

From this point on was all about getting back to the comfort of my own home, pursuing a discharge with my nurses by any means necessary. Unfortunately, we ran into a processing hurdle with my discharge. On the Friday (day 4), my INR follow-up had not been arranged at my general practitioner surgery, who were subsequently closed on the weekends. According to the ward rules, they are not allowed to discharge me unless this appointment is confirmed to be in-place, meaning I would be forced to stay in hospital until the following Monday. As a 23-year-old in a wardroom with three, much older and much more unwell individuals who would cough sputum continuously all day, not only was I using up a valuable hospital bed space, but I was also aware of my increased risk of a hospital-acquired infection with no real benefit of me still being in hospital. This is where I started to develop some frustration and further worry, feeling like I had been let down by the

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procedures in place. Upon expressing these concerns to an excellent senior nurse, I was fortunate enough to be moved into a side-room temporarily. After some good discussions with some friendly and understanding registrars and nurses, they put their faith in me to pursue a follow-up INR appointment independently and discharged me which I was very grateful for. In fact, I am unbelievably grateful to every single person involved in my care, from the expert surgeon and his team, my caring consultant, and all nurses and practitioners who have ultimately improved my life expectancy tremendously.

Now, 2 months post-operation, I will end this piece on the following note:

I would like to put my journey into perspective by appreciating the fact that, thanks to the excellence of modern medicine, a 23-year-old "healthy" individual had very complex open-heart surgery to treat a prognosis-threatening congenital abnormality that had absolutely zero presenting symptoms. This is an example of medical screening and preventative interventional cardiology at its very best and I am eternally grateful.

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