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The Upside of Down Syndrome: Math is My Superpower!

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Abstract

My son Isaac has Down syndrome. He was born in 2015, within a year of me receiving tenure at Simpson College. The experience of being his mother has had a profound effect on me as a mathematician. Having been with him through eleven surgeries over sixteen hospitalizations, I wanted to learn about his medical complexities and, more generally, about coordinated health care for those with chronic illness. To accomplish these goals, I've looked to my teaching and research. In the spring of 2016, I designed a sophomore-level mathematical modeling course on the respiratory system. In the summer of 2016, I led a group of three undergraduates to utilize location analysis as a means of understanding patient access in the health care system. We used p -median and maximal covering models to investigate patient access to Down syndrome specialty care clinics in the United States. More recently, together with a graduate student in medical anthropology and a handful of undergraduates in mathematics, I've initiated a project on family perspectives of attending a Down syndrome specialty clinic. Through teaching and research, I've used math as my superpower to help understand and improve health care for individuals with Down syndrome.

In the summer of 2014, I naively thought that I had a good grasp on work-family balance. I had just earned tenure in my dream job at Simpson College, where I could teach a variety of courses and routinely conduct undergraduate research. Despite a healthy dose of imposter's syndrome, I was able to publish work with my undergraduates and faculty colleagues and obtain grant funding. I was asked to contribute about best practices in undergraduate research for the 2015 Committee on the Undergraduate Program in Mathemat-

ics (CUPM) guide. One of my proudest achievements was becoming a co-PI on a [Center for Undergraduate Research in Mathematics](#) (CURM) project from 2012-2017. These professional achievements occurred as I adjusted to motherhood. My son Max was born after my third year at Simpson. My colleagues supported me through maternity leave while staying on track for my tenure clock. I even submitted my portion of the CURM grant proposal one month postpartum, while I had too many hormones surging through my body to feel like a coherent part of society.

Then my second son Isaac was born and everything changed.

I learned that I was pregnant with Isaac in the summer of 2014, one month before I submitted an NSF Scholarships in Science, Technology, Engineering, and Mathematics (S-STEM) proposal as the principal investigator. In March 2015, when we first learned that the proposal was likely to be funded for over half a million dollars, I had actually forgotten about the proposal. My friend and co-PI on the project had to call me and tell me to read the email from the program officer with the good news. Isaac was three weeks old at this point and we were preparing for his first surgery, a closed heart surgery to repair a patent ductus arteriosus (PDA). I revised the budget for the grant from Isaac's neonatal intensive care unit (NICU) room at the hospital. When the official word came in June that the project was going to be funded, Isaac had just been released from the NICU and was battling a series of bouts with pneumonia. I was essentially living at the pulmonologist's office and hence not available for an official comment when our PR department and local news outlets contacted us about the project. When the students supported through this scholarship program first came to campus for orientation in the summer of 2016, I was at the cardiologist's office planning a cardiac catheterization to assess Isaac's pulmonary hypertension and plan for an open heart surgery to close his septal defects.

Isaac has Down syndrome and a host of associated conditions, including congenital heart defects, multiple airway defects (subglottic stenosis and tracheobronchomalacia), and severe gastroesophageal reflux disease (GERD). He has had eleven surgeries and sixteen hospitalizations, with more significant procedures planned for the future. He has had a tracheostomy tube since he was two months old and has been on a continuous positive airway pressure (CPAP) machine for over two years to support his respiratory effort.

Since becoming Isaac's mother, I have encountered several other mothers of medically fragile children. I have seen them cope with the stress by developing "superpowers". Some superpowers include leaving the workforce to care full-time for their child, changing careers into something in the medical or special education field, or starting nonprofits to improve education about sensitive diagnoses. I have learned that math is my superpower. I have used my experiences of being Isaac's mother to inform my teaching and research. Through teaching, I have learned to become a better advocate for Isaac, and through research, I am learning how to better impact the broader Down syndrome community.

Teaching

In November 2015, Isaac was 9 months old and had been out of the hospital for a month, a personal record. We were referred to a pulmonologist at the University of Iowa to ensure that our treatment plan for Isaac was following best practices. Although we only met this doctor once, the consultation set into motion a revolution in my approach to teaching. He was the first doctor to give me scientific literature about my son's conditions, and he was the first doctor to talk to me as though I were a mathematician and a mother.

During that conversation, we talked about the Hagen-Poiseuille Equation [2], which can be used to measure the air flow in the trachea. It states that

$$\Delta P = \frac{8\mu LQ}{\pi R^4},$$

where ΔP is the change in pressure across the trachea, L is the length of the trachea, μ is the dynamic viscosity, Q is the volumetric flow rate, and R is the radius of the trachea. In Isaac's case, the radius of his windpipe just below his vocal folds was reduced by 71%-99% and his left bronchus was periodically collapsing during the exhalation process. Thus, I was able to quantify Isaac's respiratory distress for the first time in his life.

I wondered what else I could learn about Isaac's situation and ultimately designed a mathematical modeling course to help me learn how to become a better advocate for Isaac. Indeed, I have always learned best by teaching to others. Having never taught modeling before and having never taken a biology course at the college level, I enlisted the help of my colleagues in

designing and running the course. I worked with a developmental biologist to introduce the students (and myself!) to the anatomy and physiology of the respiratory system. In a dramatic moment after the first lecture on this topic, my colleague decided on a whim to take the whole class down to our cadaver lab to look at real lungs. That was a hands-on learning experience that none of us will soon forget!

We used BIOPAC equipment from the biology department so that students could measure different aspects of their lung function. These led to some basic models of things like hiccups, asthma, or exertion during exercise.

From there, I introduced students to a more complex model of the respiratory system published by Vincent Rideout in *Mathematical and Computer Modeling of Physiological Systems* [1]. In this model, the respiratory system is viewed as an analog to a resistor-capacitor circuit. My friends in the physics department taught us about the basics of resistance, capacitance, and current, and how these ideas could translate to airway resistance, compliance, and airflow. We learned Kirchoff's laws for loops and junctions. We learned how to take a circuit diagram and translate it into a system of differential equations.

Once we had a basic understanding of circuitry and the respiratory system, students modeled different pathologies, including Isaac's subglottic stenosis and tracheobronchomalacia. We also modified this framework to account for things like having a tracheostomy tube to breathe through instead of a nose or being dependent on a ventilator to help with breathing function. We were also able to revisit some of the models that students had developed earlier in the course with the BIOPAC equipment so that they could compare their measurements to the model predictions.

This course ran two times and was appreciated by the students. Feedback on course evaluations consistently praised the interdisciplinary nature of the course, citing that it was useful to have multiple professors lecture and act as resources for questions. One student acknowledged the personal nature of the subject matter, stating "I admire your courage and allowing us to play around with something sensitive to your heart." Overall, I found this to be a most fulfilling teaching experience, and eventually, I would like to adapt this content to a first-year seminar setting or develop it into a supplement to an upper-level differential equations course.

On the home front, this course helped me to be more conversant with Isaac's pulmonologist, cardiologist, and ENT. Not only do I have a basic understanding of things like airway malacia, pulmonary hypertension, or subglottic stenosis, I also have a bevy of peer-reviewed research articles that my students vetted for me in their annotated bibliographies. I routinely use these resources to frame better questions and to understand the nuances of the situation. In one example, the questions that I asked the cardiologist about Isaac's pulmonary hypertension hastened Isaac's open heart surgery to be scheduled for 2017, instead of 2020.

Research

In August 2015, we had our first coordinated care conference for Isaac. This was in advance of his fourth surgery, a fundoplication to help with his severe GERD. At the end of the conversation, I asked if we could have care conferences annually and not just for emergent surgeries. One of Isaac's specialists responded "If I had regularly scheduled care conferences for each of my complicated patients, I would never have time for my patients in the clinic." I understood his dilemma, but wrestled with his comment. Was this necessarily true? If medically complex patients had routine coordinated care, would they need as many hospitalizations or follow-ups in the clinic? What are the existing models for coordinated care for people like Isaac? How effective are they? What obstacles do patients face in accessing this care?

It took me about half a year before I started to tackle these questions in earnest. Things started with the senior capstone project of Sara Reed, Simpson College Class of 2016. In order to learn about existing coordinated care models for individuals with complex medical diagnoses, Sara and I thought it would make sense to start by investigating Down syndrome specialty clinics. One of my colleagues in the biology department knew Dr. Brian Skotko, the co-director of the Down Syndrome Program at Massachusetts General Hospital, and helped us connect with him. Dr. Skotko met with us via the phone a few times during the project and helped us understand the goals of a Down syndrome specialty clinic. This capstone project laid the foundations for me to understand Down syndrome specialty care clinics and general models for coordinated care. Sara presented our research at MUMS (Midwestern Undergraduate Mathematics Symposium) in the spring of 2016.

This work led to more important developments. First was a location analysis project. Our department is lucky to have the Dr. Albert H. and Greta A. Bryan Summer Research Program.¹ Set up through the generosity of our alumni, this research program is designed for first and second year mathematics majors to conduct eight weeks of summer research under the guidance of faculty. I led a project in the Bryan Program in the summer of 2016 with Emma Christensen, Nick Joslyn, and Maddy Kersten, three Simpson College students who had just finished their sophomore year. Sara's senior capstone project had allowed me to understand services offered at Down syndrome specialty clinics, but I wanted to better understand the network of Down syndrome specialty clinics across the country. In particular, I wanted to know what percentage of the eligible population was utilizing these services, and how best to improve the access to these services. We used models from operations research. At the end of the summer, my students had a basic model that could optimally add a clinic to the current network so that patients would have minimal travel times and clinics could serve the largest number of patients. They presented this work as a poster at the 2017 Joint Mathematics Meetings held in Atlanta, USA, and gave a talk on it at MUMS (Midwestern Undergraduate Mathematics Symposium) in the spring of 2017.

The whole project took an exciting turn when Dr. Skotko visited Simpson as the McBride Lecturer in October 2017 to talk about the latest research in Down syndrome. During his visit, Dr. Skotko met with my research group to talk about the project. He had just designed a virtual Down syndrome clinic, in which patients could ask questions and discuss medical history over a computer interface, with reports generated being sent to primary care physicians and the families.² We realized that the work done in our summer project could help to build an important case for the need of a virtual clinic. Indeed, we have an analysis of the travel times for patients with Down syndrome to attend specialty clinics and can determine average travel times by region to show disparities in access across the country. All five of us are currently working on a manuscript on this work to be submitted to a scholarly journal in August 2018.

¹*Dr. Albert H. & Greta A. Bryan Summer Research Program*, <http://simpson.edu/math/bryan-summer-research-program/>, last accessed on July 3, 2018.

²*Down Syndrome Clinic to You*, available at <https://www.dsc2u.org/>, last accessed on July 23, 2018.

The second development from Sara's capstone project was a contact with a new collaborator. Dr. Skotko helped me connect with Anne Kohler, a graduate student in medical anthropology at the University of Connecticut. We are conducting a study to learn more about the value added for patients and their families enrolled in Down syndrome specialty clinics. Anne is in the process of collecting data at the Down Syndrome Clinic at Massachusetts General Hospital for her dissertation. I joined her for observations during my fall break in 2017.

I am fortunate to have the opportunity to continue this work during the summer of 2018. I have just started to work with a new group of undergraduates through the Bryan Program: Graham Brooks, Levi Lefebure, and Mason Remington. Together we are working to model patient utility at Down syndrome specialty clinics, with the hopes of quantifying which services are necessary for which groups of patients with Down syndrome. Anne visited us during June 2018 to work with us. We have preliminary data from a survey that circulated nationally during the spring and summer of 2018. Among other things, the survey asks families for experiences and hindrances with Down syndrome specialty clinics. We are conducting qualitative and quantitative analyses of these data, and Graham, Levi, and Mason will present our work at the Joint Mathematics Meetings in Baltimore in January 2019. This is the start of a productive interdisciplinary research program.

When I first learned of Isaac's diagnosis of Down syndrome, I felt that I had gone down the proverbial rabbit hole into a strange Wonderland. I was in a parallel universe where things felt familiar, and yet so different. I'm lucky to have math as my superpower to help straddle both worlds that I exist in. I have not only been able to use my mathematical training and career in academia to cope with my son's medical fragility, I have also used this as an opportunity to challenge myself in new avenues of teaching and research. Along the way, I am developing exciting collaborations and delving into new areas of mathematics that I would not have otherwise known. Through our work, my collaborators and I are poised to positively impact the broader Down syndrome community.

References

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- [2] Salvatore P. Suter and Richard Skalak, “The history of Poiseuille’s law”, *Annual Review of Fluid Mechanics*, Volume **25** Number 1 (1993), pages 1–20.