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TELLING THE *ATYPICAL TRUTH*:
DISABILITY COMMUNITY-BUILDING THROUGH PODCASTING

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A thesis submitted to the University Honors Program
in partial fulfillment of the requirements for the
Honors Certificate with Thesis

Approved by

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Southern Illinois University, Carbondale

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Abstract

The community of disabled and/or medically complex individuals represents a relatively small demographic worldwide; therefore, it is difficult for community members to find and build relationships with others directly within the local community whose lived experiences reflect their own. As a result, many individuals within the disabled and/or medically complex community experience isolation and depression. Social media and other digital resources often serve as a mechanism for community-building in such situations. *Atypical Truth* is a podcast that episodically explores a variety of topics that relate to life as caregivers, disabled individuals, and/or individuals with complex medical conditions.

I used *Atypical Truth* to collect qualitative data from two groups of participants, the listeners (audience) and the podcast guests (interviewees). The data collected were used to evaluate the effectiveness of utilizing a podcast as a platform to provide caregivers, disabled individuals, and/or individuals with a complex medical condition the following: (1) sense of personal connection, (2) sense of community (3) helpful insight into the personal lives of the guest, (4) helpful and informative resources, (5) a new or deeper understanding of the lived human experience, and (6) personal gain/benefits from the content. In addition to qualitative survey data, I also drew upon personal narrative in order to nuance the phenomenon of podcasting as a community-building resource.

Intro

The soft sounds of a sweet lullaby echoed down the hallway, serenading the rooms of women like myself who were in active labor. “They play that every time a baby is born,” the nurse explained. I smiled at the thought of how that sound would soon float through our colorful room just as the nurse would be placing my daughter on my bare chest as we began a lifetime of magical bonding. It was going to be a perfect moment, with perfect warm lighting, with that perfect lullaby playing as both my husband and I lovingly gazed down at the perfect little human we had spent our entire pregnancy imagining.

The familiar sounds of a now muffled lullaby echoed down the hallway and everything on the peripheral went blurry as I anxiously awaited the most precious sound of all, the cries of my newborn. The cries never came, and I felt a sinking feeling in the pit of my newly squishy stomach. The room was bright white, sterile, and cold. I tried catching a glimpse of my baby who was now across the room, surrounded by a chaotic crowd of gowns and scrubs. I turned to my husband for a sign of reassurance but quickly looked away when I was met with the look of sheer fear on his face. All at once, time stood still and moved at warp speed. I was supposed to be crying tears of joy and happiness as this lullaby was finally playing for the arrival of my child. Instead, I was frozen in fear and experiencing an intense throbbing pain that radiated from the depths of my heart. *Something was wrong.*

If seconds felt like a lifetime, the minutes felt like ages before she was placed in the safety of my loving arms. The faint and distant sound of the lullaby played on; this time, it wasn't for me, it was for the next new mom. As the sounds of the lullaby dimmed in the background, I wondered if that other new mom was spending this precious skin-to-skin time examining her child as meticulously as I was. In a room whose light felt like it was growing dim

despite the morning sun growing brighter in the sky, I gazed down at my child with worry; I instinctively knew that something was not right. I wanted to be basking in the glory of her perfection, her ten little toes, her tiny little hands, her perfect head of hair. Instead, I couldn't help but to examine her with concern...*Why didn't she cry? Why is she so limp? Where is all her hair? What are these skin abrasions and lesions? Why won't she grasp my finger? Why is her head so small? Why is she jerking? Why is she purple?*

The lullaby thundered down the hallways, as intruding and disturbing thoughts of jealousy flooded my mind while I imagined all the other families on that floor joyously celebrating the experience I had dreamed of, but never received. Instead, I laid in the empty dark postnatal room-of-doom, violently trembling with fear as my body began to physically recover from the trauma of birth, while simultaneously breaking from the heartache of having a newborn who was now many rooms away and struggling to survive.

As if just to mock me, the revolting sounds of that repulsive lullaby roared down the hallways and the lights seemed to flicker with every step as I walked past all the rooms housing happy new parents of healthy new babies. For the next several days, I would have to repeatedly walk past those joy-filled rooms, past the nurses' station where they all looked at me with pity as I waddled by, past the locked room that housed barrels of my precious pumped breast milk, up to the sink for a 3-minute sterile hand scrub, and into the special nursery where my baby laid motionless except for the uncontrollable and spontaneous convulsions that tremored throughout her body. There she was, adorned with wires and tubes instead of being swaddled comfortably in a soft receiving blanket. She was not bundled in the warmth of my arms as I had longed for, but in the warmth of a special incubator instead.

Traveling from my room to the special nursery, again and again, with tears swelling up in my eyes, I would walk those lonely beige halls, passing all the rooms filled with new life and golden light which peeked through but never poured out far enough to touch me. With every breath I took, with every pounding heartbeat that vibrated my chest, I was left to wonder if my freshly born child would even have a chance to live a life at all. It was on these walks when I first had to learn to come to terms with the reality that my journey into parenthood was anything but textbook; my journey was not like my peers nor the majority of people experiencing parenthood.

The lullaby was replaced with the sounds of beeping machines, alarming monitors, and hordes of people crowding in to observe my child with the puzzling medical condition. I had to learn how to advocate, voice my concerns, read monitors, interpret lab results, point out discrepancies, determine seizures from dystonia, listen for problematic lung sounds, and be mindful of all possible medication interactions. I became an honorary nurse, doctor, neurologist, dietician, therapist, pharmacist, and somewhere in there I was still just trying to figure out how to be a new mom. In various hospital rooms filled with well-educated and well-weathered experts who were all scratching their heads with shared confusion, I became the uneducated and inexperienced expert of my child with a rare disease. I had to learn how to become anything but silent.

* * *

Telling the *Atypical Truth*: Disability Community-Building through Podcasting

In this thesis, I am going to introduce you to my world—the world of rare medical diagnoses, disabilities, and medical complexities. Those who live in this world often experience obstacles related to social isolation, finding and maintaining personal connections, fragmentation

of care, and lack of emotional support. I also explore the use of a podcast (*Atypical Truth*) to address these struggles faced by our community. Using data collected from surveys, I share both respondents' and my own opinions regarding the impact of the podcast and possibilities for what the future content of the podcast should include. I reflect on how this research has impacted me and the community I identify with, and conclude this thesis with a personal narrative detailing how this podcast has shaped my experience as a caregiver.

This thesis takes on an unconventional form, an atypical form if you will. Rather than providing a more conventional literature review, methods section, data analysis and discussion, and conclusion, I take seriously Fisher's (1984) contention that humans are storytelling beings, and Langellier's (1989) argument that personal narratives communicate *the every day*. I follow in the footsteps of scholars who make storytelling the format of their research (e.g., Ellis & Bochner, 1992; Green, 2003; Langellier, 1989; and Scott, 2018). As such, this thesis tells the story of this disability podcast, and my efforts to better understand how a podcast might function as community building. I set out to gauge the extent to which *Atypical Truth* provided listeners and guests with a sense of connection and community, resources for the phenomenon of complex medical conditions, and insight into human experience.

In addressing the importance of these themes—connection, community, resources, and the lived human experience—I draw upon storytelling and surveys. I tell my own stories and put them in conversation with the stories of my podcast guests and survey respondents. I put that in conversation with scholarship on disability and complex medical conditions, as it involves community-building and the people impacted. Storytelling as research allows me to foreground the human component of disability. As conversational partners perform a communicative dance, the conversation I have in these pages moves from my storytelling on the *Atypical Truth* podcast,

to my storytelling in real-time while writing this thesis, to the contributions to this story from the survey respondents, to the stories told by my podcast guests. And like a conversation, these turns aren't always neatly structured, but rather, find their own flow. My goal in writing this way is to allow readers to find their own way into this flow, regardless of the extent to which they relate to this world. This is the *Atypical Truth*.

Creating a Podcast

Atypical Truth (Stearns, 2021a) is a podcast project that I have spent the last four years imagining and the last year actualizing. As a person who grew up with disabilities, and now as the mother of two terminally ill and medically fragile children, I wanted to address the realities of our life in a way that will serve as a beneficial resource to families like our own, with the goal of helping them to feel connected and understood. Through episodic storytelling and conversations, *Atypical Truth* explores a variety of topics that relate to life as caregivers, disabled individuals, and/or individuals with complex medical conditions. I naturally weave into each conversation a variety of relatable topics that impact our community daily such as anticipatory grief, navigating advocacy, social inequalities, inspiration porn, financial obstacles, relationships, and resource limitations. *Atypical Truth* serves as an easily accessible public space for people who are on similar complex journeys to share truths of their lived experiences facing healthcare challenges, financial struggles, emotional and physical obstacles, accomplishments, and loss.

Audiences got their first taste of *Atypical Truth* with the release of the trailer on February 8, 2021. In the first season of *Atypical Truth*, I invited several guests to join me for a recorded interactive interview. The guests ranged from personal caregivers (parents, legal guardians, and family members), medical professionals (nurses and doctors), social workers, and a friend of a parental caregiver. Ellis et al. (1997) describe interactive interviewing as “an interpretive

practice for getting an in-depth and intimate understanding of people's experiences with emotionally charged and sensitive topics" (p. 121). Ellis et al. explain the art that turns a conversational dance into an interactive interview:

Interactive interviewing reflects the way relationships develop in real life: as conversations where one person's disclosures and self-probing invite another's disclosures and self-probing; where an increasingly intimate and trusting context makes it possible to reveal more of ourselves and to probe deeper into another's feelings and thoughts; where listening to and asking questions about another's plight lead to greater understanding of one's own; and where the examination of comparison of experiences offer[s] new insight into both lives. (p. 122)

Much like a conversational dance, the back-and-forth sharing done in an interactive interview often takes a narrative form. Personal narratives are the everyday stories we tell—from explaining the events of an extraordinary experience to sharing about the mundane details of an ordinary day; the personal narrative serves as a part of the performance and cultural expression of everyday life (Langellier, 1989). Personal narratives not only give researchers the opportunity to listen on the margins of discourse, but they also offer a voice to those within our society who have historically been silenced (Langellier, 1989). Langellier (1989) champions storytelling and personal narrative as forms of research that challenge the boundaries of traditional research by promising a revolution in the innovation of theories, designs, and methods of analysis.

Podcasts offer the ability to blend both interactive interviewing and personal narrative. Podcasts are a relatively new and innovative form of audio media that serve as a platform to widely broadcast our conversations and share our stories. While every podcast differs in content

and style, they are often presented in the form of episodic spoken word featuring one or more recurring hosts who discuss various topics and subject matter with each other and/or with rotating guests (“Podcast,” 2021). With an estimated 22 million listeners each week, podcasts offer an accessible platform to share stories, start conversations, create a social network, and cultivate a community of like-minded individuals (Cunsolo, 2019; “Podcast,” 2021). Podcasts are usually free to stream, can be downloaded to save for later, can be listened to anywhere on a mobile device, and at any time that is convenient to the listener. Based on the popularity and accessibility of podcasts, in addition to my own preference for podcasts as a means of therapeutic entertainment and information, I understood podcasts to be an effective and efficient means of reaching, connecting, and providing information to other caregivers and individuals impacted by disability and complex medical conditions.

Approach

The first season of the podcast, *Atypical Truth*, served as an artifact about which to collect both qualitative and quantitative data through two sets of surveys: 1) offered only to guests *on* the podcasts, and 2) publicly available to listeners *of* the podcast. Both surveys examined the effectiveness of utilizing a podcast as a platform for caregivers, disabled individuals, and/or individuals with complex medical conditions. I worked with the Institutional Review Board (IRB) to craft the survey, participant solicitation, and consent forms, until the IRB approved my materials and data collection processes.

The *listener* survey was made available on the podcast website and was promoted on the podcast and through the podcast’s associated social media. Each *guest* received two emails with a link and instructions to complete the voluntary guest survey. Both surveys were designed to measure how well the podcast provided the following to caregivers, disabled individuals, and/or

individuals with a complex medical condition: (1) sense of personal connection; (2) sense of community; (3) helpful insight into the personal lives of the podcast guest; (4) helpful and informative resources; (5) a new or deeper understanding of the lived human experience; and (6) personal gain/benefits from the content.

The guest survey included additional questions. One question sought to determine if they perceived their personal contribution of sharing their story on the podcast to be helpful and informative for those within the disability and/or medically complex community. Another question asked guests to describe when and how they had ever personally benefited from learning about the personal or professional experiences of someone within the disability and/or medically complex community. Finally, the guests were also asked if the podcast provided them the opportunity to tell a part of their story that they do not usually get to share.

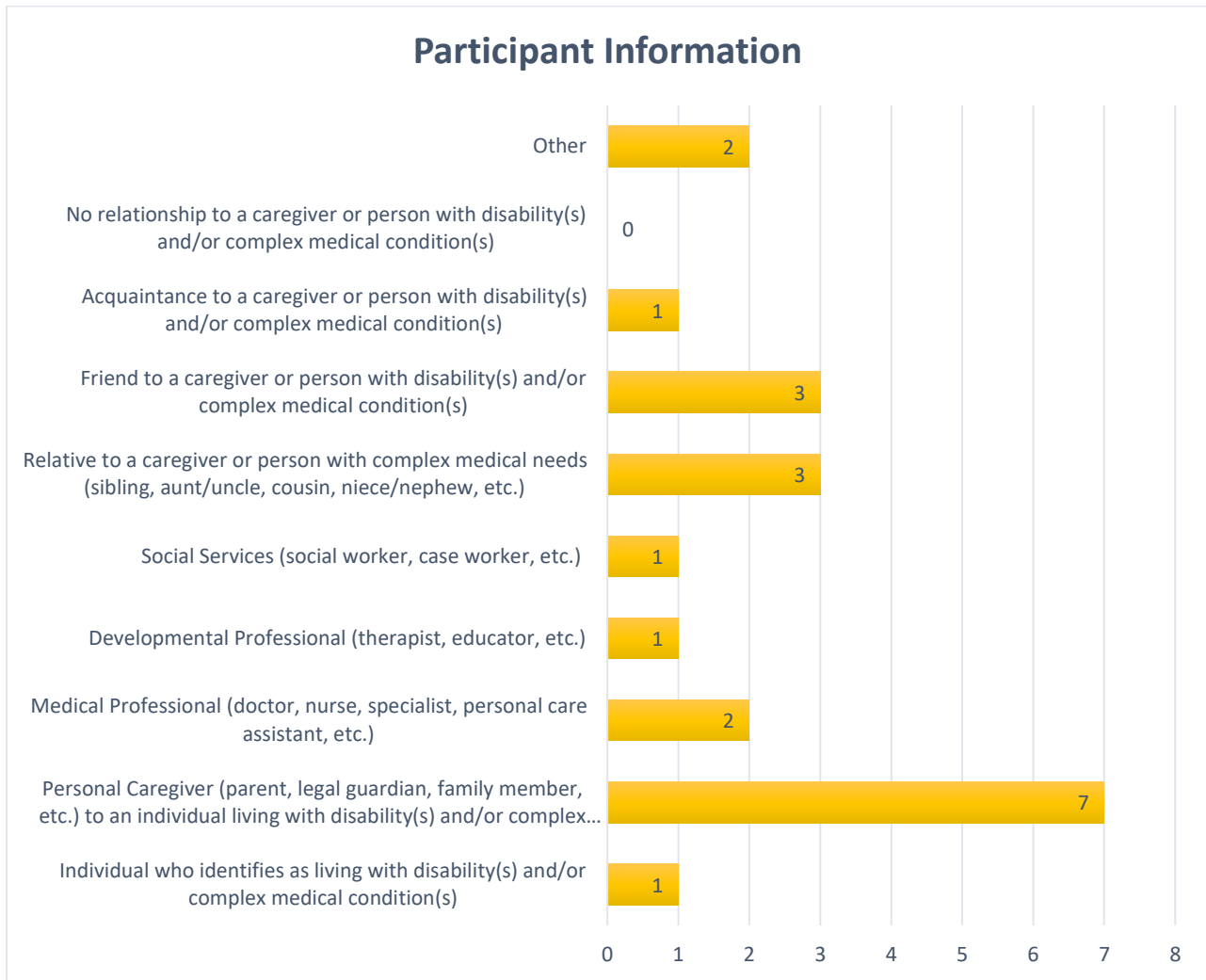
Each guest on the first season of *Atypical Truth* received correspondence in advance which provided a synopsis of the show and an outline of the discussion topics and questions to be addressed. Each interview was recorded through Zoom with the consent of the guest. The interview then underwent an extensive audio engineering and production process which included: editing out irrelevant content, adding music, adjusting volumes, mixing for best sound quality, creating show notes, transcription, promotional graphic design, and social media marketing. The guest episodes were published biweekly with personal reflection episodes (titled “Afterthoughts”) published between each.

A total of 16 respondents (listeners and guests) participated in the surveys. Understanding that relationships can intersect in a variety of ways, the participants were asked to select from options that best described their relationship(s) to the medically complex community.

Respondents were given the option to select any that apply (and so any one respondent could choose up to 10 options). (See Figure 1 for a breakdown of responses.)

Figure 1

Participant Information



Note. Participants selected any description that applied.

I took an informational approach to my data and used the survey responses to inform my understanding of how the podcast was received. Knowing *who* took the survey—knowing how many respondents were caregivers, knowing how many were friends, and so on—provided a context with which to examine the ways the podcast functioned for each of these roles. While

the number of respondents may seem low compared to more conventional survey data, I believe it helped me to hone in on specific responses and experiences in a way that a higher number of survey responses would not have allowed. Thus, in my data analysis, I was able to look at each response individually, rather than seek to draw generalizable conclusions.

In what follows, I present the survey data in a conversational, storied form, woven together with my experience shared publicly on the podcast and privately through my everyday lived experiences. I contextualize our stories with current research in the fields of disability and complex medical conditions to explore the benefits of using podcasts as a platform for creating a sense of community and emotional support to counter the isolating experience of caring for medically complex children. My goal is to present a cohesive and nuanced story of how one type of resource—a podcast—might be of service to those who live in the world of medically complex diagnoses.

Atypical Motherhood

With Margot stuck in my birth canal, I pushed and I pushed for four hours. That should have never been allowed, intervention should have happened sooner. Forceps were eventually used to help deliver my daughter. I instinctively knew that something was wrong. Margot didn't cry. Margot had zero muscle tone. Margot failed her newborn APGAR test. Still, no one said a thing to us. No one seemed concerned. Moments after she was placed in my arms, I knew something felt wrong. What an awful feeling for a new mother to have to experience. But I knew. I knew instinctively that she was struggling. (Stearns, 2021f, 5:41)

Research has shown that women, especially marginalized women, are often dismissed when it comes to their healthcare needs. Women residing in the United States are most likely to

die from complications related to pregnancy or childbirth. According to the Centers for Disease Control and Prevention [CDC] (2020a), currently 5.7 infant deaths occur per every 1000 births in the United States. In a 2016 study, Doris Chou, medical officer at the World Health Organization [WHO], found that low-income and marginalized women faced an even higher risk of death during pregnancy and childbirth, even in the wealthiest of countries (WHO, n.d.). In a study that examined mistreatment of women during childbirth, researchers found that one in six women experienced one or more types of mistreatment ranging from verbal abuse, stigma, discrimination, being ignored, and refused treatment (Vedam et al., 2019). I am *one out of six* women.

I requested that the neonatal hospitalist return to the hospital and explain herself. I was informed that she could not—she was getting her hair done. At that point, I asked to speak with management and we demanded an explanation and a transfer to somewhere more equipped to care for our child. Within those critical hours, soon after the nurse found that the MRI images had never been interpreted, a neurologist at the hospital in St. Louis reviewed Margot’s MRI and called to request that she be transferred immediately. At this point, the local hospitalist returned—with her hair half done. She and the care team admitted the error in their ways, they agreed that they would have advocated just as fiercely had it been their own child. They seemed understanding with our frustrations...and yet, they managed to deliver one final blow to us as they handed me paperwork they had filled out indicating that she was receiving an *unnecessary* medical transfer. Can you feel my rage now? (Stearns, 2021f, 9:58)

In the second episode, “Afterthoughts - Complex Medical Care,” (Stearns, 2021f) I shared the extremely traumatic and vulnerable details of my first child’s birth story in detailing

how the healthcare system failed us both. Revisiting these memories was both painful and empowering. The pain was visceral. Knowing that it was impossible to change the past to help save myself with the knowledge I currently possess, I realized that I had to change the power dynamic of the characters within the narrative, me against the failures of the healthcare system. Essentially, I had to flip the script of the story; where I was once the powerless victim of negligence, I am now the fierce voice of accountability.

Little did they know, I drafted paperwork like this for a living. I knew to read the fine print and I held that doctor accountable right then and there in our daughter's hospital room. I asked her to look at our child and repeat to me what she had just said a moment earlier, "I would have done the same if this were my child." (Stearns, 2021f, 11:15)

As I spoke each word with conviction, I felt empowered by the thought that it might help prevent another woman and newborn from experiencing the same unnecessary trauma I had experienced. At first, I was overwhelmed with fear and found myself shaking as I hit the "publish episode" button. I feared that I had overshared, I feared that people would be put off by the intensity of the details. I had never shared so openly and publicly about my experiences and there was a large part of me that doubted if my story was even worthy of being shared. I comforted myself with the thoughts regarding the potential this podcast harnessed in helping others.

Immediately upon release of the episode, I began receiving messages of support and encouragement from friends and family who now had an open invitation to hear about the experiences they had always wanted to know more about but never felt comfortable enough to ask. A few days after the episode's release, I received an unexpected phone call from our pediatrician who expressed immense gratitude and support for me sharing my experience. The

pediatrician explained that it had moved them, challenged the way they thought, and inspired them to make changes in how they practiced medicine. With that single conversation, I knew that I had done the job I had set out to do. The podcast had influenced a change in the way one person thought, let alone, the way one physician now practices medicine. Receiving this feedback was promising. If this early episode of the podcast could have an impact on the way medicine is practiced, what other changes might the life of the podcast inspire?

After listening to the podcast, friends and family began reaching out. I noticed a shift in their tone from one of pity and concern, to one of awe and encouragement. By sharing this part of my journey on the terms that I had so carefully chosen, I had offered people a new, if not rewritten, perspective. As I recounted my experiences, I no longer felt like a helpless, grief-stricken, unfortunate statistic. By changing the narrative, I changed myself. Rewriting the narrative gave me strength and empowerment. I was no longer an unlucky woman who experienced a series of unfortunate events; I was now an outspoken advocate who was holding systems (and the people who make them) accountable to prevent other women from ever having to endure what I did. One listener survey respondent and fellow caregiver described the following reaction:

I've never been more emotionally impacted than listening to Erica's unbelievable introduction to motherhood. This episode hooked me and even though my experience wasn't the exact same, I felt an instant connection to her as a mother who has felt helpless, desperate, infuriated, and isolated.

Sharing my story had provided another caregiver the feeling of connection through our shared experiences of having felt emotions that are not commonly associated with newborns, motherhood, nor parenting; and that was exactly the intention for starting the podcast.

Rare Reality

The beginning of my journey as a complex needs parent was equal parts sad and frightening as it was happy and exciting. But the wildest thing about all of this, was my realization that the sum of my life experiences had prepared me to be exactly the mother my children needed me to be. (Stearns, 2021b, 4:29)

In the United States, a disease is considered rare when it affects less than 200,000 individuals, while in the European Union, a disease is considered rare when it affects less than 2,000 people (GARD, 2021). According to the CDC (2020b), approximately three percent of all babies in the United States are born with birth defects, which are also the leading cause of infant deaths. That means that in the United States, the likelihood of a child being born with birth defects is approximately 1 out of 33 births (CDC, 2020b). It is estimated that the worldwide annual rate for infants born with serious birth defects is approximately 7.9 million (6% of global births) and that nearly half of these cases have no known cause and result in children experiencing lifelong disabilities (Lobo & Zhaurova, 2008).

My birth story did not mirror the images I had spent my entire pregnancy digesting through social media. It felt extremely isolating to be thrust into a “new norm,” a world of complex caregiving and disability advocacy. Unlike the experiences of a typical pregnancy, birth, postpartum, and parenthood, there are no guidebooks to help parents like myself. In truth, I probably would have never read that book had it existed because, like most new parents, I did not believe that would happen to *my* child. Despite being born with birth defects myself—born with paralyzed vocal cords which required numerous life-saving surgical procedures, life-sustaining medical devices and equipment, rendered me mute until the age of 3, and trach dependent until the age of 15—I had never considered the rate at which children were born with

birth defects and rare diseases because, again, I just did not think it would happen to *my* child. No one ever does.

I had no way of knowing that my pregnancy would be the last time in my life as a parent when I would be able to relate to my parent-peers in celebrating typical milestones and bonding over shared experiences. I became hyper-aware of the differences between my life and theirs, and with each comparison, I grew more isolated from the “normal” life others were experiencing, the life I was supposed to have. While I had fantasized about life as a new mom in the comfort and privacy of our home, I was shocked to experience the feeling of fear and anxiety when our daughter was discharged from the NICU. After several long months, we were finally free to live life outside of the bustling hospital walls, but with this new freedom came an entirely new way of living, a phenomenon that is often referred to as the “new norm.”

When examining the reconstruction of normality following the diagnosis of a rare childhood disease, Germeni et al. (2018) found that caregivers expressed the most difficult and psychologically distressing part of their journey to start at the first appearance of symptoms and to last until a diagnosis is reached. During this time, parents are left wading in the unknown. While a diagnosis may feel shocking and saddening, there is also an immense amount of relief because it often signifies a turning point (Germeni et al., 2018). For many, a diagnosis leads to information which then leads to treatment. Parents expressed that receiving a diagnosis allowed the family the opportunity to begin reorganizing their life to adjust to their new definition of normal (Germeni et al., 2018). This is not the case for *all* rare diseases, hence the reason they are called “rare.” The *more* rare a condition is, the *more* challenging it becomes and the *more* time it takes to reach a diagnosis—that is, if a true diagnosis is ever reached. When a diagnosis cannot be determined, if it is extremely rare, or when it is taking years to discover it,

families and patients expressed experiencing fragmentation of care, limited resources, a fragile sense of control, and extreme feelings of social isolation (Germeni et al., 2018).

Having a child with an extremely rare disease, complex medication issues, and drug-resistant epilepsy meant that my worries were complicated by numerous uncontrollable, unknown, and confounding factors that occurred spontaneously and often without warning. In a loud and crowded restaurant, we quickly learned that leaving our home to adventure into public spaces was just not an option. Every loud sound was a seizure trigger, every flash of light resulted in an epileptic response. My stressors were directly related to the life or death of my child. My dreams of the future were in the form of minutes and days rather than years. The victories we celebrated were measured by inch-stones instead of milestones. Our child did not have a clear diagnosis, no known cause for the condition, nor a clear-cut path for treatment; there was no simple nor pretty nor easy way to explain to others what was going on. Our lives were atypical from the norm.

The word *atypical* was one we began to hear on repeat throughout the first year of our children's lives. Initially, I despised this word and all that it stood for because it felt like a medically PC way of saying "different from everyone else." But really, the most despised aspect of this word was understanding that it meant we were heading down a path rarely traveled by others, a path where no miracle drug exists, a path with no road signs directing what turns to take or advising what decisions to make, nor any indication what the future might hold. Instead of a fork in the road, our path led us directly to the abyss where science ends and faith begins. (Stearns, 2021b, 5:05)

Life at home was supposed to be easier, but it was precisely the opposite for us. I had imagined life with a new baby to be busy: the nights to be sleepless from clustering feeds, the

house to be messy from the cloth diapering, and our home to be filled with adoring visitors anxiously awaiting the chance to hold the new baby. Life was, indeed, very busy. I spent countless hours on the phone with doctors, nurses, insurance companies, therapists, and social workers. The nights were, indeed, sleepless. Stacked on the nightstand were endless notebooks filled with data from tracking, timing, and video-recording hundreds of clustering seizures, constantly debating when to make the dreaded trip to the emergency room. The house was, indeed, very messy. I tried my hardest to make the life-sustaining medical equipment fit into the decor of our home, but there was no disguising their loud and large presence. Our home was, indeed, filled. From the mountains of cardboard boxes of medical supplies, to the countertops filled with medication bottles and syringes, our living quarters felt less like a home and more like a field hospital. There were few visitors, and the visitors we had likely sensed my uninviting anxiety. They came excited to hold our child and to see us thriving at home, but once they walked into our make-shift field hospital, it was noticeable how quickly the excitement shifted to nervousness. We were all nervous and experiencing discomfort that stemmed from the fact that our child was medically fragile and our lives were unlike anything they had ever experienced before.

I do not want to dismiss or gloss over the fact that this has been one of the most difficult and trying times in our lives as individuals and as a couple. For every beautiful and positive moment that we share, there are about a dozen very sad, depressing, ugly-crying moments that we don't talk about. And to be honest, I really want to change that. You all deserve the truth; that is, in fact, the whole point of this podcast. I want to be sure that new parents on this journey are not just hearing about our experiences with any sort of rosy retrospection; instead, I want them to understand they are not alone in experiencing

a full spectrum of emotions, thoughts, and feelings—all of those that can range from dark and scary, to light and optimistic. (Stearns, 2021c, 15:20)

I was shocked to learn that the very things I had avoided talking about in social settings and made me feel apprehensive about having people over, were exactly the things *Atypical Truth* listeners benefited from hearing about. One listener survey respondent described why they found this aspect of the podcast to be effective:

I love getting glimpses of her life as a caregiver of her two kids and her honesty and vulnerability regarding the joys and difficulties of her reality. Also just hearing how the system actually works (or doesn't work) within the family, from finding nurses to getting the mental health support necessary, to getting equipment, to advocating for the children - the actual impact of the life of these caregivers is so all-encompassing and that has taught me a lot.

Two social trends come into play when thinking about the difficulties that caregivers face. First, despite the popular phrase “it takes a village,” the normative social construct of parenting within our culture is one that is deeply rooted in the notion of what Caldwell calls “taking care of your own” (as cited in Currie and Szabo, 2020). At the same time, Lin et al. (2018) describe how our healthcare systems are becoming more community-centered, rather than hospital-centered. This seems like a good shift, on the surface. However, expecting families to become responsible for the care and wellbeing of patients in the comfort of their own homes can be overwhelming without the proper social supports in place (Lin et al., 2018). These two current societal trends result in isolation for parents who identify as caregivers to children with disabilities and complex medical conditions. Suddenly becoming solely responsible for the care of a child with medical needs as a result of being born with a rare disease, complex medical

condition, and/or disabilities, caregivers expressed the experiences of detachment, fear, and stigma from others (Currie & Szabo, 2020). The rarer and more incurable that a child's condition is, the more isolation caregivers experience because their peers are often unfamiliar with the condition and are not experienced with navigating the challenges that come with a prognosis that cannot be improved or resolved (Currie & Szabo, 2020).

So we have a couple of really cute baldies, and they have a whole lot of complex needs. As their adoring parents, we take immense pride in their care and happiness. However, it needs to be said that our path to happiness and joy in this life—it's been fraught with heavy grief, exhaustion, stress, sadness, and fear. For our family, there is no “overcoming” their prognosis. There is only acceptance. Acceptance for what we know now and have in the present, and acceptance for all the unknowns that the future holds. Understanding that our kids have a life-limiting condition, we try to make a point to enjoy our time with them as much as we can while they are here and with us now, because we are never guaranteed a tomorrow. (Stearns, 2021c, 14:28)

Our adjustment to the new norm was not without growing pains. While everyone else seemed to be living peacefully, we were always sitting at the precipice of extreme. Where most children would survive the common cold, for our children it was a battle of life or death which often resulted in helicopter rides to the children's hospital as we raced through the middle of the night in the car trying to keep up. Where other parents talked about their crabby babies teething, our children were struggling not to choke and aspirate on their drool which frequently led to pneumonia. Our lives were constantly lived in the red zone and at a certain point, we just had to learn how to embrace that. It often felt to me as though there was no other person on the planet

besides my husband who truly understood the nuances of our life, and while that certainly made our marriage stronger, it is more than two people should ever have to bear.

Need for Connection

Our new lives as medical caregivers to our children distanced us from the lives we lived before. It distanced us from our social life, our careers, and our relationships. Tools we once used to cope through difficult times were no longer applicable in a life where the resolution to the perceived hardship—the death of our terminally ill children—is unimaginable. In addition to the medical skills and knowledge that we had to quickly acquire, we also had to learn adaptable self-care skills to help us to simply exist, survive, and eventually thrive in a reality that very few people could even imagine, including ourselves. These transitions and this forced growth resulted in feelings of immense loneliness. We no longer shared relatable experiences with our peers. Our lives were drastically different from those who got to experience parenthood without the medical caregiving component.

I craved connection and I yearned to meet other families whose lives resembled our own. The unfortunate reality is that our children's conditions limit our ability to leave the house for anything beyond necessary medical appointments. With the inability to physically get out and meet people, there is the added limitation of residing in a rural area where no known events occurred which would have allowed me the opportunity to meet other caregivers like myself. Furthermore, other caregivers like myself also experienced their own set of limitations in being able to safely gather and socialize. While there was a deep need for connection with my caregiving peers, in-person, real-life friendships with other caregivers felt impossible.

To say that this experience has been isolating feels like an understatement. Through many years of conversations with our children's therapists, I began to learn that I was not

alone in experiencing feelings of isolation. Many other families felt the same way and longed to connect as much as I did. But there were some big obstacles that I faced, and I think that many other families like our own face, in finding and feeling connected to those other families. (Stearns, 2021c, 16:38)

Sweet et al. (2019) review multiple studies that detail the social isolation experienced by people with disabilities, many of whom have few friendships outside their family members and paid caregivers. Disabled people are frequently faced with constant challenges and obstacles in their pursuit to establish, nurture, and maintain social relationships with others. In a society that has largely deprioritized accessibility, disabled people experience many social and physical barriers that make it difficult to organize and communicate with one another (Sweet et al., 2019; Stough et al., 2015). These same barriers often exist for parents of disabled individuals; however, few studies have been conducted to focus on the social needs of the family members and caregivers of people with disabilities.

Our circumstances are so rare, what were the odds of finding families like our own within our local rural community? How do the professionals in our lives connect us without violating HIPPA? How do we navigate meeting one another when our children are medically fragile and there are virtually no public spaces that accommodate our children's needs long enough to spend quality time getting to know one another? And how the hell do we get out to meet alone if one does not have the luxury of having the support of another person who is capable of caring for our children? And what about just not having enough time to devote to meeting new people and investing in new friendships, because you barely can find the time to take care of yourself? (Stearns, 2021c, 17:12)

With the revolution of the internet, modern technology, and social media, many people suddenly gained the ability to connect with others residing all over the world. The combination of modern technology and social media offers unprecedented access to spaces and conversations where marginalized individuals, who were often left out of these spaces and conversations, can now easily meet, connect, and organize with one another (Storer & Rodriguez, 2020). These advancements in technology, which connect many people at a virtual level, have provided a unique evolution in our concept of what defines friendship, intimate connection, and community. Entire groups of people who share commonalities, concerns, and passions can now connect and share information “at a scale that crosses institutional and geographical boundaries faster than previously possible” (Keir et al., 2021, p. 2).

Hashtags used as search engines on popular social media sites, such as Twitter and Facebook, have revolutionized traditional methods for organizing, outreach, advocacy, and prevention (Tufekci, 2018). In my own experience, utilizing hashtags related to the symptoms our children were experiencing was the most helpful resource we had in connecting us to Facebook groups of families whose experiences resembled our own. For example, the hashtag #mmspi, which is the acronym for the type of rare and catastrophic seizures that my children experience, is what led me to connect with the podcast guest and fellow caregiver, Jenny Park. In our conversation together, she shared how informative these groups have been, to the extent that medical providers have been known to suggest social media as a supportive resource.

I've learned so much through our Facebook support group, from you, and other moms.

Other parents who are living this and just being able to see the faces of these kids, it's been such a resource for me. I mean, even Josie's doctors have said, “Well, ask in your Facebook group about this medication, or about this treatment,” because we are lucky to

have that wealth of knowledge. So I do, I turn to our support group quite a bit. (Stearns, 2021g, 28:04)

In a study conducted to examine the patient and caregiver use of social media, Hamm et al. (2013) discovered that social media is both a cost-effective and efficient means for varying interventions. When considering the ease of access to social media, Hamm et al. determined that social media is capable of effectively providing an online supportive community for those who may not have the ability to participate in support groups in-person due to physical and/or proximal limitations.

In a scoping review of social media use by patients in healthcare, Gupta et al. (2020) found that while the most popular patient use of social media is the search for information pertaining to a diagnosis, social media also offers a unique platform for patients to receive emotional support. Gupta et al. noted that patients not only look to others with shared diagnoses to learn more about their personal experience with the disease, but also enjoy and benefit from sharing their own stories and health experiences. They further explain, “Social media allows for anytime anywhere access to and dissemination of information around the globe” (p. 5). The accessibility of social media makes for a useful tool for patients to alleviate feelings of isolation because it allows many people from all over the world, who share a similar diagnosis, to experience social and emotional support from one another (Gupta et al., 2020). Through the use of social media, patients expressed feelings of empowerment from receiving information and advice from their virtual community (Gupta et al., 2020).

Germeni et al. (2018) found that personal contact with other caregivers was fundamental to parents of children with rare diseases. Not only were other caregivers understanding of the language and the nuances of medically complex lives, but they also shared resourceful life-hacks

to everyday problems and provided emotional support when other caregivers expressed hardships during challenging times. Through the photos of their happy, thriving, and aging children, they helped to reduce fear and uncertainty about the future of other children living with the same disease (Germeni et al., 2018). As explained by a listener of *Atypical Truth*:

When my grandmother was dying of scleroderma it was very helpful to understand what she was going through by talking with another friend that had an amputation [about] what that entailed for the[ir] daily life. Obviously [this is] different from the disabilities talked about on *Atypical Truth*, but know[ing] what to expect or be prepared for is empowering.

It was confirming to learn that when faced with a life-changing prognosis, others find comfort in hearing from people who have a shared lived experience. Understanding that our shared experiences not only help caregivers, but also the family members and friends of the patient, gives just a glimpse of the potential range of people this podcast will serve--more than I had originally predicted.

Finding support through social media was undoubtedly the single most helpful resource I came to find as a caregiver to children with a rare disease. I thoroughly enjoyed the connections that I made, the friendships that I found, and the wealth of information that I suddenly had access to in the form of other caregivers sharing their experiences. It is important to note that finding the right groups, forming new friendships, reading through blogs and Facebook pages of other children living with disabilities and rare diseases. . . all of this searching took precious time. Rather than looking down at my child, my face was illuminated by the screen of my phone. Rather than doing paperwork, organizing, and tending to the peripheral needs of myself and my family during my downtime while my child napped, my time was consumed by the words of others which provided me insight into how to manage life as a caregiver. While this

insight was critical in prompting the healing chapter of my journey as a parent and caregiver, there were drawbacks and limitations to searching for connections to others when scrolling through social media.

The filtered photos to enhance the beauty and perfectly edited captions to describe an experience made the content shared on social media feel superficial, as people are often only portraying the positive aspects of their lives. The unscripted, unedited, and unfiltered reality of one's life is rarely portrayed on social media, leaving many to feel inadequate and insecure about their own lives. Our house looked like a field hospital disguised as a home, it was messy and cluttered by all things medical. Meanwhile, the photos I saw on social media of other families were bright, white, organized, and pristine. These seemingly staged differences between their life and ours only made me feel further distanced from the very people I had wished to connect with.

I found social media to be severely lacking the intimacy of the personal connection one receives when being able to meet with others face to face. Due to the word count limitation of many social media platforms, the content of a social media post is reduced to what can fit in the text box. The context of the post is dependent on how the reader receives and internalizes the information; therefore, the intention of the post can be lost on the audience without the person and the voice delivering it. I needed to *hear* the voice of other parental caregivers; I needed to *audibly* process the full humanness of their experiences. As a busy caregiver, I needed the option to *hear* these stories at my convenience and leisure.

I want to hear from parents like you, parents whose lives look similar to my own, those who are tired of applying the filters of positivity and perfection for the world because we are learning that if you want to accurately convey the reality of our lives being both

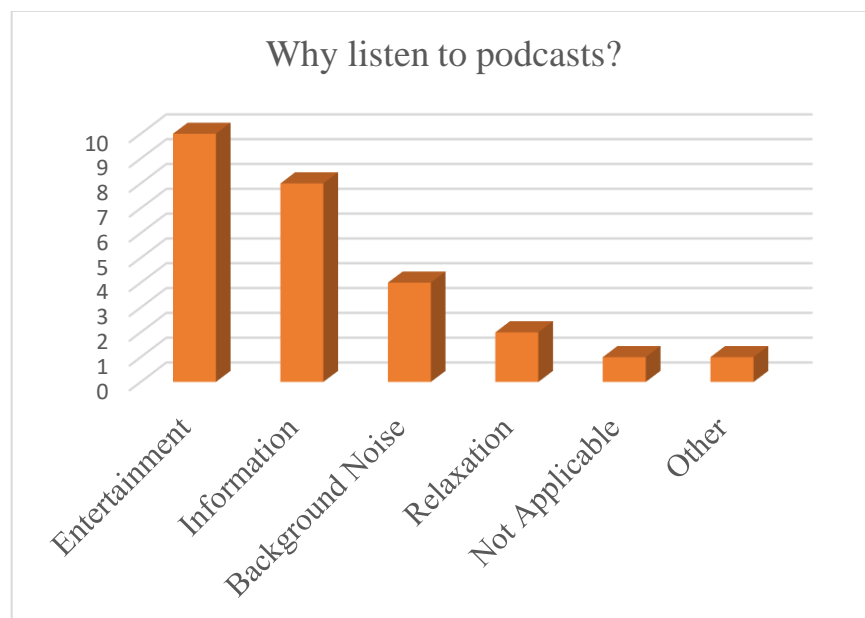
unimaginably hard and rewarding all at once, you do so by sharing your hard-earned, unapologetic truths. (Stearns, 2021c, 22:24)

The same revolution in technology that made social media successful pertains to podcasts as well. Based on the popularity of podcasts, in addition to my preference for podcasts as a means of therapeutic entertainment and information, I suspected the use of a podcast to be an effective means of reaching, connecting, and providing information to other caregivers. Nearly five years ago when I first sought out podcasts that related to my life, being both disabled and a caregiver to disabled children, there were none to be found. Nearly a year ago I had managed to find two. Today, I know of several, but it took me becoming a podcaster to find them.

When addressing why people listen to podcasts, the listener survey respondents cited “entertainment” and “information” as their primary reasons, as shown in Figure 2. Some survey respondents noted that they had never listened to a podcast before (“not applicable”) or only listened because of their relation to the podcast host and creator (“other”).

Figure 2

Why Listen to Podcasts?

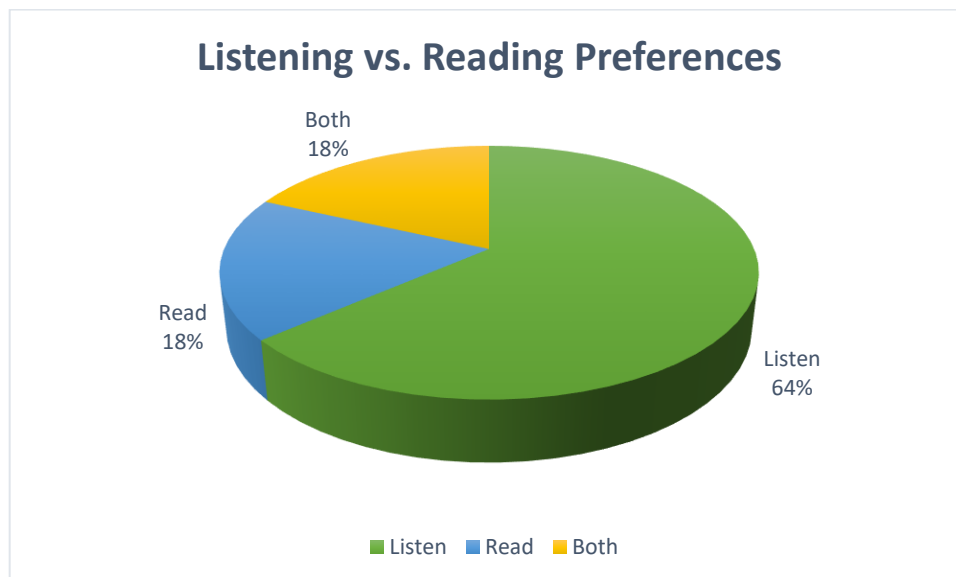


Note: Participants indicated the reasons they listen to podcasts.

When asked about their preference between *listening to* and *reading about* the personal experiences of individuals within the disability and/or medically complex community, 80% of my listener respondents reported the preference of listening, as shown in Figure 3.

Figure 3

Listen vs. Reading Preferences



Note. Participants indicated their information processing preferences for learning about the personal experiences of others.

A listener survey respondent and fellow caregiver explained that they preferred both options because they provided enjoyable opportunities to acquire new information and expand their compassion for others.

I personally get a lot from reading/hearing other people's stories because I learn about situations of which I may have had no prior understanding. And I can use this new knowledge to grow my compassion. It's like a catharsis for me as well.

This information is promising for the field of podcasts as it informs podcast content creators that there exists a desire and preference from the audience for the experience of audible

information processing. However, this information cannot be generalized to represent the wider population, as we need to acknowledge that preferences for information processing are unique to each individual and that not all people, especially the Deaf community, have the option nor preference for processing information audibly.

Our Stories Matter

My journey into podcasting began many years ago before parenthood when I was a devout Sunday listener of the NPR show, *This American Life*. I loved how this show allowed me a glimpse into the lives of others through the stories told, by the voices of people with a wide variety of backgrounds and life experiences, as they shared about their struggles, their achievements, and all the weirdness in between. When this show became available as a podcast, my world changed. I began a deep dive into the land of podcasts to the extent that I found myself looking forward to mundane tasks so that I had an excuse to pop on my headphones and get lost in someone else's story. This was especially the case when my children were frequently hospitalized.

I don't know what this says about me, but I'll never forget pumping in the lactation room while listening to the first episodes of *My Favorite Murder*. From true crime comedy by two ladies who felt like friends who I had never actually met in real life, to unusual love stories by my voice idol Phoebe Judge—podcasts became my hands-free therapy, my zen, my ability to take a mental break from the emotional toll I was feeling during this time in my life. (Stearns, 2021h, 2:07)

I had noticed that there existed very few stories that reflected my own lived experience, specifically the experience of being a disabled person and being a caregiver to a child with disabilities. As of this writing, I am unable to locate any podcast platform that uses the word

"disability" as a search term category, nor is it an option amongst nearly 70 different sub-categories which include subjects like "alternative health," "fitness," and "nutrition." I was frustrated by the health-centric and ableist nature of podcast categorization which resulted in a lack of availability and access to disability and caregiver-themed podcasts, which only mirrored the lack of representation I experienced in all other aspects of life. Listening to podcasts was a convenient, efficient, and accessible form of free therapy; it was the ideal and preferred source of entertainment for me as a disabled adult and caregiver because it required very little in return. With my hands free and available to still tend to my responsibilities around the home and to my children, when listening to a podcast I could put my earbuds in, set the show to "play," and find myself engrossed for hours in the stories of others; but rarely did these stories reflect my own.

Driven by a combination of frustration with lack of representation in the world of podcasts and the desire to use the voice I was originally told I would never have due to my disability; I was inspired to utilize the platform of a podcast to express my own personal narrative and the personal narratives of others through a series of biweekly episodic interactive interviews and personal reflections in the form of "afterthoughts." Understanding that I had a unique and multidimensional perspective of life as a disabled child, a medical professional, and a caregiver to disabled children, I felt that I could navigate and relate to a variety of topics with individuals whose lives were, in some way or another, impacted by disabilities and complex medical conditions. This context inspired the birth of *Atypical Truth*.

Participant Contributions to the Conversation

The survey respondents from both listeners and guests proved to be wholly informative in letting me know not just *if* podcasts seemed to be a helpful resource, but also whether

Atypical Truth specifically serves as a helpful resource. When asked if the podcast helped to provide the listeners with a sense of personal connection to caregivers, disabled individuals, and/or individuals with complex medical conditions, all listener survey respondents answered *yes*. As one listener and fellow caregiver simply but powerfully stated, the most beneficial thing they learned was, “I am not alone in being a mom to a child with complex needs.” This answer resonated deeply with me. Not only could I relate to understanding the power of what it feels like knowing that we are not alone, it was equally powerful to know that was the feeling others were left with when listening to *Atypical Truth*.

Another listener and fellow caregiver explained, “Hearing the experiences within this community, even if they are not the same as my experiences, helps relieve the intense isolation that comes with being here.” This perspective was validating and specifically addressed my concerns regarding how beneficial the podcast would be to caregivers if the disease, disability, or medical complexities did not perfectly mirror the diagnosis of their loved ones. When asked if they felt like the podcast provided a sense of community and support for caregivers, disabled individuals, and/or individuals with a complex medical condition, all listener survey respondents answered *yes*.

Similarly, all listener survey respondents said they felt they gained helpful insight into the personal life of the guest(s) on the podcast. A listener and fellow caregiver stated, “I have felt a deep sense of connection and community with the guests on the show thus far.” This response was especially helpful in understanding that the listeners experience a feeling of connection to the guests despite not knowing them or having met them before.

In the creation of the podcast, I had intended for the content to serve as a helpful resource for information pertaining to caregivers, disabled individuals, and/or individuals with a complex

medical condition. Listener survey respondents overwhelming indicated that, *yes*, this podcast was serving as a helpful resource. This survey response provided by a listener who identified as a friend to a caregiver or person with disability(s) and/or complex medical condition(s) was extremely impactful: “My reality is nowhere near Erica’s, but I have come to realize what others go through.” This listener’s words show that regardless of our experiences being different, the mere acquisition of the information regarding these differing experiences was considered helpful.

Another listener responded with the following statement which spoke strongly to the resourceful implications of this podcast:

Hearing stories of other parents and families helps me both feel less alone as the parent of a medically complex child. [It] further informs me, as a nurse, with insight into the struggles [and] things that are important to patients & families navigating the medical system.

This response is important because it acknowledges that caregivers exist in a variety of roles and identities beyond their experience of being a personal caregiver. It is important to recognize that our lives are not mutually exclusive to one role and that what one caregiver experiences may be drastically different from a fellow caregiver’s experiences. It further speaks to how informative and helpful it is to learn more about the differing experience so that knowledge can be applied to other facets of their life.

When asked if the podcast helped to provide a new or deeper understanding of the lived human experience of caregivers, disabled individuals, and/or individuals with a complex medical condition, all listener survey respondents answered *yes*. A fellow caregiver expressed it best when stating, “I have gained insight to the heavy emotional roads we feel, as well as support in being an advocate to my son.” Another listener shared, “The most beneficial thing for me is the

sense of connection and knowing that other people are dealing with similar circumstances and experiences.” I appreciated this response because the listener is a personal caregiver, medical professional, relative, *and* friend; to know that someone who wears all of these hats can find a connection by listening to *Atypical Truth* helps me to know that podcasts can be effective as a resource.

When asked if they have ever personally benefited from learning about the personal or professional experiences of someone within the disability and/or medically complex community, all listener survey respondents answered *yes*. A disabled listener provided the following example of the benefits:

I’ve learned a lot more about what disabled children go through, especially when they have multiple medical issues. This has helped me mentally prepare to advocate for my son (he is [non-dis]abled as far as I know, but I have hEDS, which he has a 50% chance of inheriting). I learned that you can balance loving disabled kids and thinking they are exactly who they’re meant to be, and finding the day-to-day difficult. There are ways to talk about that without being ableist.

As a disabled person myself, I understand that the experiences of disabled people vary greatly and that being a disabled parent does not mean that by default you know how to navigate raising a child with disabilities or a rare disease. You may be able to relate to and understand the challenges a disabled child will face while growing up, but it does not mean that you automatically know how to advocate for a disabled child because that was a role your parents experienced, not your own.

When asked to indicate how the experience of the podcast was received by the listeners, listeners were invited to check any answer that applied. It was encouraging to see that listeners

indicated a wide range of reactions, primarily noting that the content shared was a completely new perspective, was informative, and was helpful. It is important to note that one personal caregiver felt the content of the podcast reflected their own experience, provided a new perspective, and was informative, helpful, and triggering all at once. This indicates that while this podcast may serve as a helpful resource, it may also bring about memories and feelings that are difficult to revisit for some individuals. It was especially comforting to know that the listener respondents felt that the content of *Atypical Truth* was not offensive, harmful, nor useless. (See Figure 4 for listener reactions.)

Figure 4

Listener Reactions



Note. Participants indicated any reaction that applied to their experience of hearing the stories shared on *Atypical Truth*.

These responses, when compiled, signified an important overarching theme for the community of caregivers, disabled individuals, and/or individuals with a complex medical

condition: people want and appreciate a glimpse into our lived experience. Fellow caregivers benefit from knowing they are not alone, friends and family want to learn more about the challenges we face, and our non-disabled peers want to better understand how we navigate making the decisions when addressing said challenges.

Free of Judgement

I want to remind everyone that this podcast will be a safe space, where others can share about their own vulnerable experiences without the fear of judgment from others. To set that example, I felt it was best to start this off by sharing some of my own thoughts and feelings of a very personal nature about the things that have influenced me to start this podcast. (Stearns, 2021c, 0:43)

In the research of narrative exchange through interactive interviews with mothers of disabled children, Green (2003) explains that except among very close friends, many parents of children with disabilities often feel they need to “withhold or at least severely edit” (p. 2) their parental experiences when in social situations and conversations with other parents. The demographic of parents/caregivers for medically complex patients is very small; therefore, our experiences are unlike many other typical parental experiences and often result in a reaction of sympathy, discomfort, or awkward silence. One listener respondent—who is also a personal caregiver—described the following:

I follow three mothers of medically complex children on Instagram. Through their honest stories I have learned about the harm done by ableism, have had my compassion expanded by the sharing of their profound pain, and have learned new ways to understand my daughter and her situation. I have also seen these vulnerable women be shamed by uncaring and hateful comments. I better understand toxic positivity. I see these women

trying to do their very best for their children, and by posting a portion of their hard lives, trying to make the world a better place for themselves and their children.

I knew all too well what it felt like as a caregiver to be indirectly but strictly monitored by society. Due to the vulnerability of our children and the history of exploitation they have experienced, the content shared by parents of disabled children is more heavily monitored and policed by society than the content shared by parents of typically developing and nondisabled children. In everything that we do, say, and publicly post, we run the risk of offending someone, making someone feel uncomfortable, and potentially sharing too much. I often felt like the weight of our experiences was too heavy for public consumption. Conversely, I knew that if I did not share about my experiences, however heavy they felt or uncomfortable it made people feel, these experiences—my experiences—would never get closer to being normalized. As the host of a publicly broadcasted podcast, I realized that it was my responsibility to set the rules of engagement and be an example of openness.

This will be far from perfect. Take caution. I am going to mess up, say the wrong thing, and stumble in my efforts of using the correct language because that is what happens when you attempt to unlearn a lifetime of internalized ableist thinking; and I say that as an adult who is only now learning how to embrace my disabled-self, rather than trying to prove myself in spite of my disabilities. Together, we will navigate sensitive subjects that many of us are too afraid to talk about publicly. (Stearns, 2021c, 19:50)

The personal narratives of parental caregivers have historically remained unvoiced due to the parental fears of social misconceptions and negative stigmas associated with illness and disability (as cited in Currie & Szabo, 2020). Parents of children with neurodevelopmental disorders experience higher levels of stress compared to their peer parents of neurotypical

children (as cited in Currie & Szabo, 2020). Mothers of children with neurodevelopmental disorders experience faster rates of declining health when compared to fathers (as cited in Currie & Szabo, 2020). In a study conducted to examine the experience of social isolation and exclusion of parents who care for children with complex conditions, parents expressed experiences of detachment, fear, and stigma from within the medical, social, and family settings (Currie & Szabo, 2020). These parents felt further isolated because their children were perceived to be socially and medically different, and the rarity of their conditions resulted in the dismissal of their experiences, struggles, and needs (Currie & Szabo, 2020). When interacting with other families of typically developing children, parents of children with rare diseases expressed guilt and discomfort from feeling like a social taboo due to social stigma surrounding their unconventional parenting struggles with a disabled child (Currie & Szabo, 2020). Parental caregivers often felt judged more harshly than other parents for their reactions when standing up and advocating against the discrimination of their children (Currie & Szabo, 2020).

At first, I deeply feared the judgment and was extremely careful with every word I meticulously chose to speak. Eventually, I grew braver and was inspired to start expressing my uncensored thoughts and feelings. Still, with each new episode, I perpetually feared that I had gone too far, said too much, and surely offended someone who I cared about. My fears were eradicated by the public reactions to each episode. With each publicly posted comment on social media, every private message of encouragement, and each person who relayed to me that they related deeply to the content on the show, I realized that the more I spoke my truth, the more listeners embraced my lived experiences and wanted to hear more. One listener and fellow caregiver stated the following:

I love how you stressed the aspect of trying to be nonjudgmental in this forum. I think being judged as both a parent/caregiver and as a disabled person makes it difficult to trust yourself and others. Keep this conversation going so more people become acquainted with perspectives and choices faced by loved ones who have, or care for those with disabilities.

Reactions and responses such as these informed me that I had created a safe space as intended and that our truths, no matter how taboo they may be, are worthy of being heard. I have since come to learn that this raw vulnerability shared on the podcast is precisely what makes it appealing. Vulnerability turns out to be the secret ingredient that results in content that captivates and intrigues the masses, not just the community who identifies with the disabled or medically complex experience. As humans, we intrinsically want to know that others share in the experience of navigating hardships. Providing a safe space for the guests and the listeners to explore these sensitive subjects, however far we may be from having them all figured out, is what facilitates the feelings of connection for the audience. I personally felt that this secret ingredient of vulnerability is exactly what was missing from the podcasts I had heard before.

Layered Lives

I strongly believe that sharing our personal narratives provides a powerful opportunity to make virtual connections through learning about our common experiences and our differing perspectives. I hypothesized that a podcast would be the ideal platform for a large and diverse audience to hear our stories and to learn about our journey, the purpose, and the intentions of those who are impacted by disabilities and complex medical conditions.

There are many layers to the lives lived for those involved in complex needs caregiving, and I personally crave to hear the raw and unfiltered truth about them. Not only do I

crave to hear stories from my peers in the trenches of this life, I also want to hear more about the lives of the people who help to pull us out of those trenches. (Stearns, 2021b, 07:38)

In the research on interactive interviewing and narrative exchange between mothers of disabled children, Green (2003) describes that the goal of a personal narrative is to facilitate change and personal growth, that the simple act of telling one's story has therapeutic benefits. In this study, Green references the narrative research work of Romanoff, citing that the therapeutic value not only resides in the telling of the story, but also the listening of the story. As noted by Green, the community of people with disabilities has expressed growing frustration with professionals from a wide variety of disciplines whose work has left them feeling marginalized and even pathologized rather than understood, respected, and valued.

Currie & Szabo (2020) suggest allowing parental caregivers the ability to voice their perspective, and validating caregivers' personal experiences in the systemic success and failures of the healthcare and social systems. Not only would this reduce the feelings of isolation and exclusion, it would also assist professionals with the development and implementation of policies and services that could directly benefit the lives of the parental caregivers and the children they care for (Currie & Szabo, 2020).

I will never forget how overwhelming it felt to not only be a new mom, but to suddenly learn the skills of being a nurse, neurologist, therapist, caseworker, and equipment technician. Having a child with a rare diagnosis often means that by default, you become the expert on them because the likelihood of your care team having experience with the rare condition is fairly slim, and that is further reduced when your child has a perplexing condition that remains undiagnosed. Many parents have no choice but to research their child's condition

beyond the limited information they are given in the clinical setting. An excerpt from *Atypical Truth* episode five, “Love Needs No Words,” is worth quoting at length. It details the personal account between a fellow parental caregiver, Jenny Park, and me as we discuss our own search for information from our peers in a Facebook support group for parents of a child with the same seizure disorder as our own children.

Erica: I mean, they will admit they see things that are comparable and based on maybe some certain developmental issues, they can say with confidence, “maybe this is possible, or it might not be possible,” but at the end of the day...

Jenny: They don't know...

Erica: ...it's hard to say when it comes to these rare genetic mutations, they just don't know.

Jenny: And I think that's the hard part. Our kids are such a step ahead of science. At this point, we have to learn everything that we can.

Erica: And isn't that crazy?

Jenny: Yeah, that for many years, I think that broke my heart the most. My daughter will not get the cure, she probably won't see in her lifetime, the medication that's made that can actually help her seizures or some treatment that might stop these collaterals. What's helped me is, I feel like part of Josie's purpose is to maybe help. The next time a doctor does see a kid with the same diagnosis, maybe Josie's information in her life can help further kids and further treatment. (Stearns, 2021g, 30:33)

Rupert et al. (2014) examined provider reactions to patient and caregiver use of online health communities. Due to the time constraints during clinical appointments with health care providers, patients expressed difficulty in obtaining diagnosis-specific answers pertaining to the

home management of treatment and emotional support which resulted in the patients (and caregivers) referring to online health communities for these needs (Rupert et al., 2014). In this same study, healthcare providers recognized the clinical time limitations as a barrier, but their support for the patients' desire to obtain outside information regarding the management of their diagnosis was mixed. In addition to discouraging patients from seeking information beyond what they are provided in the clinical setting, some healthcare providers dismissed and discounted the accuracy of the information patients received online (Rupert et al., 2014). When patients and caregivers reported a negative experience with their healthcare providers, they expressed feeling marginalized, disempowered, and chastised (Rupert et al., 2014). These negative reactions from healthcare providers did not, in fact, discourage patients and caregivers from seeking out information online; instead, it jeopardized their relationship and prompted patients to find new providers (Rupert et al., 2014). The most fascinating aspect of the Rupert et al. study is that it revealed that individuals primarily sought online health communities for emotional support and nearly always shared information with their healthcare providers for confirmation of accuracy and relevance of the information to their own illness, or the illness of a loved one. In the following transcription, Jenny and I talked about two positive and supportive reactions from healthcare providers when confronted with our pursuit for information online:

Jenny: I think, I think too, when you have a child with such a rare diagnosis, you have to know the ins and outs of them and their treatments and because I can't tell you how many times I mean, we've never been in a medical setting where a doctor or nurse said, "Oh yeah, I've heard of that," or, "I know what that is." Instead, they're asking you questions about, you know, this genetic condition and so you have to really know your stuff and be

able to educate the professionals on this and be the best advocate for your child. It's difficult.

Erica: I think, from what I've heard so far, they appreciate that.

Jenny: They do.

Erica: I mean, it's amazing that we found one other family that we're certain of, we now have the data—the shared DNA report, that their daughter had the same condition as ours. We found each other through Facebook.

Jenny: That's insane.

Erica: He [doctor] said, “We are in a world now where you can find the answers faster than our research just by getting out there sharing your story and finding people who are experiencing similar things.” They see hundreds of thousands of patients a year, and yet they still see so few of us rare cases, and that makes sense when you look at how small our group is specifically for malignant migrating epilepsy. (Stearns, 2021g, 28:54)

In examining the parent’s perspective of caring for a child with a rare disease, Currie & Szabo (2018) found that despite the parents being the primary source of knowledge on the disease, health care providers did not utilize the parents as resources when navigating and coordinating care. This is unfortunate, and Currie & Szabo suggested that health care providers recognize the value in the interactions with and the contributions made by parents of children with rare diseases. Thankfully, there are medical professionals out there who do see the benefits of learning from parents, as well as the medical field. A guest respondent and medical professional described how they have benefited from learning about the personal or professional experiences of someone within the disability and/or medically complex community:

The benefits from learning from the medically complex community are tremendous especially when it comes to healthcare management along with the collaboration of several disciplines and stakeholders to promote the best outcome for the children.

A listener survey respondent who identified as developmental professional and relative to a caregiver or person with disability(s) and/or complex medical condition(s) (sibling, aunt/uncle, cousin, niece/nephew, etc.) had the following to say regarding the benefit of learning about our experiences:

Parent/caregiver giving details on complex medical needs and how health care professionals can help complete the “village.” A parent knows their child more than any doctor or health care professional. Always take the time to listen to the parent /caregiver.

While provider reactions are mixed in terms of whether or not they appreciate when parents seek online information and resources, it's clear that parents and caregivers need these layers of support. And in fact, the information caregivers find can be valuable sources of knowledge in understanding more about their children's diagnoses.

Humans First, Labels Later

I know that I personally learned a lot from this episode regarding the day-to-day bureaucratic obstacles that healthcare workers face when trying to deliver exceptional care. I want to paraphrase something important that I think deserves repeating: Dr. Tanios [a member of our medical team] said something towards the end of our conversation in regard to what can be accomplished when a healthy and trusting relationship exists between a care team and their patients and/or families. She said, “[We] try to do our best, knowing that nobody—neither you nor me—has a magic wand.” I could hear it in her voice, as I have heard it in the voice of so many other

dedicated healthcare workers; they are here to help, they want to fix us all, but sometimes the impossible becomes just that, impossible. They are, after all, humans just like you and me. As hard as it is to hear that, I think it is important to remember this. (Stearns, 2021f, 21:38)

Our access to the skills, knowledge, perspectives, and opinions of medical professionals is limited to our physical and geographical proximity to the healthcare facilities they are employed by. Additionally, our clinical appointments with medical professionals are limited by strictly scheduled time constraints that leave little room for them to get to know us as persons separate from the symptoms, let alone for us to know them at all. These limitations directly hinder our ability to relate to these professionals as humans outside their roles in the clinical setting.

Professionals, especially medical professionals, are often provided with a snapshot of information regarding our presenting clinical status. The wellbeing of our health, or the health of a loved one, is greatly dependent on the support we receive from these professionals; however, we rarely have the opportunity to know them as unique individuals outside their professional role, nor do they have the opportunity to know us as unique individuals outside the diagnosis that has brought them into our lives. It is for this reason that I felt it was necessary for the podcast to include the perspective of medical professionals (doctors and nurses), developmental professionals (therapists and educators), and social workers.

Before addressing any aspect of their lives as being impacted by disabilities and/or complex medical conditions, with each guest interview on the podcast I made a conscious decision to ask them a series of questions about who they are as a person. I considered this component of the interview the “humanizing” component. Allowing the guests to share details

of their lives that we do not receive at the surface level or in the clinical setting, helped to frame the remainder of the conversation from the perspective of a human—free from the labels of caregiver, doctor, social worker, etc. In return, I openly responded with whatever reaction came to me naturally.

This style of interaction removed the feeling of hierarchy from each of us, making both the guest and me feel more comfortable and relaxed because we were attending to each other conversationally as equals. An example of this can be heard in conversation with Dr. Tanios on the first episode, “Complex Medical Care,” where I open with a variety of humanizing questions. Dr. Aline Tanios has played a tremendous role as a physician in our medical tribe from the early days of our journey as caregivers. She has advised and supported us through a number of highs and lows, both medically and personally. As one of the first people to greet our fragile son after his birth, she has witnessed our family grow in numbers and in strength. She knew so many details about our family and in our opening Q&A, I was able to learn more about Aline, outside of Dr. Tanios.

Erica: What is your favorite song currently to turn the volume up for?

Dr. Aline Tanios: Okay, there are several and in different languages. I love "Roar" from Katy Perry and I love "What Doesn't Kill You Makes You Stronger" from Kelly Clarkson. These are like, I think the whole neighborhood can hear, [laughs] can hear me driving by if they are on. It just gives me lots of positive energy and confidence. And yeah, these two, I like. Like I said, I do have others that are in Lebanese that I just feel like dancing to when I'm driving. [Laughter] I'm driving, and my kids look at me like, "What's wrong with her?" But they got used to that.

Erica: There's something about both of those songs that can make me go from sitting to just standing up and going, "I've got this. I've got this. I've got this."

Dr. Aline Tanios: Yes, yes. Absolutely. Like it's just so amazing. I think one time I was leaving work not too long ago, and I had a long, exhausting mentally draining day, and this song popped up and I'm like, "That's it. This is a sign! That's it!"

(Stearns, 2021e, 3:30)

Regarding this “humanizing” segment of *Atypical Truth*, one guest and medical professional stated, “I really enjoyed this experience. Erica did a great job keeping the conversation casual and free and this led to an easy forum to share more personal feelings and experiences that is usual for me.” A listener and fellow caregiver confirmed the importance of these humanizing questions: “The interviews with the doctors are SO interesting. We never get to hear the human side of their lives and perspectives.” These two individuals, who have vastly different experiences *with* and relationships *to* the person being cared for, recognize the value of sharing one’s humanness.

Throughout each episode, I follow a specific interactive interview structure that not only allows the guest’s humanness to shine through but also allows them to share about their experiences, both personal and professional, as a person first with the label to follow. Approaching the conversation in this style provided the guests an opportunity to share about their lived experience as people first, and then allowed for the natural flow of their personal or professional experience as individuals impacted by disabilities and complex medical conditions to come through. For patients and caregivers who rarely see their medical team in any other capacity outside the clinical setting, this approach to an interactive interview provided the audience a new perspective of these individuals as imperfect, fallible, loving, and caring

peers—not just strictly professionals. One listener survey respondent stated the following about their experience of the podcast as a whole:

The information, experiences, and stories help me as a mother and a nurse. Stories from the medical side help remind me how human we are as medical providers and how emotionally invested some providers get to the wellbeing of patients and understand the limitations of medicine. Even though I know them from the nurse[']s side, it is harder to separate when it involves my daughter and I'm less likely to be understanding of mistakes or miscommunications regarding her care. The objective reminder of these things helps me feel less misplaced resentment toward people involved in her care. Stories from the caregiver/patient side help me feel less alone and give perspective to what we've been through.

A guest respondent and medical professional had the following reaction to being asked if they felt like they were able to tell a part of their story that they do not usually get to share:

This is a unique and different experience for a special cause; sharing with others how we have the ability to provide a glimpse of kindness, attention, and hope when things may not be typical is a doable mission. The idea of the podcast is noble and exceptional, and I truly believe that this will be well received and beneficial to larger than the medically complex community.

Another guest respondent and social worker stated, “This was the first time I had ever talked about what it was like to work with families with children with disabilities. I hope people realize that people like me are here to help others and enjoy doing that.”

When guests were asked in the survey if they have ever personally benefited from learning about the personal or professional experiences of someone within the disability and/or

medically complex community, all agree that they had, in fact, benefited at some point in their lives from learning our stories. One guest and medical professional provided this example:

I have benefited greatly as a medical doctor from hearing how acute and chronic medical diagnoses affect not only the patient at hand but also the larger family and friend support network. I believe it has made me a better and more caring physician.

Another guest (social worker) had the following to say about the personal benefits of hearing stories like my own: “I feel that by getting to know the families that I work with, and learning more of their day-to-day routines, struggles and successes I am better equipped to assist others.”

Another guest (medical professional, personal caregiver, relative, and friend) explained that, by hearing stories like my own, they felt like they are able to, “further my knowledge and become more aware of the life of disabled individuals, as I work in the healthcare field with disabled individuals.”

The Big Ask

We all face obstacles and limitations in our efforts either personally or professionally, as individuals who are impacted by disabilities and complex medical conditions. I strongly believe that the first step to changing or eliminating the obstacles we face is by sharing about them. This belief inspired me to ask our guests precisely what these limitations and obstacles looked like to them. It would be easy to focus on the myriad of problems in the medical system; we talk about the limitations at great length. Instead, I sought to ask this question in a way that required the guest to think not of the limitation or the obstacle, but instead what life would look like if that problem were removed. In solution-focused therapy, this technique is called “the miracle question.” I offer an example of what this looks like, from my interview with Dr. Tanios:

Erica: I'm going to have you pretend for a moment that a miracle happened overnight and suddenly, without any warning, you woke up and the health care system was perfect. It was flawless. Nobody's told you this. You just wake up, you go to work. What is the first thing that you would notice that would indicate that this was real and not a dream?

Dr. Tanios: Yep, yep, I'll tell you. Since I work primarily in a hospital setting, I'll tell you that the first thing would be seeing patients and their families being prioritized in action, not just on papers, or in the saying. Number two is to feel that the healthcare professionals caring for these patients, who should be their priority, [being] well supported by the system at every level, and not pulled in a million directions, so they can focus on their mission because they are in that field for a reason. And last, would be to let the people who handle the business aspect, or the policy aspect, look at these two groups of people, patients/families, and healthcare professionals, look at them from all these angles and say, "How can we help them so everybody can thrive, therefore, the community will thrive, the whole system will thrive?" But when you are, like, loading patients and families with tasks that can be handled by others in a timely manner, efficiently, thoroughly, then as simple as like making a phone call for an insurance company, making a phone call for the therapy service, and you name it, as well as if you're loading the healthcare professionals with million other tasks; you can't give 100% of yourself to one thing when you're already, like, spread out too thin. But this is a dream. Is that right? [laughter] But listen, if we keep dreaming...

Erica: Exactly! Exactly. In order to know what goals to aim for, we need to hear more about them.

Dr. Tanios: Oh, absolutely.

Erica: And I think this is a part of that question is putting it out there—how can we make this dream a reality?

Dr. Tanios: And you know, there's that saying that, if you don't ask for it, the answer will always be no. So might as well ask for it.

Erica: It also sheds some light for us on the obstacles that you face in being able to provide that kind of care that we expect walking in.

Dr. Tanios: Oh yes...

Erica: It's a very helpful insight. Thank you.

Dr. Tanios: Yeah, oh absolutely. (Stearns, 2021e, 48:10)

Listeners indicated that they appreciated this question, for the insight the guests' responses provided. One listener and friend to the disabled and medically complex community stated the following:

I love Erica's questions about "if you woke up tomorrow and everything was perfect, what would that look like?" It is one thing (and so necessary) to point out the problems that need fixing, but to imagine what the world looks like on the other side is so hopeful and I believe gives people a reason to work toward those goals.

The guest responses to the "miracle question" vary from one professional to the next, but overall, they shed light on one common theme amongst professionals: They want to help. They are here to help. They want to fix the problems that stand in their way of being able to help in every capacity, but these problems exist at a systemic level, they are far too large for any one person to fix. These are the conversations we need to be having. These are the perspectives we need to hear. Discussing these issues openly, from the people whose lived experience is impacted by these challenges, is exactly the kind of content I set out to provide with this podcast.

Personal Reflection

Utilizing a podcast as a platform to have and to share these conversations provided me with a wealth of skills, personal growth, and emotional healing that I had not fully anticipated. I had admittedly underestimated the time and expenses required to produce, host, and engineer a podcast. At first, each episode took an entire workweek to complete, but eventually, it only required an average of three full workdays to produce an episode from start to finish. There was the initial investment of the equipment and software that I had anticipated, but I had underestimated the amount of time and money that it would take to learn audio engineering, transcription, web design, and how to actively promote the show across multiple social media platforms. I learned many new skills throughout the endeavor, and I was happy to make the investment because I knew that I would continue to maintain the podcast long after research was complete.

Throughout this experience, I found that this podcast project allowed many new professional relationships to develop and be maintained. I noticed that my voice, my opinions, and my personal experience were met with respect and appreciation both personally and professionally. Family members reached out to tell me that they felt I had found my calling. Parental caregivers who I had never interacted with before began contacting and communicating with me, specifically wanting to know more about my perspective as a child growing up with a tracheostomy because they wanted to better understand what it was like for their children who were growing up with one. Physicians who I had previously only had brief and very patient-focused conversations before, were now asking me about the podcast and sharing about their own unique personal experiences that led them to the specialty of medicine that they now practice. In a strange way, I felt that the accountability that the podcast so publicly

garnered had positioned me into a place of mutual respect in spaces that I had previously felt unnoticed.

As noted earlier, becoming a podcaster myself introduced me to more rare disease and disability-themed podcasts. In finding and following these podcasts on social media, I was introduced to various styles and approaches in the art of sharing our stories, each unique to the skills and strengths of the host. I developed friendships with fellow podcasters and was invited to join a disability-parenting podcasting group that meets monthly to share our experiences. In my efforts to create a virtual community for my caregiving peers, I came to find that more communities existed where our identities intersected as caregivers and story-sharers.

Knowing that my style differed from what already existed, I edited each new episode with sincere excitement knowing that it was content I had wanted to hear all along, that it was exactly what would have helped me when I needed it most. With each new episode, I felt my voice grow stronger. My confidence in navigating difficult subjects and “socially taboo” topics grew stronger as well. In speaking with each guest, I was left with a jubilant feeling of weightlessness from the conversation that was had and the connection that was made. Not only had we formed a connection, but I was allowed access to explore many aspects of the guests’ lived experience that made them so completely relatable as a person, and in return, I felt better about sharing similar aspects of my own lived experiences as well. This intimate exchange of our experiences was the secret ingredient that added the richness of authenticity to each episode. One listener’s response provided all the assurance I needed in knowing that the first season of this podcast project was, overwhelmingly, a success:

Hearing perspectives from parents and doctors of medically complex children has been huge for me—even as a close friend of a mother of children with complex medical needs

and hearing her stories, it has been eye-opening to hear frank discussions of the medical equipment, time, outside help (nurses), hours driving to hospitals, hours in the hospitals, and the list goes on and on to the amount of care and time these parents have to constantly advocate for the sake of their child. Something that comes so easily to some families is made nearly impossibly difficult for families with medically complex members. We all do the best we can for our families and it's just really sad to see how systems have been built to make it so hard for families that require more care because of extenuating circumstances.

Sharing the Mic

There was one factor in this project that I feared would place an expiration on the podcast as a whole. The intimate exchange that was shared between my guests and myself, that secret ingredient of authenticity, was the direct result of having known each guest in some capacity, personally or professionally, prior to recording. There already existed a relationship and a mutual trust between each of us. I knew that I could not have these same conversations with a provider I had never met. I knew that I could not speak confidently about a disability or medical condition that I had no personal experience with, nor informed knowledge of. Above all else, I knew that there were more stories beyond my own and that it was equally important to use this podcast as a platform to share those as well. And the listeners agreed, as evidenced by their wish list for future episodes:

- I would love to hear more from disabled parents.
- My suggestion for improvement is more speakers with more stories!
- I will love to hear from more people with different backgrounds and histories.
- Parenting while disabled, children with invisible conditions, later-in-life diagnoses.

- I wonder what are the options for those with complex needs and/or disabilities when they become older? What happens if something happens to their family? Who advocates for those alone in the world? I'm sure it's far from a perfect situation. How good or bad is it? What should be done to improve the life of those with no advocates or family to care for them?
- Experiences of disabled but "healthy passing" individuals. Quality of life conversations. Ally Corner (or [a] better name) with suggestions and advice for able-bodied people who want to help but aren't direct caregivers. "Day in the Life" perspectives. Anecdotal stories where medical complexities or disabilities had an impact (Erica's personal stories are so good!).
- More on how to get and push the medical attention and treatments the kids and people need when you don't feel heard.

These are all highly important and relevant topics that disability podcasters should address. As a disabled person and caregiver, having created space to publicly account for my experiences is a privilege. In acknowledging this privilege, I feel it is critical to share this platform with others. In future seasons of the podcast, I will be sharing the podcasting stage with a new guest-host every season who will join me in sharing about their own complex journey with disabilities and rare diseases. They will be having conversations with the people who have been involved in their own medical journey, both personally and professionally. My presence will remain consistent in the podcast, as I will be reading the intro and outro for each episode, regardless of the guest-host. The first season of *Atypical Truth* sets the mood and the style for future seasons to come, and with my own voice continuously woven into the experience, I will assist others as they provide the same intimate glimpse into their own lived experiences.

* * *

Outro

I hear the faint sounds of the oxygen and heart rate monitor alarm sounding from the room below me. I wake up from a deep sleep with sheer panic racing through my veins; I sit straight up and wait just a moment to determine if this was just another phantom alarm that occurs in my mind from time to time. I could not tell you what came first, the choking or the alarm, but by the time I stumbled down the stairs to reach my youngest child, he had vomited and was panicking from his inability to clear his airway on his own. My eyes have yet to adjust to the darkness before my husband is standing next to me with our makeshift crash cart, handing me the necessary equipment to clear his airway and stabilize our son. Just as things start to calm down, my daughter begins to awaken in an apneic spell from all the commotion. My husband takes over comforting our son while I begin to calm and comfort our daughter. It's 4:00 AM, this is our second round of overnight emergency stabilization and at this point our adrenaline will not allow us to rest. I can hear the sound of my son's lungs rattling from across the room, and I realize that this situation is going to require him to be held upright for the remainder of the night.

As I settle down in the recliner with the warmth of my baby on my lap and his thunderous breathing against my chest, I make sure to lovingly grab a couple of handfuls of his sweet chubby thighs and plant some kisses on his irresistible chubby cheeks. I think to myself a thought I have often, how I just wish that they could stay small chubby babies forever. This is not an uncommon thought for parents to have as we all wish for time not to fly by so fast. This thought is often followed by a sense of sadness with the reality of knowing that our children will always be babies, cognitively speaking, but their bodies will continue to grow, like any other, into adulthood. As I have watched my 4-foot long, 5-year-old daughter rapidly grow, I know

that my son's chubby thighs will eventually melt into skin and bone; one day soon he will barely fit on my lap and become too big to carry or hold.

To stop these intrusive but honest thoughts, I turn on the TV and eventually we both catch a few minutes of sleep before the home health nurse arrives, complete with two barking dogs to greet her. I awaken with a crick in my neck from sleeping upright, and I hand the children's care over to the nurse so I can begin tackling the day's long list of things to do. My house is a massive mess from the explosion of hospital supplies we received during the most recent and unnecessary trip to the children's hospital three hours away. Had a pharmacist simply taken the time to explain to me that the antibiotic most recently prescribed to my son would result in blood-red stools, it would have saved me two sleepless nights in the hospital and 3 days of avoidable interruption from my schedule. I have to ignore it and deal with that issue another time. I have far too many other things to do, things with deadlines and people depending on me.

I take a mental count of what needs to be prioritized personally, professionally, and academically. I need to contact the DME (durable medical equipment provider) to inquire about an error in the shipment of supplies we received and a replacement CPAP machine because I just saw on Facebook that my daughter's sleep apnea machine has been recalled due to foam particles dislodging, resulting in the occurrence of dangerous lung debris. The draft of my thesis is scheduled to be reviewed in three hours. A mobility agency representative will be visiting shortly after my thesis meeting to take measurements for the track system of the ceiling lift we are preparing to battle Medicaid to cover.

The nurse deserves some attention and a lunch break. The kids would like a kiss and some love at some point before I have to put them in what looks like torture devices to the

untrained eye; they need their braces and special equipment in order to stand upright, allowing them to bear weight through their fragile bones.

The laundry needs to be rotated in between, and the sink of dishes needs my attention, too. The shipment of medical supplies needs to be unpacked and organized. I need to stop by the pharmacy for the weekly list of refills. I should probably ship these boxes of food while I am out, another family is depending on these because their insurance refused to continue covering it and we have extra now that our kids are on a different tube-fed formula due to repeated GI intolerances.

The disability podcasting Facebook group is awaiting my announcement for the theme of our next monthly conversation that I am responsible for hosting. I reasoned with myself that the podcast episode, which was scheduled to air yesterday, is just going to have to be postponed. I thought back to the introductory episode when I stated:

I want to promise you a new episode every other week, and I am fairly certain I will be able to provide that the majority of the time. However, you know as well as me, that this life of ours is unpredictable at best. We often joke that the only consistency in our lives is the nature of them being consistently inconsistent. This certainty of unpredictability—it's what has prevented me from starting this sooner. So please bear with me if you see an unplanned gap between shows and reach out if you feel so inclined. Radio silence is usually an indicator when parents like myself are in need of support the most. (Stearns, 2021c, 22:52)

“Family comes first” and “I don't owe anyone anything” were two mantras that kept repeating in my head as I struggled to justify the need to skip the release of an episode this week. I felt like I was letting down my audience by not having an episode prepared. While I

know that I do not owe anyone an explanation, I still felt obligated to explain my feelings of defeat which resulted in the unplanned break from the regular schedule. This was a promise I had made to my audience, to be true regarding the content I shared, and the truth is: my life is crazy, messy, busy right now. They deserve to know this. They deserve to know that I am struggling, that managing a podcast on top of everything else, feels impossible right now. I needed the audience to know that I am human too, with tasks I cannot complete and feelings of defeat that surround that experience.

I posted on my social media pages the words “I can’t & I won’t” in an upbeat 70’s-themed graphic with a caption that explained in detail exactly why I simply cannot do all the things. “Since my kids were born, I have had to set some strict boundaries with work/life balance. It takes sincere and constant effort to remain cognizant of my personal limitations with stress, especially the stressors that I have some control over, considering so much of my life is affected by stressors that I have no control over.” Within minutes I began receiving notifications for comments left on my post. Words of support from fellow caregivers, family, and friends came flooding in and with them came a deep breath of relief. They get it. They see me.

The phone rings. It is the medical team I have been anxiously awaiting to hear from. Empowered by my research and fueled by knowing that I am not alone, I am inspired to get vulnerable and relate to them as a person—an extremely tired and frustrated mother who lovingly refuses to give up hope for my son to experience comfort and happiness in his life. I pour my heart and soul out, pleading for them to come up with a plan of action, and then I am told to standby for a return call.

As I wait, I am caught off guard by a post from a fellow disability parent podcaster, a 22-year veteran of medically complex caregiving stating that she was feeling defeated as well, and

giving up her podcast: “I hope you light the world on fire for your kids and don’t reach the harsh reality I have. That no matter the battles we fight, no matter the platforms we stand on, it’s never enough. Disappointments are a way of life in our world, and I can’t keep doing it all.” Those words struck a sensitive chord within me. As the hours went by and the day turned to night, I still had not received that return phone call from the medical team and I could not help but think of this fellow caregiver and wonder, “Is this all worth it?”

We are currently nearing the end of 2021 Disability Pride Month and I still see so little representation of disability in mainstream media. Disabled people have to fight against multiple systems for their right to merely exist, let alone receive equal rights and access to the pursuit of happiness. Despite disability affecting people regardless of their ethnicity, socioeconomic status, gender, culture, and religion, the voices of disabled people are rarely brought into the conversations surrounding current events and social movements.

Disabled and medically fragile people around the world were denied life-sustaining care and were not prioritized for vaccines for the COVID-19 pandemic. Disabled and chronically ill people are currently being advised to shelter in place while the rest of the world reopens and resumes normal life as though the COVID-19 virus has been eradicated, despite all research indicating that it remains active and has now mutated into a new and more transmissible virus.

With a promise to reform the federal program that provides vital income assistance to disabled U.S. Americans of all ages, the Supplemental Security Income (SSI) Restoration ACT of 2021 is being introduced to the house and the senate. Disabled people and families of disabled children are currently forced to live below the poverty line in order to receive medical coverage, are unable to marry without jeopardizing their benefits, and are unable to ever have more than \$2000 in total assets before their SSI benefits are reduced, if not denied

completely. This reform would allow families to live at the poverty line rather than below it and would increase the dollar amount of allowable assets to \$10,000. This still doesn't feel like a fair shake for our community, especially when you take into consideration that some disabled people are dependent on this assistance for the use of mobility aids such as wheelchairs and standers which typically cost more than the \$10,000 we are allowed to save.

Currently, airlines allow emotional support animals on flights while simultaneously refusing disabled people the right to remain in their wheelchairs for the duration of a flight. While a dog sits comfortably in first class, disabled people are denied the comfort and security of their mobility aids which serve to provide physical support, mode of movement, and independence. Instead, they are forced to store their wheelchairs in the cargo where their expensive mobility aids are frequently mishandled and damaged without repair nor compensation.

Rather than investing in special-needs education reform, there exist numerous parent-training seminars to help teach parents how to fight against educational systems that attempt to deny disabled children access to services and resources to save money. Meanwhile, families of disabled children transitioning into adulthood must suddenly begin navigating life without nursing assistance because the funding stops at the age of 21, no matter how poorly or well a person functions with the help of nursing care.

When I go online to address the issues of the ableist podcasting world lacking a disability category, I am reminded that there remains a negative stigma surrounding the word *disabled*. I publicly address the fact that there are categories for alternative health, mental health, and nutrition; and I propose that we petition to have a category for disabilities so that our community is provided equal and easy access to a selection of disability-themed podcasts. Instead of gaining

allies, I am left to battle an onslaught of comments from non-disabled individuals who repeatedly inform me that “disabled” is a bad word and that I should use the label of “gifted” or “special” instead. These comments inform society that disability equates to undesirable, which continues to perpetuate the negative stigma of being disabled. A doubled standard clearly exists when non-disabled people harness control of the language we use to identify ourselves when engaging with society, yet we are required to identify as disabled in order to receive federal assistance or have the ability to park in designated handicapped spots.

It is true that this podcast has given my voice and my story a platform. It has amplified my voice in spaces I had previously felt unheard. Yet, so often it feels as though this amplified voice is just screaming into a void, with no idea of who my content is helping nor how it is inspiring change. *Is it really benefiting my kids where they need it most? Is this directly benefiting their health and wellbeing?* I think again of the words from the fellow caregiver and recently retired podcaster, “no matter the battles we fight, no matter the platforms we stand on, it’s never enough,” and I can’t help but wonder how long my voice will carry on before it fizzles out from defeat. *Will I survive another 10 years of advocacy work despite the realistic potential of neither myself nor my family ever personally benefiting from the changes and outcomes of this work? Or will I feel consumed by the weight of disappointment this lifestyle is plagued with?*

Between the children's choking spells, oxygen desaturations, repeated emesis, and some breakthrough fevers, I manage to tackle the day’s to-do-list and feel especially proud for managing to accomplish tidying the home and doing some laundry. I spend a blissful hour holding my son in one arm as he falls asleep while holding the hand of my daughter, seated next to me, as she drifts to sleep as well. I lay them down and with a damp spot still on my shirt from sleep-sweat and drool, and I head upstairs for a scheduled interview with the guest-host, a mom

whose son has a life-threatening congenital heart condition, and the cardiologist they will be talking to for season two of *Atypical Truth*.

As I explain the technical logistics of the recording process, I recognize the excitement and the nervousness from both guests. As the guest-host asks the humanizing questions, I observe that both guests begin to relax. Laughter ensues at the randomness of the responses, the similarities, and the differences shared by the two individuals. Hearing the conversation, watching the glow radiate from these two people as they share about their experiences, I notice my own body relaxing as I sit in the background nodding my head in agreement and smiling from the joy of the experience. I may have no concept of what it is like to be a “heart mom” nor a cardiologist, but I can relate to the two individuals as humans whose lives are forever intertwined through a complicated medical diagnosis. I perceived there to be a desire for a relationship beyond the focus of the diagnosis, but also the apprehension of overstepping patient-doctor boundaries. In my personal experience as a podcast host guiding the interviews, I felt those boundaries fade as the interaction morphed into a conversation, and I was pleased to see that happen between the season’s guest-host and their guest. As the conversation ended with the doctor’s heartfelt answer to that final “miracle question,” I found myself moved to the point of tears.

As I studied the reactions of the guest-host, I noticed a lightness come over them and I recognized that lightness in myself. It was the observation of a weight being lifted, a sense of healing to have transpired. I felt humbled and energized to be witness to this transformative process. I felt anything but disappointment for being a part of this complex world of disabilities and rare diseases.

The next morning, I receive the anticipated return phone call from the medical team; they sensed the urgency in my concerns and the specialist will be meeting me in a telehealth appointment in two hours. This kind of expedited appointment is unheard of in the medical world where typically the wait time for a specialist is several weeks, if not months. The doctor greets me from the inside of his home. It is his day off, but he does not want to postpone addressing these issues any longer. For the next 45 minutes, we discuss the medical history, the concerning symptoms, and the variety of treatment options we must choose from to rule out and determine exactly what is going on. He repeatedly must stop to herd his children out of the room, shush them to be quiet, and leave the screen to ensure the office door is once again closed for privacy. I recognize that he is not just meeting me as a medical provider, he is meeting me as a concerned father who wants to help by any means necessary. When he returns with his doctor hat on, he places no expiration or time limit on the conversation while he proceeds to respectfully educate me regarding what is occurring internally to cause the symptoms we are observing externally. I end the call with tears in my eyes. I am caught off guard by the humanness of the conversation, I am left feeling hopeful for having my experiences acknowledged and my concerns addressed not just by a doctor, but by a fellow parent who seemed to understand.

What if this podcast is enough, if even just for me? Before now, I would have never thought to voice my vulnerable feelings of defeat so honestly to a medical professional. Maybe that was the necessary, but missing, component all along. By confronting the harsh realities of this life instead of letting it consume us, perhaps these conversations are enough. If I continue to use the podcast as a platform to include and amplify the voices of others, I might see a day when

my voice does not have to carry this advocacy work on its own. Perhaps *we will* light the world on fire for our kids, and for yours.

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statistics. She instilled confidence in me every step of the way. She gave me all the tools I needed to approach this thesis in a style that felt professional and polished despite me being a novice.

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Biographical Note

Erica J. Stearns is a first generation, non-traditional, undergraduate student in the psychology program at Southern Illinois University Carbondale (SIUC). She is a member of The Honor Society of Phi Kappa Phi, and graduated *magna cum laude*. Growing up with a complex medical condition and now being a mother of two disabled children, her life experiences have motivated her to pursue a career in the field of disability advocacy as the Southern Illinois representative for a national nonprofit disability advocacy organization, The Arc (of Illinois).

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