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A CASE STUDY OF A COLLEGIATE INTERSEX ATHLETE

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A CASE STUDY OF A COLLEGIATE INTERSEX ATHLETE

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Abstract

This study explored the experience of one collegiate intersex athlete. Grounded in a transfeminist perspective, narrative analysis was used to tell the story of the athlete's experiences in life and in sport. The analysis revealed several themes, which are told through a series of five vignettes. The storytelling approach illustrates how the athlete negotiates the terrain between sex and gender and how her intersex condition has affected more than just her sporting experience. The themes that were pulled from the interview covered the medical side of CAH, her personal experience with CAH, how it has affected her family, her sporting experience, and how she feels about advocacy. Overall, this athlete's experience is vastly different than what current popular press has to say about intersex athletes. Her story sheds light into the vast differences between each intersex condition and adds to the discourse of intersex athletes and the practice surrounding intersex children.

A Case Study of A Collegiate Female Athlete

Since the beginning of organized sport, competition has been split into segregated play between men and women. The gender binary is an ideological construct that possess that there are two genders or sexes that a person can fall within, either male or female (Eckert, 2014). Sport is an arena that reinforces this gender/sex binary. Beyond competing within the binary, competition has always been cemented in the idea of fair play. However a person defines fair play, competition will never truly be equal because there exists many physical advantages and disadvantages among peoples. When the advantage becomes a questionable inborn physical characteristic, the athlete is policed. Here stands the issue surrounding the experiences of an intersex athlete.

Disorder of sexual development and intersex conditions are referring to the anatomical variations that occur in humans in chromosomes, gonads, or interior/exterior body parts where a person possesses features that are typically found in both males and females (Lenhart, 2015). When it comes to the intersex condition, conventional wisdom is challenged. The binary is met with the challenging disorders of sex development. The Intersex Society of North America (ISNA) (n.d.) states that intersex is an umbrella term for a variety of conditions that an individual may be born with that affect the reproductive organs or physical features of a person's sexual anatomy. An intersex person does not fit into societies typical definitions of what is male or female. While in some cases an intersex condition can be spotted at birth, the ISNA states that many people may live an intersex life and go without knowing about their condition until puberty. In the case of intersex athletes, they may not know until they are chosen or forced to be sex-tested.

The controversy surrounding intersex athletes is cemented in the idea that intersex female athletes are actually men and therefore should not be allowed to compete amongst other women. The controversial topic surrounding intersex athletes has begun to be more recognized internationally and in popular press (Cooky & Dworkin, 2012; Hurst, 2010; Peterson, 2010). The controversy comes with many questions. Should we let intersex athletes compete? On what team do we let intersex athletes' play, the men's or women's? What sex is this person? In reality, these questions are irrelevant. In 2009, a track and field athlete by the name of Caster Semenya sprung into international prominence due to her outstanding performances. Semenya was described as having a very muscular build, flat chest, and deep voice. Because of her appearance and outstanding performance, she was forced to undergo sex testing by the International Association of Athletics Federation (IAAF) (Krane, 2015). The results of the testing was leaked to the press and revealed that Semenya was intersex and did not meet the requirements to compete as a woman (Berlin, 2009).

Essentially, the argument has been made in the popular press that intersex athletes have an advantage in the women's world of sport (Viloria, 2014) and therefore sex-testing is necessary to see if there is an unfair advantage. The advantage being that some female athletes have more testosterone and therefore are better performers. Sex testing is something that only occurs in women's sport and is a way for the larger governing bodies (e.g., IAAF and International Olympic Committee (IOC)) to provide a way to "prove" that an athlete is female (Tucker & Collins, 2010). This testing completely disregards the experiences and identity of a person who is scrutinized at such an intense level. Semenya had to see a gynecologist, endocrinologist, psychologist, internal medicine specialist, and a "gender expert" to determine and interpret her sex (Schultz, 2011). The simple fact that we determine and interpret an

individual's sex continues the policing of bodies in women's sport. Governing bodies are deciding if an athlete is male or female by interpreting lab tests and physical exams, while ignoring what might be right in front of their face, an athlete stating that they are female and have been their entire life. The focus needs to move beyond the binary and into how the policing of intersex bodies affects the experiences of an intersex athlete. The research on the experiences of intersex peoples and intersex athletes is very limited (MacKenzie, Huntington, & Gilmour, 2009). This study is concerned with opening the door to understanding the experiences and challenges that exist for an openly intersex collegiate athlete.

Before we begin to discuss the challenges surrounding intersex athletes and sport we need to first define the difference between sex and gender. Intersex refers to biological sex, which is based on the physiological, hormonal, and chromosomal aspects of each person. The intersex person has characteristics of both biological sexes (Lenhart, 2015). Sex refers to "the physical body, including the anatomical, hormonal, chromosomal and physiological composition of bodies" (Krane & Symons, 2014, p. 121). Whereas gender is "socially and culturally constructed and refers to behaviors, social roles, and attitudes" (Krane & Symons, 2014, p. 121). For example, someone may be assigned female at birth, but psychologically they identify as having an internal sense of being male. It is important to recognize the difference between sex and gender because intersex peoples are often compared to being transgender (ISNA, n.d.). A transgender person is someone who does not feel that their gender identity aligns with the sex assigned to them at birth (Enke, 2012). The ISNA states that although it is rare, intersex people may identify as transgender, but in general they tend to identify as male or female (much like the general population of people). This is not because they are "choosing" their gender; rather they are not having psychological dissonance with their gender. Meaning, for example, that they are

female and they *feel* that they are female. A transgender person would be assigned a female based on biological sex, but feel their gender identity is male and vice versa.

What does it mean to be intersex?

The term intersex is used in the medical field to describe anyone whose sex chromosomes and internal or external sexual anatomy do not fit into the binary of the male/female norm (Lenhart, 2015). It is very hard to determine how many intersex people exist or the frequency in which the intersex condition occurs. The medical field agrees that about 1 in 1500-2000 births result in an infant having atypical genitals (ISNA, n.d.). However, not all atypical genital anomalies show up at birth nor is this the only indication of intersex conditions and that makes the estimate inaccurate. The intersex condition can come in many forms (Lathrop, Cheney, & Hayman, 2014; Lenhart, 2015). For some individuals, the differences may exist between their internal and external sexual features. For example, a female at birth may have external genitals that resemble the female anatomy, yet also have internal undescended testicles. Another example may be within the chromosomal make-up in which a person has something other than an XX or XY pattern. In some cases, the intersex condition may not appear until puberty. What was described as “normal” genitalia at birth might change with the introduction of sex hormones. For example, a female’s genitalia will masculinize in puberty or she may not begin to menstruate. A male in puberty may not develop secondary sex characteristics like a deeper voice or facial hair.

Starting in the 1950s, the standard protocol for treating newborns with ambiguous genitalia was to surgically alter the “unacceptable” to what could be perceived as “normal” (Greenberg, 2012). Without considering what gender the baby might express later in the life, the doctors would assign a sex to a baby based on the visual aesthetics. A boy who had what was perceived as an “adequate” penis would be raised as male. If the phallus were considered to be

inadequate by doctors, the child would be surgically altered to look female and be raised as female. Little girls were rarely assumed to be males and were left unaltered in most cases. However, in the 1950s most intersex children were outcast as “freaks” even if they were never operated on (Greenberg, 2012).

We have since moved beyond this practice of immediately making a decision of sex/surgery based on the size of baby’s genitals, but not by much. Presently, intersex children generally still are operated on at birth if the external genitalia are ambiguous (ISNA, n.d.). In the 1990s, the practice of operating on intersex infants began to change (Greenberg, 2012). Better understanding of trauma, shame, humility, and gender identity all began to create a conversation on what impact this medical decision has on a child as the child continues to develop through life. The “Consensus Statement on the Management of Intersex Disorders” (Lee, Houk, Ahmed, & Hughes, 2006) encourages open communication and decision-making among parents, children, and doctors, and promotes a multidisciplinary treatment approach. Presently, the common medical practice with intersex infants is to wait until the child can participate in the decision-making process (Dreger & Herndon, 2009).

The simple fact that we place an inadequacy on an infant based on sexual anatomy adds to the negative discourse among people with an intersex condition. Traditionally we turn inadequate little boys into girls and we leave the girls to fend for themselves. We see the same in sport. Female athlete bodies are scrutinized when they are not typical of what we expect of women in sport. They are then put under a microscope and pulled from competition. There may not be one approach to handling the intersex condition, but the policing of female intersex athletes needs to be addressed in the same way that the discourse surrounding intersex infants has changed.

The Problem

In 2009, Caster Semenya, at the World Championships in Berlin, outran her opponents in the 800m by almost 2 full seconds. However fast her time was compared to the competition, her speed was not quick enough to break any world records. Behrensen (2011) wrote that a story released by the media, during Semenya's time in Berlin, sparked the turmoil over Semenya's gender leading to the decision made by the International Association of Athletics Federation (IAAF) to force Semenya to undergo sex testing. Semenya's assigned sex became scrutinized due to her "male appearance" and quick rise to athletic success. Semenya is just one of many intersex athletes (e.g., Dutee Chand, Santhi Soundarajan, Maria Patino etc.) who have been put under a microscope due to the biological variance that occurs among humans. The IAAF kept the results of Semenya's gender verification test confidential and allowed her to retain her medal, money, and title (Behrensen, 2011). However, the story was leaked to the popular press that Semenya had the external genitalia of a female and the internal genitalia of a male (Hurst, 2009). The IAAF never supported this claim, but the sports world accepted the popular press report as true. Sport policy currently shuns the intersex athlete and forces them to "prove" their sex and popular press accepts what they want to believe when it fits within what society considers being "normal" and fair (e.g., Semenya's sex testing results being leaked).

The current IAAF policy on gender verification, established in 2011, states that females with hyperandrogenism (high levels of testosterone) are allowed to compete in competition and the terms gender verification are not to be used (Cooky & Dworkin, 2013). The International Olympic Committee (IOC) also recognizes that athletes with hyperandrogenism can compete (Krane, 2015). The issue with this is that both of these policies are based off of the suspicion that an athlete might have this intersex condition. The suspicions are grounded in stereotypical

expectations surrounding femininity. Athletes who have stereotypical masculine features, often related to athletic success that an athlete might possess (e.g., muscles) are scrutinized. As we saw, Dutee Chand was removed from competition in 2014 for her hyperandrogenism condition.

There is one common theme that surrounds the intersex athlete debate and sport. All of the athletes who have been scrutinized and questioned are women (Kauer & Krane, 2012; Schultz, 2011), never men. It all comes back to fair play. Those in power (e.g., governing bodies, sport administrators, coaches) believe that it is only fair for a woman to compete against another woman (Krane, 2015; Reeser, 2005) because men are perceived to be more powerful and stronger. This is why female intersex athletes are so widely policed, because those in power are trying to “protect” the women’s game by keeping the men out of it. If a woman is competing against other women and perceived to be too masculine, then it is argued that play is unfair. This is where the testosterone debate comes into play. If a female athlete has high levels of testosterone, the dominant male hormone, then she must be a man and we need to keep her away from the woman’s game. It comes back to the hegemonic notion and societal construction that men are more capable, stronger, powerful, and athletic than women. It has long been understood that sport is an arena where hegemonic masculinity, gender inequality, racism, classism etc. are perpetuated and supported (Messner, 2002). These guidelines set forth by those in power are riddled in hegemonic ideals. That is, they support the gender binary. Men are to act a certain way, be strong, powerful, muscular, and show no emotion, while the women are to be feminine, small, and fragile. When a woman’s performance begins to blur the lines of femininity and masculinity flags become raised.

Dominant groups have the power and an intersex athlete challenges that power. If a woman, especially in the case of an intersex athlete, has masculine features then she is perceived

to have an advantage over other women, which is unfair. Schultz (2011) asked researchers to look beyond defining what it means to be a “woman” and instead take an intersectional approach (e.g. psychologists, physiologists, doctors, working together) to defining what conditions support an unfair advantage. Schultz argued that research needs to analyze whether there are actual biological factors at play that would give an athlete like Caster Semenya an advantage such as cardiovascular or musculature advantages over other female athletes. Cooky and Dworkin (2013) argue that if the goal of sex testing in sport was to support fair play, then all athletes should be tested for genetic conditions that support increases in athletic performance. The reality of the situation is that it is not just about an unfair advantage. That is the façade that governing bodies like to use because it is a sentiment in sport that most believe in. It is more about intersex athletes challenging the binary and not fitting into societal norms.

In 1972, Title IX was established to prohibit educational institutions from participating in sex discrimination. Title IX is best known for the impact it made within athletics (Edwards, 2010; Fraizer & Caines, 2015). Seeing that most institutions receive federal funding in some capacity, Title IX must be followed. Athletics is an arena where gender inequality exists among other things (Messner, 2002). Hence, Title IX has been prominent in promoting gender equity in sport. However, in the original statute, the law said nothing about athletics (Zaccone, 2010), but upon further analysis athletics was an arena in which inequality based on sex was extremely common.

Why address Title IX? Because not all athletes who are intersex are international competitors like Caster Semenya and they could face discrimination at every level. There are intersex athletes in youth sport through college and Title IX affects each and every one of those athletes. Zaccone (2010) wrote that when an intersex person fails to conform to a binary sex they

are discriminated against when their anatomy does not align with their gender identity. If “sex” is referring to anatomy of what is male or female, then intersex athletes are protected because it is based on the right to participate regardless of anatomy. If “sex” is meaning the status of actually being male or female then the intersex athlete is stuck in the middle without protection. The discussion today needs to be inclusive of intersex people. Within this discussion, we should consider how to protect intersex athletes from discrimination in sport (Zaccone, 2010). As it currently stands there is little protection for intersex athletes in sport and that is a problem.

Identity and Intersex

Understanding how being intersex affects varying aspects of a person’s identity is important because of the fundamental nature of identity formation that every human being goes through (Erikson, 1968). The psychological component to being intersex has not been widely studied. Hird (2003) described a variety of issues surrounding the intersex identity that could benefit from mental health practitioners working with the intersex condition. For example, practitioners might work with clients who have had repeated traumatic surgeries, exposure to countless medical practitioners, treatment of bodies after surgery, family relationships, gender identity issues, body image issues, and parent relationships to name a few. It is important to note that when bodies do not fit within the binary categories set before them, it is likely that there is a dissonance between mind and body (Krane, 2015). This dissonance creates a burden for an athlete and forces them into neat male or female boxes, which affects their identity.

Although not widely researched, the impact of the parental reaction to the news of a child born with ambiguous genitalia can have an immediate impact on a child through parent’s feelings of shame and guilt (Howe, 1998). Parents may also express confusion, denial, anger, shock, rejection, and disbelief (Carmichael & Anderson, 2004; Slijper et al., 2000). Gough et al.

(2008) described the need for psychologists to intervene on the behalf of parents and provide services to parents in need. Gough et al. (2008) continued that not only would counseling provide emotional support, but it also can also act as an educational support to help parents understand more about sex, gender, and intersex. It is widely known that the relationship between parent and child is important in the development of children. If a parent expresses shame, guilt, and resentment towards a child, what is the impact on that child? How does a parent's reaction to an intersex diagnosis impact the development and self-understanding that a child learns from their parents? With little research conducted on the experiences of intersex persons many questions are left unknown.

MacKenzie et al. (2009) conducted a study to gain insight into the experiences of intersex people and to give them a voice on their condition. MacKenzie et al. noted that it was hard to find participants due to the marginalization and invisibility of intersex peoples. They were able to interview three people: two who identified as intersex and one who identified as female. MacKenzie et al. found three main themes within their interviews: managing silence, coping with difference, and developing acceptance. The intersex participants felt an awareness of silence surrounding them, but they were unsure of what the silence meant or its reason for existing (MacKenzie et al., 2009). The participants felt different because of this silence, but were unaware of what the difference was. Two of the participants had surgery when they were infants and neither were ever told why. The silence they felt helped forced them to cope with their differences. The participants stated that they were unsure of what sex they were and it led them to identifying with what they were assigned at birth. Eventually, the silence ended between parent and child and each participant's intersex condition was discussed, which allowed for the

participants to accept their condition. This supports the argument that creating an open dialogue (Lee et al., 2006) is more beneficial than silence and surgeries.

The intersex condition is one that can be hard to navigate. There are many different things to consider between doctors and parents, and parents and child when it comes to decision-making and its impact on identity. The impact that silence and confusion have on an identity can be harmful (Preves, 1998). It should be the goal of all practitioners and parents to begin to change the discourse surrounding intersex people so that the process for navigating this identity can be easier on a child and family. This can be done by reducing stigma and creating a more inclusive environment for intersex peoples.

Theoretical Framework

This current study is framed within a feminist cultural studies and transfeminist approach. Utilizing a feminist cultural studies perspective allows the researcher to explore how power is constructed through normal everyday life (Krane, 2001; 2015). In particular, feminist cultural studies focuses on the hierarchical differential related to gender (Tolvhead, 2013). The age-old assumption is that men are to be masculine and women are to be feminine. We see this supported by society in how we treat men and women differently. In Western athletics, there are certain truths that are widely accepted when it comes to commonplace knowledge about young girls and boys engaged in physical activity. For example, boys will not want become a gymnast because that is a girl's sport and young girls are expected to play volleyball whereas young boys play football. Men are to be strong and powerful and women are to be submissive and quite. Society reinforces these ideas by who is in a place of power (Krane, 2015). When it comes to sport, the power is given to the governing bodies like the IAAF, IOC, and NCAA. They decide on the

policies and who can participate in sport and who cannot. They exert power over female athletes by saying what levels of naturally occurring testosterone is too much.

When looking at media coverage of sport it is dominated by men's sport (Cooky, Messner, & Musto, 2015). The naturalness of the power differential is so commonplace that it goes unnoticed. People do not notice that women's sport is never on television, they just accept the information about men's sport. Utilizing a feminist cultural studies lens, the researcher questions ordinary actions that support gender discrepancies in sport.

One of the biggest issues surrounding intersex athletes is the focus on their anatomy (Viloria, 2014). That is why this study draw upon the conceptualization of transfeminism (Enke, 2012). Transfeminism challenges the binary and dichotomous nature of sex and gender by pairing feminism and transgender studies. Although it is a common misconception to compare intersex peoples to transgender peoples, the focus and societal issues related to each is based on biological sex. A transfeminist approach allows the researcher to question the emphasis on anatomy, while analyzing the lived experiences of those who do not fit within the binary. Intersex is about biological sex, not gender. Transfeminism (Enke, 2012) focuses on the inequality surrounding people who do not fit within the gender binary with a focus on biological sex. Because intersex people do not fit within the binary of biological sex, they may face discrimination in sport. Utilizing transfeminism will allow me to analyze how inequalities around not fitting the dichotomy of biological sex impacts experiences in sport. The research questions guiding this study are: a) what are the experiences of being an openly intersex athlete? b) What are the athlete's challenges being an openly intersex athlete? c) How does being intersex impact the athlete's athletic experience?

Method

Framed within a transfeminist framework, this study used a narrative approach (Sparkes & Smith, 2009) to understand and share the experiences of an intersex athlete. The narrative approach in research is used to generate a story to share a person's experience from his or her own worldview. In narrative research, the story of the individual is the object of the research (Riessman, 1993). I want to share the sporting experience of what it is like to be an intersex NCAA student-athlete.

Participant

The participant in this study is a current NCAA Division III soccer player who is referred to by the name of Amanda. Amanda is a pseudonym used for the participant as way to protect her identity. Amanda was diagnosed with congenital adrenal hyperplasia (CAH) when she was born. CAH is a condition that affects the adrenal glands in the kidneys and blocks the production of cortisol and in some cases the glands do not produce aldosterone (Sheikh, Alebrahm, Kaddoura, & Al-Fahoum, 2015). When the hormone production out of the adrenal glands is imbalanced the glands produce too much androgen. Androgen is the male-like hormone that is needed in both young boys and girls for normal development. However, when there is too much androgen in young girls it can cause a child to grow too fast, develop pubic hair and acne at a young age, and cause a child to stop growing too soon. In young girls specifically high levels of androgens will cause external genitalia to be atypical and cause irregular menstrual cycles in puberty if not addressed. CAH can be dealt with through medication management (Sheikh et al., 2015).

Procedure

The participant, Amanda, was recruited through an academic relationship. Amanda had mentioned previously that she would be interested in sharing her story about what it is like being an intersex athlete within the NCAA. Upon receiving approval of the university Human Subjects Review Board, Amanda was formally recruited through email contact. She then contacted the interviewer formally agrees to be a participant. In this initial contact between Amanda and the researcher, we discussed the study procedure and confidentiality. In this first contact, we also scheduled our interview. The informed consent was emailed to Amanda before the initial contact and her questions about the study were answered. Immediately prior to the interview, we reviewed the consent document Amanda gave her verbal consent and we began the interview.

Amanda engaged in one interview, which was framed using a narrative and life history approach (Smith & Sparkes, 2009), while focusing on Amanda's sporting experiences. Using a narrative approach is important because Amanda's experience could be told through specific stories and memories that have impacted her throughout life. The initial interview lasted around 50 minutes. I conducted the interview from a private office and Amanda a private location of her choice. Amanda chose the time and date that the interview was most convenient for her. The interview was audio-recorded and transcribed verbatim. The interview was semi-structured (Markula & Silk, 2011), which allows the researcher to cover a variety of topics while creating an open conversation between the researcher and participant. A semi-structured interview allowed Amanda to go on tangents and create a narrative for her experience. The purpose of the first interview was to gather the history of Amanda's condition. The interview guide was developed to gather information about her condition, family, experiences in sport, and feelings surrounding her identity. The interview was focused on painting the whole picture of what it is

like being an intersex person in sport. This interview was conducted over telephone. A check-in email was sent to Amanda about a week after the initial interview was conducted. This was to ask follow-up questions and ensure that I understood her story correctly. Although long-distance based interviews are not as preferred as face-to-face interviews, research has shown that Skype and similar medium based interviews are still capable of achieving a strong rapport and sensitivity (Oates, 2015).

Several strategies were used to ensure the trustworthiness of the research. Markula and Silk (2011) list several areas that a researcher must be aware of to ensure that research is trustworthy. They are authenticity, believability, and fidelity. Authenticity expresses the reality of the participant's experiences. This can be seen in how Amanda shares specific memories of doctor's visits and family reactions. Believability refers to the coherence of the story and its impact. The coherence of her life experience is seen in how the vignettes are strung together to create a story. The semi-structured approach allowed Amanda to create a flowing stream of thought. The vignettes were condensed to create a coherent story of Amanda's words. Fidelity refers to the researchers ability to express the aims of the research. The follow-up email ensured that Amanda was comfortable with the story that was being told and that her experience was being understood correctly. Throughout this research the author used these tenets to ensure that Amanda's story was being told honestly and through her own words.

Data Analysis

In this research, a narrative approach (Smith & Sparkes, 2009) was used to tell Amanda's story by interpreting the way in which she sees her world, makes sense of this world, and then performs in this world. The purpose of using the narrative approach is to see how Amanda, in different settings, responds and reacts to her social world (Smith & Sparks, 2009). The interview

was transcribed verbatim and then read and reread for emerging themes (Markula & Silk, 2011). Amanda's story emerged in the form of several mini-stories or vignettes, which is a similar narrative approach used in previous sport research (Krane et al., 2014; Waldron, Lynn, & Krane, 2011). The vignettes shared are in the participant's own words, however they are condensed to create a more cohesive and stimulating narrative. Due to the interview being semi-structured Amanda was able to flow from thought to thought. Condensing her story connects all of the themes that she addresses.

A layering approach (Ely et al., 1997) was also utilized, which alternates between the participants voice and the researchers theoretical discussion.

Results and Discussion

The following themes emerged from the narrative analysis and storytelling approach to understand Amanda's experience. The purpose of using the narrative approach is to see how Amanda, in different settings, responds and reacts to varying forms in her social world (Smith & Sparkes, 2009). This approach allows the researcher to share Amanda's story without having to make interpretations. The who, what, when, where, and why are told by Amanda alone.

In the analysis of the data, it was revealed that there are several stories that impacted Amanda and her lifelong experiences surrounding her CAH condition. Consistent with the narrative format used by Waldron, Lynn, and Krane (2011), below I present five vignettes designed to share Amanda's experience. The text is composed of direct quotes from Amanda. The "goal of such a format is for these stories to resonate with readers and create deeper understanding of the psychological and emotional components of [this athlete's] experiences" (Waldron et al., 2001, p. 115).

Much of the discussion is centered around Amanda's understanding of her condition and the impact that CAH has had on her and her family. Interestingly, much of the discourse in popular press surrounding intersex athletes is that the diagnosis of being intersex is negative or something to be scrutinized (Hurst, 2009; 2010). However, Amanda's narrative views the CAH diagnosis as something to be proud of and something that instilled confidence in her life. Together, these vignettes illustrate how this condition is not something that hinders Amanda in any way; rather it is a part of her that she brings into every aspect of her life.

Vignette #1: Medical Side of CAH

Amanda shared her memories of working with medical staff and her understanding of her condition. Amanda personally feels that her time spent with medical staff was very positive. She spoke highly of her physicians and attributes a lot of her self-confidence to the decisions that were made by medical doctors and staff along the way. Amanda also struggled to put into words her condition in medical terms. She felt that her interpretation of what she deals with is more important than understanding the science behind what is actually happening with her body. She also expressed some things that bother her about sharing her medical history based on how society views some of the medications she has used in the past.

Well if I have it correct, I suppose when I was born, I was born with congenital adrenal hyperplasia. I don't know the full extent of it. But it is also called CAH. I mean, I guess, the term intersex was not like a huge thing, you know as big as it is for other people. Um because it was more of, I was very much a female that had just a few symptoms that needed to be changed around. I think the first time I really realized; I don't think I really realized that anything was wrong with me, in terms of intersex, it was more that like I was always going to the bathroom, like constantly, and that [CAH] it had affected that. But it was probably around like first grade maybe, end of first grade, and then by the end of second grade that was kind of when they [my parents] realized that there was a need for surgery.

Basically CAH means my adrenal glands don't work and as I grew older it messes with your hormones a lot. So as I grew older, by the time I was in second grade, some of my internal organs kind of were out of place. I don't know the full extent of it. But I'm sure there's research on it. But back when I was 2 weeks old the first thing they had to do when you are said to have congenital adrenal hyperplasia is to double check your [sex]. So [the

test] said I was a female when I was born, but when I was diagnosed with CAH they had to double check to make sure I was still a female. Because of my adrenal glands, they affect my hormones a lot, that's mainly the biggest thing. I get tested every couple of months for my testosterone levels and my estrogen levels and so on and so forth. I take... what is it called dexamethasone every night and I take uh--um I can't remember the name--but it is another pill in the morning. Oh! Hydrocortisone. Every morning I take those, I have taken hydrocortisone my entire life. Since I was a baby. Dexamethasone, I have been on for the last I don't know five or six years. Then I took growth hormone shots every night for 8 years because CAH or at least my version of CAH affects my pituitary glands and it made my bones grow a lot faster than my age dictated. When I was 6 my bones were 12, which was making me, it would have made me stop growing a lot faster. They predicted me to be 4'11. And with the growth hormones shots they caught my bones, um they caught my bones down for my height or something like that and it made me 5'7". It kind of bothers me that, on a side note, that HGH tends to get a very negative connotation because of sports. A lot of, you know, athletes tend to use HGH as a steroid in large doses. But for me, it was this incredibly positive experience that made me you know a 5'7" average height female and its sort of an incredible drug that can help so many people. But it's, you know it's crazy when I tell someone I'm on HGH and they're like you're on steroids! You know that's crazy.

[Beyond the medications that I took] around second grade I had to go in for a massive surgery that would fix my, you know, lower region and make it more female than it was, not that it wasn't entirely female before but it definitely had more of a male's perspective in a sense. I'm not a doctor, but that's definitely what caused me to have to go to the bathroom constantly, but after I had the surgery its all been good and totally fine since then. But the biggest thing for me was that my doctor at the time wanted me to wait until I was about 15 or 16 and done with puberty and everything before I got it done. My parents were very kind of set and made them do it when I was younger. They talked to the specialist who would be doing the surgery and he recommended doing the surgery younger as well. And if anything, I think that was the biggest thing that impacted my life because I don't think I would be the confident young woman that I am today if I had been living with that through puberty and into high school.

[Speaking of doctors, my experience with medical experts has been] fantastic. I started at [hospital 1] and then my parents took me to [hospital 2] and where my current doctor was. They are kind of the leader in all of the research for CAH. She basically was this amazing woman who got me in this study and has been treating me ever since I was two-weeks old. She helps with everything and she has known me my whole life. She is the only person who calls me by my first name. But she has been amazing. From there we have had some amazing fellows that have helped us along the way [naming names]. Blood takers have been awesome as well because I hated that. But you know every so often we had a fellow that my parents didn't really like the way they did things or the way they talked and [my parents] weren't afraid to voice their opinions about the fellow, which was great because I never saw that side of things, which means that they did their jobs fantastic. Um so I never saw a fellow that wasn't treating me the right way or you know that wasn't being respectful. So I owe a lot to my parents for that and for them going through the whole thing with me.

From the beginning of the interview, Amanda was very open about sharing the details of her condition and the details she remembers. When describing the medical staff surrounding her and the medical treatment process as a whole, Amanda used positive words such as *fantastic*, *amazing*, and *incredible*. This is very different to what much of the research has shown, which suggests less respectful treatment and negative experiences within the medical community by many intersex peoples (Greenberg, 2012; Lee, 2011). It seems that for most the experience is rather negative. However, for Amanda it was not negative at all. As she described, her experience has made her the *confident young woman she is today*. Amanda gives all of the credit to her parents and doctors for making the tough decisions. It is a powerful statement to say that she would be a different person today if she had to *deal with this through puberty and high school*. This positive view is rare among intersex stories and experiences.

It is also interesting how Amanda navigates the discourse surrounding the medication she is administered for her condition. Again, she uses very powerful positive words to describe the medications she took to help her grow. The negative connotations that surround a drug like human growth hormone (HGH) are that athletes use it to get a competitive edge (Momaya, Fawal, & Estes, 2015). For Amanda, there was no competitive edge in taking the medication. Instead of thinking about HGH with anger or irritation she instead views it as an incredible medication. Instead of listening to critiques about how HGH is used in sport (muscle growth, competitive edge, increased performance, Momaya et al., 2015) she takes the opportunity to inform people that it has other uses and that it can be medically necessary and helpful.

Vignette #2: Parents and Family

Throughout the interview Amanda gives a lot of credit to her parents. She was adamant in relaying the fact that she is happy with the manner in which her parents responded and handled

her condition. It is important to see the connection that Amanda makes between being the person with CAH and watching how it has affected the people around her. She is very responsive to understanding that it was not only physically challenging for herself, but as well as for her family. Amanda also tells her experience in terms of short memories, which really provide a visual into how her parents responded to a diagnosis of CAH.

Well, I mean as long as I can remember [the family] just never, you know, made CAH into this big thing. [My parents] never really viewed it as a disability or something that defined who I was. We went to the doctors every four months. It isn't much of a disability because it doesn't stop me from doing anything. It doesn't keep me from playing sports. If anything it just makes me more responsible because I just have to take my pills and watch out for myself. I think because that was their view on it, at least to me, in front of me, I just never grew up with it being this big deal. [They had to make a tough decision] and I believe that if I had waited [to have surgery] it would have been harder on me when I was learning about everything sexually related. It's hard to explain, but I think that when you go through puberty you can become self-conscious and you are learning a lot of new things and to be a little different is hard. Especially if you don't fully understand it, so I don't think I would have become the confident person that I am sexually today if I had waited.

I mean I knew I had to do these things, take my pills and be responsible and watch out for myself. But, I never thought of it as something that would affect me. When you're little you don't know that, so you look to your parents to kind of set the path of how you should approach it. And my parents were very on top of me to take my pills and take me to the doctor and to give me my growth hormone shots. If they didn't do that I wouldn't have seen that it was a big deal that I had to be responsible with all this stuff. But as long as you're responsible about it you're fine. You will be okay and live a normal life.

[I remember] that I wrote my college application about when I moved to North Carolina. Every 6 months I would have to fly back to New York City and meet with my specialist and every time I did that my Dad would go with me. Instead of making it this big medical trip he made it this fun New York experience. So we would always pair a Broadway play or a nice dinner out or a fun experience at a store with the doctor's appointments. So it was never, he never made it like this big negative trip to the doctor's office that some people might hate. But instead he made it this big trip to New York City where we just happened to be stopping at the doctor's office.

[I also have to remember how much my parents had to do for me]. I would joke about how I'm the shortest one in my family because my brother is 6'2" and my Dad is 6'1" and my Mom is 5'11". But to my Dad that is a big deal, but I didn't understand. He would say, "I gave you shots for 8 years" and when it comes to my height I have to be very careful joking about it. My Dad went through a lot to give me those shots every day for 8 years. I understand a joke to him doesn't come off in the best way. So he got really mad about that with me, so I have learned not to joke about it at all. [I have to remember] what my parents went through. It was hard for me, but I think it might have potentially been even harder on my parents. I was their first child and they didn't know anything about this. I mean since I

have been born my specialist has made the CAH test one of the mandatory tests that every pregnant woman gets to check if her child has it. That was her big push and I think that's amazing. But with that my parents didn't know anything about this. They have been through it emotionally more than I may have. I think it is really important for me to realize that I was the one getting the shots and the surgeries and the physical stuff. But emotionally, they went thorough you know a lot and I always have to be very careful about how I, you know, maybe joke about my disorder. Because they had to do a lot with me. My Dad gave me my shots. You know they had to make sure my brother didn't get it. But, yeah, I think that's the most important thing.

Amanda's relationship with her parents reflects how she feels about the decisions they made for her regarding what surgeries she would have and when she would have them. Previous research shows that parents are generally silenced when it comes to sharing the impact of making tough medical decisions for intersex children (Murray, 2009). Amanda expresses that she understands and supports the decisions made by her parents, which seems rare relative to the literature about intersex children (Greenberg, 2012; Thorn, 2014). The biggest potential problem in early decision-making is that the parents decide on the incorrect gender for the infant. Thorn (2014) stated that the surgeries are more cosmetic in nature and waiting until the child can give consent to the surgery should be the standard practice. In many cases, parents are blamed for making a rushed or incorrect decision. Most notably, the story of David Reimer, a baby born intersex and selected by his parents and doctors as female grew up confused and lost due to the fact that he felt that his gender was male (Dreger & Herndon, 2009). Unlike Reimer, Amanda praises her parent's decisions and attributes it to her confidence later in life. Dreger and Herndon (2009) stated that intersex children should be treated in a way that privileges their long-term development. It is clear that Amanda feels that the early decision-making on her behalf very clearly privileged her long-term development.

Amanda's support for this early decision-making process challenges the current discourse surrounding the practice of genital surgery and infants (Dreger & Herndon, 2009). Amanda's

experience is vastly different than David Reimer's. It may be that Amanda felt nothing but love and support from her family and medical doctors. There also may be a stroke of luck that Amanda did not have any gender identity crises. When comparing the two very separate experiences, there is a clear difference in the amount of support that each received starting at birth, which shows how important the parents role is in this process. Instead of adding to the dialogue that parents and doctors need to wait and let the child decide what sex and gender they prefer, Amanda supports early decision-making. It is interesting how she explains how this decision affected her later life development. She feels that her parents making the decision for her saved her from a lot of self-doubt later in life, which speaks more about how society places an emphasis on what is "normal" rather than being confident in your own body.

Vignette #3: Personal Experience with CAH

Amanda has gained incredible confidence that she has attributed to how her parents handled her condition. She views her CAH as something to be proud of and she talks openly about it with people. Naturally, she has some areas of her condition that she avoids talking about, yet she also has a tattoo about CAH. In all, Amanda has taken control of the discourse surrounding her condition. Amanda has empowered herself to share her condition with others around her.

I have always been really proud of my CAH as it being something that I like to talk about and help people about because you know, I mean I think I'm lucky in the sense that unlike other disorders it's not affecting my life. I'm not afraid to talk to people I'm not afraid to you know talk about things that are pretty hard to talk about for someone else. I know how to deal with things in a light way, while also being able to be a listening ear for someone because that's what I had when I was growing up and everything. So if anything CAH and intersex stuff affected me which then affected how I approach later life things. But again I have had parents that have kind of instilled the responsibility in me to take my pills and do my shots and a lot of people don't have that opportunity to have parents that are so on top of them. But I think it didn't really affect any of who I was or anything. It made me more confident in myself and proud of who I was. For example, my freshman year of college I went and got a tattoo about my CAH and just like, you know, kind of paying homage to the thing that made

me who I was. [My tattoo] is on my back on my adrenal glands and it's an infinity symbol with CAH in the lines. Basically meaning that whatever you have, whatever you got, I have CAH, whatever it is that is affecting your life the most. You just kind have to figure out a way to live with it and make it who you are and kind of not let it dictate who you are, but you know nothing can stop you. You got to keep rolling with it.

Often times [I talk about my CAH] when I talk about my tattoo because everyone asks me what's in your tattoo? What are those initials? And then I say oh it's for my disorder. And then they ask me what it is about and then I tell them. But I guess in the past it was always about why are you wearing a medical bracelet, or if I had to go to New York. It was always very situational. It never really was something that I felt like I needed to go tell everyone because I didn't think it was that big of a deal. You know if I get an A on a paper that's what I want to tell everyone. I don't need to go around telling everyone I have a disorder just because it's not a big deal to me or an issue or something I think that everyone needs to know because it doesn't define me as a person. But it is more of a situational thing where if someone asks me about it then I will tell them about it. But it is something that I am so open about. I have even considered doing a TedX talk. I just would have to figure out what I would talk about.

It's more of an empowering thing where you kind of just, I think it's amazing for people to just accept what you have already and make the most out of that. [When I tell someone] they think it's awesome. I think it is just because it is something different. When I tell them I took HGH they say that's unreal! You took steroids! They don't understand the full extent of it they just say it's cool. I've never had a bad reaction from someone. You know, I'm so proud of it that I did a 7th grade science project on it and I showed my friends how I gave myself the shot and pills I took and the day and the life of me going to the doctor. So if anything it has been not something to shy away from or something I try to hide. I mean I think sometimes I will be like when I was two-weeks old they had to make sure I was a girl or something like that. And they will be like, "wait, what you were a boy?" And to me, I let those things roll off my back. I think it's funny because I make fun of it too. Because I'm confident with who I am and that I am a female and whatever. Sometimes I don't try and explain to someone the ambiguity parts of it. Mainly because I don't know the full extent [of the medical aspects] or how to explain it the best way. I mean it's not like I say, "oh I have CAH let me tell you all about it." But I'm not afraid to talk about it if someone asked. I always think it's funny that even until, to this day when someone's like can you tell me more about it, but you don't have to if you don't want to. For me, it's like "oh yeah sure like it's not a problem." But you know I was never afraid, even my parents never made me be upset with what I had or look at CAH as something that was going to like affect my life in a negative way. They just kind of viewed it as something else that we had going on. You just have to kind of like deal with it.

But I think my entire life has always been about it, because I have never seen it as something negative. The only thing I really skate over is my surgery. My surgery was really big. I may lack some confidence describing my surgery just because I don't know the full jargon that would describe it in the best way so that someone could understand it. I always feel like someone might take it out of context—"oh so you were a boy? Or did you just have guy parts or what was it?" But I just needed surgery to fix my internal organs, just so, like [I don't talk about it] so it doesn't get misconstrued. But I don't think there really is anything

that I don't have confidence in. I mean I have typical female areas where I have confidence issue, like boys and you know normal girl stuff. But not in terms of CAH.

In this narrative, Amanda unknowingly negotiates conventional views of gender and sex and that affects how she shares her story with people. Amanda purposefully skates over discussing her surgery with people, not because it is a private matter, but because when you address genital surgery it leaves the door open for people to question her sex or gender. Instead of outsiders accepting that Amanda is female, outsiders might make the assumption that something is amiss if they knew that there was a reconstructive surgery. United States society likes to keep people in uniform boxes. The proverbial box is being either definitively male or female. When someone does not fit neatly into a box of clearly male or clearly female questions arise. This is the gender binary. Amanda skating over her surgery is a way that avoids questions being asked of her to explain which box she fits into. It makes sense that Amanda would try to avoid these conversations because in Western society people like to "fix" and "normalize" sex and gender (Lee, 2011).

Amanda also allows herself to control the discourse surrounding her CAH diagnosis. As she stated above, she does not mind sharing and telling people about it. She has a tattoo, which opens the door for discussion. How Amanda controls what is said allows her to normalize her condition. She does not view her CAH as intersex and, therefore, when she is sharing it with outsiders they do not view her condition as an intersex condition. However, we know that CAH is one of the more common intersex conditions (Guth et al., 2006). Amanda's discourse surrounding her CAH challenges what many define as a disorder of sex development because as Amanda explains it, it does not fit within that category.

Vignette #4: Sporting Experience

Amanda's sporting experience has been limited when it comes to the impact that CAH has had on her development through sport. It was more or less just something else she had to carry around with her. Unpredictably, her sport experience has been positive and unaffected by this condition.

For me, I don't think CAH really affected sports at all. I mean it was never really a big thing in my family. It's very different for a transgender [person] who identifies with something else or wants to change. For me it was, I was always a female so I never had this feeling that I wasn't. And the surgery that I went through, I always felt when I was little that it was to make me stop going to the bathroom all the time. In later years, I realized that it wasn't. I still don't know the full like jargon for it, but I was just happy that I wasn't in the bathroom all the time. I mean my parents they never let it affect how I played sports. Sports are always a big part of our lives. They put me in soccer and put me in softball and I loved all sports that I did. But I never really came out to a team in my sport world. Which is nice. In terms of like my career, later in life, I don't think it has affected that exactly. If anything it has affected me and I've affected my everyday life you know. Knowing I have what I have. It has made me an outspoken and confident individual, which has, in turn, affected how I approach all my later life sport things.

In terms of soccer, the only thing is that I have to tell my coach and my best friend that if I break a bone or pass out on the field they just need to make sure my medical bracelet gets to the doctor. My trainer also knows. But only in terms of like, not in terms of like, "oh my god, this girl has something." But more in terms of like if I get hurt they need to call my parents and make sure my medical bracelet gets to a doctor so they can give me the right dosage of medication. But to them that's like, "oh okay well everyone has something, you have this." I mean when my trainers found out or when I submitted my medication or medical forms of the beginning of freshman year it's not like they found out and immediately asked if I'm okay. They didn't treat me any differently. I'm sure they have seen thousands of different things a year. It is just something else for them to be aware of. They were just like yeah okay. I mean okay you got something, we will watch it and make sure you're good. They don't make it a big deal. They don't make you feel special or anything you're just another athlete playing sports and they are taking care of you. If anything, if I talk about it more, they are like that's really cool tell me more about it. But it's not like they search me out and say, "oh my god are you okay what is this?" It's like another allergy. Because it doesn't affect how I play or how anyone needs to treat me. Because that is literally the only thing that it would affect is if I had an issue on the field. There would be no other reason. It's not like having asthma or something like that. It's just like if I get hurt they need to make sure I get the right medication.

[When it comes to my current team], I mean some of them probably know and some of them probably don't know. I mean it's not something that you know that affects the locker room or how I play soccer or anything like that. They react in the same way that any other person reacts or someone who asks what my tattoo means or something like that. But I'm

sure my friends know or someone that has asked about my tattoo knows, but I don't think my entire team knows or really needs to know unless they ask me about it. It hasn't affected my play in college at all. It didn't really affect me in how I approach playing college soccer either. I'm trying to think if there was any way that it would affect me at all. Like I said before I think in some ways it affected playing soccer and playing sports because it affected who I was and how I approached it. You know my first doctor when I was a baby, my mother told me this, they said that I was going to be a stubborn one. If anything I think that helped me own myself. And just kind of be that kind of player on the field. Kind of taking the idea that everyone's got something to deal with. How does this make me any different and approaching it from that way.

Unlike some professional athletes at the international level (e.g., Caster Semenya, Dutee Chand), Amanda has no fear that her CAH condition will hold her back from playing sport. Amanda does not feel that her body needs to be policed and does not fear that her condition will ever create a negative reaction to her playing sport. This can be seen in how she does not feel the need to hold back from sharing her story with trainers if they have questions and in how she does not even see how it is relevant to her playing soccer in general. Similar to Semenya (Brady, 2011), Amanda has always identified as female and was very adamant that she has never identified otherwise. The idea that CAH might affect her ability to play college soccer has not even crossed Amanda's mind.

Amanda's experience in sport is also very different than many athletes with an intersex condition in sport have experienced. Again when looking at Dutee Chand or Caster Semenya their bodies and conditions have been put on display and scrutinized (Magubane, 2014). Amanda, her trainers, coaches, and friends treat it like any other allergy, which is a vastly different response than most female athletes in sport with an intersex condition. The difference in how people respond to her CAH might be due to the fact that Amanda views it so nonchalantly. To Amanda her CAH is *what it is* and she accepts the condition and moves on. Her response and reaction to the condition might be impacting how others perceive the seriousness of the diagnosis, which in return does not raise any red flags for outsiders.

Vignette #5: Advocacy

Another focus of the interview was on Amanda's own activism or advocacy of other intersex athletes or the condition itself. Surprisingly, Amanda shared that she does not really view herself as intersex. Though, talking about her condition and learning more about it has started her thinking a little bit differently about her condition.

I guess, I mean before I heard about your study I never considered this intersex so I don't know if I would be an activist for intersex or just an activist for just accepting everything [about yourself]. Just accepting what's given to you and making the most of it. Being outspoken and not being afraid of who you are. I mean at any rate, it affects other people as well to a different extent. But being more of an activist for being yourself and making the most for what you have and what you are given, rather than specifically for intersex because I don't identify totally with that. Honestly, I don't know too much about the term intersex. But I guess for me, I have lived as female since I was born and I was always a female in my family. My family and I, we always identified me as a female. So in terms of my sexual orientation and my gender, that has always been a constant and that has never been like an issue or something that I was confused about or anything like that. I think I just never heard the term intersex used very much. So it is hard, I mean I can see how, if all of what happened to me when I was little happened to me more when I was in high school, I feel like I would be a totally different person. And I think I could see that side of it more. But because it happened to me when I was little and I have a small memory of the whole process. You know I can't remember when I was two weeks old and they had to double-check my gender. But you know it helps me in that sense.

I mean the only athletes that I always hear about are the people that come out, whether it's the guy that came out at Stanford recently for being gay. I think like the first D1 gay athlete to play in the sport like that. I mean I always think that's always the top news things these days. The Michael Sam's, all these kinds of things. You know you see Abby Wambach who is out and proud and wins the world cup. The first thing she does is go kiss her wife. You see all of this kind of stuff. But you don't really hear, in terms of CAH, its not, it is a big deal for me and my parents, and we went through a lot. But there are people with diabetes and people with lupus and crazier things than what I have. And then dealing with [CAH as a family], making the most of it. So you kind of hear about those [other situations] more. I guess for me, I don't know if CAH did this or my parents did this, but I'm a very accepting person. As long as you're doing what you love and you're happy with who you are, that's the most important thing. So I look up to those people that can do that in the media. Rather than who has CAH and who's living with that.

[People like Caster Semenya] influence sport. I mean I feel like there always has to be somebody that is the first. You know you're not the only one in the world that is dealing with what you're doing. You know there's not, you're not the only person who has some sort of rare disorder that has never been heard about. Usually someone else has it. They just haven't come out. I'm sure there are other people like her that haven't been under fire. But you kind of have to, it's hard, there always has to be someone that is the first person. You know of

course, I don't think the public handled it right. People are always focused on what you're doing wrong when you're doing so well. But it's just like it is really hard because half the time people don't understand it and their reactions come from what they don't understand. It is a very quick reaction, that's why I don't usually talk about the surgery very much or the boy/girl thing very much because you know half the time I would have to sit down with someone and describe it and go in depth and it's just not really worth it. I mean I think as we get older and as the times start changing people are a lot more open and I don't think this will be kind of a problem, but it will be less and less and less of a problem over the next 10-20-30 years and stuff. But, I mean it's always tough but when something like that happens to an athlete, they get scrutinized.

It is never something that has ever really crossed my mind [having to prove my gender]. [What has crossed my mind] is doing a TedX talk. But then I was thinking to myself that like I don't really have a big overarching topic about acceptance. But then again it's not like I'm rolling around with some crazy disorder or something that I have to wear a pump or something like that where it's like really really really affected. I mean I think the fact that it's something like what my Mom said. You know it was something big that you went through and it was something my family had to deal with and we all had to do it. But I always look at what's even worse than what I have and there are a lot of other things, [like Caster Semenya]. So in terms of like a TedX talk I always thought it would be kind of cool because I am so open about it, but I would have to come up with a good way of going about it that wouldn't offend anyone. I think it is interesting that some people view themselves in that way [as intersex]. I was talking to [family member] about it and she mentioned it to me and I was like well I have never really viewed it in that way, but I guess that makes sense. So I think this has been helpful to at least open my mind about it [being intersex], I appreciate that. I think what is weird is that CAH hasn't really affected me as much as it has other people. And it comes back to the TedX talk. How can I justify giving a TedX talk when I don't know other people's perspectives on the struggle? My Mom is always telling me that it is a big issue, we did a lot, and you did a lot. I'm like you know it's not that big of a deal and we got through the hardest part. I'm a normal person or as normal as someone can be. But my Mom is always showing me how it is a bigger deal and I think I'm starting to see that more.

This narrative is particularly compelling because we see Amanda challenging her own intentions of becoming an advocate. Her Mom encourages her to share her story because her mother sees the impact and importance of her daughter's condition. Whereas Amanda has taken the opinion that she is not special in the sense that this condition was not an obstacle to overcome. She struggles with the idea that this condition has impacted her life enough to matter. However, much intersex activism is grounded in feminist writings about how society constructs gender (Dreger & Herndon, 2009). Essentially, the argument is that society has several constructs surrounding gender; such as men do not cry, and this construct impacts females and

males differently. If this construct did not exist then the lives of these men and women would be impacted differently. Amanda avoids conversations where her gender may be misunderstood. Although she does not see it, she is quietly avoiding the discussion on the intersex condition and the question of gender. Chase (2003) wrote that the obsession within society to ask the “gender question” is harmful to intersex peoples. This might explain why Amanda is hesitant to share her story and resist taking more of an advocacy role because she does not want her gender to be questioned or to be scrutinized by society.

Overall, these vignettes give insight into how Amanda’s experience living with CAH has not only affected her, but the people around her as well. While she currently does not identify as intersex, living with and coping with CAH has taught her responsibility and her confidence and pride. The future for Amanda might hold activists engagement such as public speaking to educate people on self-acceptance. Although Amanda might not see those opportunities as advocacy, her outspoken nature and confidence about her condition show that she is, in a sense, an advocate. Not specifically for CAH or intersex conditions, but for more than just what conditions might define a person.

Conclusion

Sport is an arena where the intersections of gender and sexual identity can become a focal point for an athlete who might fall within the LGBT umbrella (Walker & Melton, 2015). The intersex identification falls within that umbrella because it is a variation of sexual development. Athletes who are gender non-conforming or sex variant face exclusions and biases in sport (Krane, 2015). We also know that historically sport has not been accepting of intersex athletes (Peterson, 2010). In some cases, the intersex athlete is pulled out of sport (e.g., Caster Semenya, Dutee Chand) presumably to ensure fair play for other athletes. Amanda herself does not identify

as an intersex person, yet she has one of the more common intersex conditions (Guth et al., 2006). However, it is important to note that there is not one specific intersex condition and therefore there is not one specific way to address being intersex. The following explores how prominent female athletes compare to Amanda, how Amanda negotiates the line between sex and gender, and how the aims of governing bodies like the IAAF and its conditions on intersex athletes are skewed.

Currently, in sport, the IOC (2011) has addressed intersex participation in sport. Since there are many intersex conditions, the IOC focused on levels of testosterone (hyperandrogenism) in female athletes. There is no mandated sex testing of female athletes in sport. However, if there is a suspected case of a woman who appears to be too masculine she might be subject to being sex tested. Essentially, if a woman appears to be too masculine and has high levels of testosterone, she must be a man and therefore should not compete with the other women until proven otherwise. A female athlete in question is tested by checking the testosterone levels in her blood and she must be below the lower end of the male threshold (IOC, 2011). While there is no mandated test, an athlete can be sex tested based simply on a suspicion.

In recent years, there have been two prominent and successful female athletes who have been placed under the intersex athlete microscope, Dutee Chand and Caster Semenya. Chand is an 18-and-under track star and national champion from India. When she won the 100-meter race questions were raised about her sex due to her masculine appearance. Since she was an Olympic hopeful, tests were completed and she was found to have hyperandrogenism which raises the natural level of testosterone in the body (Branch, 2015). Due to this condition, she was barred from competing in races in 2014. Chand appealed this ruling and was ruled eligible to race by the Court of Arbitration in Sport (Branch, 2015). The court system, based in Switzerland, questioned

the athletic advantage given to female athletes based simply on naturally high levels of testosterone. This led the court to suspend the IAAF's regulation of hyperandrogenism in female athletes and the court ruling also gave the IAAF two years to provide scientific evidence to support that testosterone improves performance. At the end of this two-year period, if there is no evidence that testosterone increases athletic performance (in females) the hyperandrogenism regulation will be thrown out entirely (Branch, 2015). Since this announcement, Chand has been allowed to compete and is one of the first athletes to fight back against the larger and more powerful governing bodies.

Similar to Chand, Caster Semenya had her gender questioned in front of the entire world (Smith, 2015). After being forced out of competition following her performance in Berlin in 2009, Semenya is finally competing again. Semenya won the silver medal in London at the 2012 Olympics and is currently training for the Rio 2016 Olympics. Her performance in 2012 led people to question if she held back from winning gold to reduce any further talk about her gender (Smith, 2015), to which Semenya vehemently denies.

The successes and failures of both Chand and Semenya are crucial in the discussion of an intersex identity and sport. Semenya has since returned to the running world, but in a much different body than the one she displayed in 2009 (Smith, 2015). She is less muscular and smaller, and has a different hairstyle. Some might argue that she is displaying more stereotypical feminine features. Chand, on the other hand, is outspoken in not changing one thing about herself. She has refused to undergo any surgeries or hormone treatment (Branch, 2015). The similarities and differences between these athletes speak to why Amanda's story is important.

Amanda has not faced any of the challenges that Semenya or Chand have experienced in sport. It might be in part because of clear differences between Amanda and these athletes, these

differences being race, nation, and sex verification tests. Chand hails from India and Semenya from South Africa. Chand and Semenya are also both people of color. The intersection between race and nation has impacted how the world interprets their intersex identities (Magubane, 2014). They come from underdeveloped countries and popular press from powerful Western countries can take advantage of this and exploit these athletes. Kauer and Krane (2012) stated, “even in inclusive sport environments, the reproduction of white normativity and the ensuing marginalization of people of color often exists” (p. 10). White Western culture frame Semenya and Chand’s story as if they were “others” or “outcasts”, which portrays that they are not *normal* because they do not meet the White liberal standards (Kauer & Krane, 2012).

Being athletes of color may have played a role in how the world scrutinized their bodies. People of color tend to embrace traditional notions of sex and gender and what it means to be male or female (Magubane, 2014). Both of these athletes came from countries where it is easy for Western popular press to exploit these athletes and it is easy to critique them based on stereotypical gender roles grounded in Western ideals. For example, popular press would exploit the athletic features of these athletes as being “too masculine”. Popular press has been quoted calling Semenya “breathtakingly butch” and “boyish, with a powerful flat chest” (Levy, 2009; Malone, Miller, & Maclean, 2009). Western media exploits the athleticism of Semenya and displays her as an “other.” Amanda is White and lives in America. She is, as she described, traditionally feminine. She stated she is a “normal college female that is into boys and has normal girl problems, just like every other girl in college.” There is less scrutiny of Amanda because she fits into traditional Western feminine roles and is not of a race or nation that is scrutinized, she also is not an international competitor. Whereas, Semenya was targeted to be sex tested because of her masculine facial features, her quick rise to fame, musculature, and her

rumored deep voice (Wells & Darnell, 2014). Amanda's experience and lack of fear of scrutiny speaks to her privilege and how different "other" are scrutinized. Amanda details her experience as very positive and something that she rarely puts effort into thinking about. If we could ask Chand and Semenya how much effort or thought they have had to put into their identities, I am sure it would be overwhelmingly high.

The decision by the courts in Switzerland to have the IAAF find scientific evidence to suggest that testosterone increases athletic performance in female athletes is also very important in the discussion of intersex athletes and sport. It is important because female athletes should not be the only athletes that this scientific evidence affects. What if male athletes have higher levels of testosterone? Do we then become concerned with how fair that is for other male athletes? What about if some men naturally produce very low levels of testosterone, is that a disadvantage? Some female athletes were removed by the IOC from competing because their bodies would not process testosterone (Krane, 2015). The science and research should not only be concerned with female athletes. The biggest argument to date as to why female intersex athletes should be sex tested is that it protects the athletic environment from athletes who have an unfair advantage. Yet, there has not been one single link between athleticism and its connection to androgens and testosterone (Karkazis, Jordan-Young, Davis, & Camporesi, 2012). "There is no evidence showing that successful athletes have higher testosterone levels than less successful athletes" (Karkazis et al., 2012, p. 8). The focus, however, remains on testosterone levels in elite female athletes.

The foundational argument of why sex testing exists in sport is to ensure that there is fair play (Cooky & Dworkin, 2013), yet the only athletes who are affected by this are women. All humans produce varying levels of hormones in their bodies. If sport governing bodies are

concerned about health effects or even performance benefits, then we should be looking at the effects within everyone, not only half of the athletic population. This is an important decision by the Court of Arbitration of Sport to require scientific evidence and a positive step for female intersex athletes, but it still puts all of the focus on women in sport. This begs the question, does sport even need to be concerned with testosterone levels? If there are health concerns related to intersex condition, should governing bodies redirect their focus on that instead of forcing athletes to fit within the binary? Meaning, that if it is the health of the athlete we are concerned about; if not, do not force athletes to undergo hormone treatment or genital surgery to fit within traditional femininity. Karkazis et al. (2012) challenged the IOC and IAAF policies of gender verification based on the grounds that the tests are unethical.

For Amanda, her intersex CAH condition was not perceived negatively. She was able to correct her issues with a surgery when she was young and through current medication management. Amanda has CAH, a form of hyperandrogenism (Karkazis et al., 2012). CAH affects the adrenal glands and affects androgen production throughout the body, which can be easily managed with medication (Sheikh et al., 2015). For Amanda, her condition is manageable, which makes it “invisible.” Unlike athletes such as Chand and Semenya who had their sex put on display, people do not have to know about Amanda’s condition because it does not affect or directly impact any part of her life or career in sport. Her coaches and trainers only need to know that she has a medical bracelet in case she has an emergency; specific details about the condition is unnecessary for them to know. Unlike athletes competing at the professional or international levels, no one questions whether or not Amanda is female. She is not drug tested, which can detect testosterone levels, and she has no fear that if people were to know she has CAH that it would even become a problem. Amanda’s story supports the argument of why there should be

less concern around intersex athlete's bodies needing to change. Instead, sport could be an arena where we see more inclusivity of people with disorders of sex development because there is no evidence that it impacts performance for female athletes (or athletes in general) (Karkazis et al., 2012). Clearly, as we see in Amanda specifically, there is no direct impact on her sport performance or experience. For some (more specifically male athletes), an intersex condition might even be beneficial (e.g., if you grow to be 7 feet tall and play basketball).

Amanda's narrative is not typical of what we see in the athletic world when it comes to athletes with disorders of sexual development or in the current medical practice of handling intersex infants (Dreger & Herndon, 2009). It is important to understand that much negativity surrounds intersex athletes and sport because the focus is generally very narrow and concerns only one specific intersex condition, hyperandrogenism or high levels of testosterone in females. Yet, Amanda's story is positive and empowering. Amanda has become a successful NCAA Division III athlete. She does not fear being drug or sex tested and is able to put all of her focus into her performances. She is comfortable in her own skin and takes pride in her CAH condition (e.g., getting a tattoo). Her story might empower other individuals who play sport and have an intersex condition by showing that all intersex experiences are not negative. We see many intersex people regret their parent's decision for surgery at a young age whereas Amanda praises this decision. Her story is important because it supports that there is no one special approach to addressing an intersex condition. Amanda has shown that conditions like CAH do not hold someone back from competing in sport or living a happy life.

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