

“Support the shit out of them:” Intersex emerging adults’ socialization experiences and recommendations for caregivers of an intersex child

by

Shelby Astle

B.S., Brigham Young University, 2017
M.S., Kansas State University, 2020

AN ABSTRACT OF A DISSERTATION

submitted in partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY

Department of Applied Human Science
College of Health and Human Sciences

KANSAS STATE UNIVERSITY
Manhattan, Kansas

2023

Abstract

Caregivers can play a key role in helping intersex children face a world in which intersex issues are often misunderstood, pathologized, and stigmatized. However, there is a dearth of literature centering intersex individuals' perspectives, experiences, and needs. In order to aid caregivers in becoming more positive socialization influences for their intersex children, we aimed to (a) highlight commonly shared socialization experiences of intersex individuals across childhood and adolescence and (b) provide recommendations for caregivers of an intersex child based on these experiences. Guided by critical intersex studies (Holmes, 2009) and social cognitive theory (Bandura, 1986), I conducted interviews with 28 emerging adults (ages 18-29) who identified as intersex and/or have a variation in sex characteristics. Using thematic analysis to analyze these interviews, the coding team identified six themes of key socialization experiences that contributed to these intersex emerging adults' meaning-making around having an intersex variation growing up: (a) *We Don't Talk About This*, (b) *We're All In The Dark*, (c) *We Could Use Some Help*, (d) *I Should Be Less Me*, (e) *My Body Isn't Mine*, and (f) *I Feel Supported and Empowered*. Based on these experiences, the sample of intersex emerging adults provided recommendations for caregivers of an intersex child, which the coding team summarized in four themes: (a) *Make it Okay to Talk About*, (b) *Get Informed and Connected*, (c) *Center Your Child's Choices and Feelings*, and (d) *Disrupt Systems of Oppression*. These findings suggest that sources of influence in the lives of intersex children and adolescents, especially caregivers, work to break the silence around intersex topics, seek education about intersex issues, connect to resources, center the child's feelings and choices, and disrupt systems of oppression that harm intersex individuals.

“Support the shit out of them:” Intersex emerging adults’ socialization experiences and recommendations for caregivers of an intersex child

by

Shelby Astle

B.S., Brigham Young University, 2017
M.S., Kansas State University, 2020

A DISSERTATION

submitted in partial fulfillment of the requirements for the degree

DOCTOR OF PHILOSOPHY

Department of Applied Human Science
College of Health and Human Sciences

KANSAS STATE UNIVERSITY
Manhattan, Kansas

2023

Approved by:

Co-Major Professor
Michelle Toews

Approved by:

Co-Major Professor
Kristin Anders

Copyright

© Shelby Astle 2023.

Abstract

Caregivers can play a key role in helping intersex children face a world in which intersex issues are often misunderstood, pathologized, and stigmatized. However, there is a dearth of literature centering intersex individuals' perspectives, experiences, and needs. In order to aid caregivers in becoming more positive socialization influences for their intersex children, we aimed to (a) highlight commonly shared socialization experiences of intersex individuals across childhood and adolescence and (b) provide recommendations for caregivers of an intersex child based on these experiences. Guided by critical intersex studies (Holmes, 2009) and social cognitive theory (Bandura, 1986), I conducted interviews with 28 emerging adults (ages 18-29) who identified as intersex and/or have a variation in sex characteristics. Using thematic analysis to analyze these interviews, the coding team identified six themes of key socialization experiences that contributed to these intersex emerging adults' meaning-making around having an intersex variation growing up: (a) *We Don't Talk About This*, (b) *We're All In The Dark*, (c) *We Could Use Some Help*, (d) *I Should Be Less Me*, (e) *My Body Isn't Mine*, and (f) *I Feel Supported and Empowered*. Based on these experiences, the sample of intersex emerging adults provided recommendations for caregivers of an intersex child, which the coding team summarized in four themes: (a) *Make it Okay to Talk About*, (b) *Get Informed and Connected*, (c) *Center Your Child's Choices and Feelings*, and (d) *Disrupt Systems of Oppression*. These findings suggest that sources of influence in the lives of intersex children and adolescents, especially caregivers, work to break the silence around intersex topics, seek education about intersex issues, connect to resources, center the child's feelings and choices, and disrupt systems of oppression that harm intersex individuals.

Table of Contents

List of Tables	vii
Acknowledgements	viii
Chapter 1 - Introduction	1
Chapter 2 - Review of Literature	5
Chapter 3 - Method	18
Chapter 4 - Results	30
Chapter 5 - Discussion	74
References	85
Appendix A - Introductory Survey and Informed Consent	94
Appendix B - Interview Protocol	108

List of Tables

Table 1. Participant Demographics	27
Table 2. Themes of Key Socialization Experiences	59
Table 3. Themes of Recommendations for Caregivers.....	72

Acknowledgements

A huge thank you to our partner interACT for your invaluable input and assistance in the design, recruitment, and execution of this project. Another huge thank you to the 28 intersex young adults who shared their life stories with me. Thank you for your honesty, bravery, and vulnerability.

Chapter 1 - Introduction

Approximately 1-2% of people born in the U.S. are intersex, a term used to describe individuals with any combination of chromosomes, anatomy, gonads, hormones, and/or secondary sex characteristics that does not fit into the binary male or female biological sexes (Blackless et al., 2000). Some common intersex variations include congenital adrenal hyperplasia (CAH), complete androgen insensitivity (CAIS), and Klinefelter's (interACT, 2016b). For intersex children born with ambiguous genitalia, as high as 95% receive surgery, often before the age of two, to "normalize" their genital appearance to fit into societal norms of binary sexes (Nokoff et al., 2016). Caregivers often agree to these surgeries due to advice or pressure from medical professionals when the child is far too young to consent (Zeiler & Wickström, 2009) without understanding the negative emotional, psychological, relational, and physical consequences of these surgeries in emerging adulthood and beyond (interACT, 2017; Minto et al., 2003). With or without surgery, intersex individuals also face stigmatization and minority stress from an interphobic world that continues to socialize biological sex as solely binary, including pressure from doctors to accept surgery or hormone treatments to alter their physical appearance, difficulty obtaining legal documents that reflect their true sex, or even abandonment and violence (Open Society Foundations, 2019). Further, intersex individuals are often forced to take on a gender identity chosen for them by caregivers or medical professionals and are pressured to perform that gender rather than being allowed to identify and express their own gender identity (Jones et al., 2016). Many intersex individuals report psychological and physical trauma from enduring these events (Human Rights Watch, 2017; Preves, 2003). As posited by queer theory (Morland & Willox, 2017), labeling and categorizing sex and gender as

binary in this way can lead to stigmatizing socialization that negatively affects the well-being of those who fall outside of these binaries.

Caregivers can play a key role in helping intersex children face a world in which intersex issues are often misunderstood and pathologized. Through both implicit and explicit communication, caregivers significantly contribute to a child's understanding of issues related to sex, bodies, and gender (Kim & Ward, 2007). For intersex individuals, caregivers may send messages about sex as binary or non-binary, convey discomfort or acceptance around variations in sex characteristics or non-binary gender expression, are likely present if doctors discuss intersex-related issues during check-ups in childhood and adolescence, and may have been involved in making decisions about genital surgeries in infancy that require likely explanations later in life (Jones et al., 2016; Preves, 2002; Zeiler & Wickström, 2009). Across these contexts and many more, caregivers have the chance to provide open, honest, and supportive information to their children that can help them develop a positive self-concept and identity. Supportive and affirming messages from caregivers are especially crucial for intersex individuals, a population who experience suicidal ideation and thoughts of self-harm at rates much higher than the general public due to discrimination, stigma, and feelings of isolation (Jones et al., 2016). Improving the quality of caregiver support for intersex children can likely help intersex individuals navigate socialization experiences in a binary world and reject interphobic and hetero/cis/endonormative messaging from other sources (e.g., peers, doctors, extended family).

Despite the potential to provide positive messaging around intersex topics, many caregivers struggle with understanding intersex (Davis, 2015; Gough et al., 2008; Pasterski et al., 2014; Zeiler & Wickström, 2009) and queer topics in general (Newcomb et al., 2018), often communicating hetero/cis/endonormativity intentionally or unintentionally (Flores et al., 2019;

Martin, 2009; Solebello & Elliott, 2011). Caregivers may need guidance on how to provide positive messaging to their intersex children, as evidenced by research highlighting the perceived negative effects of caregivers' messages on intersex children's identity development (Jones et al., 2016; Preves, 2003; Steers et al., 2021), a general lack of knowledge of intersex topics, and lack of parent-child communication about intersex topics (Davis, 2015; Gough et al., 2008). In addition to a lack knowledge of intersex topics in general (Davis, 2015; Gough et al., 2008), caregivers likely have an even more limited understanding of the socialization experiences that their child may encounter growing up intersex. These barriers prevent caregivers from engaging in caregiver-child communication that can help intersex children develop positive meaning-making about their bodies and identities.

In order to aid caregivers in becoming more positive socialization influences for their intersex children, in this study we aimed to (a) highlight commonly shared socialization experiences of intersex individuals across childhood and adolescence and (b) provide recommendations for caregivers of an intersex child based on these experiences. Although not all intersex experiences are the same (Holmes, 2009), this information can provide caregivers with an understanding of potential experiences their intersex child may experience/be experiencing and provide caregivers with guidance from intersex young adults' own lives to support their child through these experiences. Guided by critical intersex studies (Holmes, 2009) and social cognitive theory (Bandura, 1986), we sought the voices of 28 intersex emerging adults to better understand their experiences and perspectives on how their caregivers discussed intersex-related topics with them, how this communication could have been improved, and perceptions of how it has affected them in emerging adulthood. As discussed in the next chapter, strengths of this study include using a U.S. sample of emerging adults with an intersex variation, utilizing

reflexive thematic analysis to allow for a rich and in-depth analysis of the data (Braun & Clarke, 2022), soliciting direct recommendations for caregivers of an intersex child, and exploring intersex emerging adults' past socialization experiences with a wide array of sources in their lives growing up (e.g., caregivers, extended family, peers/friends, romantic/sexual partners, medical professionals, teachers, coaches, religious leaders).

Specifically, we aim to answer the following research questions:

RQ1: As reported by intersex emerging adults, what were key socialization experiences in developing meaning-making around having an intersex variation growing up?

RQ2: Based on these key socialization experiences, what recommendations do intersex emerging adults have for caregivers of an intersex child?

Chapter 2 - Review of Literature

Theoretical Frameworks

Critical Intersex Studies

In this study, we utilize the definition of intersex provided by interACT (2016b): “Intersex is an umbrella term for unique variations in reproductive or sex anatomy, compared to the two usual paths of human sex development” (para. 3). This includes over 30 distinct medical terms for combinations of intersex variations that may appear in hormones, chromosomes, genitals, or internal organs (see interACT, 2016b and Randjelovic, 2017 for reviews of common intersex variations). Although others have utilized terms such as “disorders of sexual development,” we opt to use the terms “intersex,” “intersex variations,” and “intersex traits” as they are less stigmatizing and pathologizing and are preferred by intersex advocacy groups (interACT, 2016a) and one sample of Australians with intersex variations (Jones et al., 2016). We acknowledge that this terminology is an umbrella term associated with multiple meanings as each individual with intersex traits has their own unique story and labels that fit best for them.

In order to acknowledge and celebrate the diversity of intersex individuals, we utilize a critical intersex studies perspective (Holmes, 2009) which draws on queer theory (Morland & Willox, 2017) and critical disability studies (Malatino, 2019). This perspective (a) views the notion of binary biological sex as a social construction that does not reflect reality, (b) rejects the notion that intersex bodies are abnormal and require intervention, (c) prioritizes bodily autonomy, (d) celebrates bodily diversity, (e) seeks to amplify the voices of intersex individuals, and (f) acknowledges the plurality of the intersex experience. Specifically, this perspective views intersex as “not one but many sites of contested being, temporally sutured to biomedical, political and social imperatives in play in each moment” (Holmes, 2009, p. 2).

Situated within queer theory and a critical intersex perspective (Holmes, 2009; Morland & Willox, 2017), we utilize various terms throughout this paper to describe larger cultural forces affecting intersex people. First, adopting the term from SOAS University of London (2022) and adapting the definition from LGBTQ+ Primary Hub (2022), we use the term hetero/cis/endonormativity to describe discourse based on the assumption that being heterosexual, cisgender, and endosex is the norm and privileges this over any other form of sexual orientation, gender, and biological sex. Hetero/cis/endonormativity includes the assumption that (a) gender expression, gender identity, gender roles, sexual orientation, and biological sex should align and that (b) heterosexual marriage and reproduction are normative and ideal. Next, interphobia is a term that “is characterized by a dismissive attitude and negative feelings towards intersex and intersex people. The phobia manifests itself as contempt, prejudice, hatred or antipathy” (Thisisintersex.org, 2023; para. 1). Queerphobia includes interphobia but is more expansive by capturing sexual orientation and gender, defined as the “irrational hatred and fear of LGBTQIA+ people” (definition adapted from UCSF Lesbian, Gay, Bisexual, and Transgender Resource Center, 2023. para. 16). As intersex experiences are intersectional (Wolff et al., 2022), we note that many intersex individuals also experience discrimination from other systems of oppression (e.g., classism, racism, ableism, fatphobia, xenophobia, etc.), although we do not define these terms here.

Social Cognitive Theory

Social cognitive theory posits that we make meaning of the world and our place in it by observing others (Bandura, 1986). We learn most from observations modeled by someone proximal to us (Bandura, 1986), making the implicit and explicit messages that caregivers send about bodies, identity, worth, and roles very powerful. For intersex individuals, each social

interaction related to intersex variations or identity provides information which is then aggregated to help them formulate meaning surrounding their intersex identity, body, and place in society. This includes direct messages about intersex-related topics, but also indirect messages such as observations of others' emotional responses to their intersex variation (MacKenzie et al., 2009), hetero/cis/endonormative pressure from medical professionals (Alderson et al., 2004), caregivers' compliance with doctor's recommendations (Human Rights Watch, 2017), peers' acceptance or rejection of intersex bodies and identities (Davis, 2015), and caregivers' discouragement or encouragement of future life choices (e.g., discouraging intimate relationships; Jones et al., 2016). These direct and indirect messages from various sources in an individual's life are accumulated to develop meaning-making around having an intersex variation, whether positive, neutral, or negative.

Young people enter emerging adulthood (life stage between 18-29 years old; Arnett, 2014) with an understanding of the world based on an accumulation of messages they have obtained from a plethora of sources across childhood and adolescence (Bandura, 1986). For many, this period of life involves examining their understanding of the world and reassessing the messages they have received in earlier life, making emerging adulthood an ideal time to explore intersex individuals' understanding of the socialization they received earlier in life.

Literature Review

Key Socialization Experiences about Being Intersex

Multiple socializing agents contribute to intersex children's meaning-making around having an intersex variation, including caregivers, family members, peers/friends, partners, medical professionals, and other influential adults (e.g., teachers, coaches, religious leaders). Key socialization experiences with these people help intersex individuals make sense of what it

means to have an intersex variation, whether in negative or positive ways. Understanding these key socialization experiences with various sources can help us better inform caregivers about potential messages their intersex children may be internalizing, although we emphasize the plurality of intersex experiences (i.e., not all intersex experiences are the same). With this information, caregivers can likely be better prepared to intervene and provide positive messaging for their intersex children.

Negative Meaning-Making. The messages that caregivers send to children about being intersex are especially crucial as parents are often the first ones to tell their children about having an intersex variation (Jones et al., 2016). For example, in a study of 272 intersex individuals from Australia, most participants were first told about their intersex variation by a parent/caregiver, most commonly their mother (Jones et al., 2016). Participants reported that these conversations typically involved inadequate information with little or no follow-up (Jones et al., 2016). Some participants expressed that even as an adult their parents still did not understand their intersex variation (Jones et al., 2016), a finding consistent with reports from caregivers of an intersex child who felt very confused, isolated, traumatized, and emotionally unprepared to understand what was happening to their child (Davis, 2015; Gough et al., 2008; Pasterski et al., 2014; Zeiler & Wickström, 2009). In the same study, almost half of participants (48%) reported feeling “bad” or “very bad” about being intersex when they first found out (Jones et al., 2016) and attributed these feelings to the negative attitudes and emotions conveyed both implicitly and explicitly by adults.

Similarly, in qualitative interviews with 37 intersex individuals in the U.S. and Canada, participants reported that caregivers were evasive or silent about their intersex variation even when directly asked about it (Preves, 2003). This culture of silence with immediate and extended

family members, as well as medical professionals, contributed to intersex individuals' feelings of "agony," feeling like a "freak" or "monster," believing that no one would love them, and a general sense of confusion and fear around their body and identity (Alderson et al., 2004; Jones et al., 2016; Lampalzer et al., 2021, p. 477; Lundberg et al., 2021; MacKenzie et al., 2009; Preves, 2003, p. 4). These feelings of shame have been consistently reported by intersex individuals in various studies (Alderson et al., 2004; Human Rights Watch, 2017; Jones et al., 2016; MacKenzie et al., 2009; Preves, 2003). In addition to this cultural silence around intersex, peers' and partners' negative responses to participants' disclosing their intersex variation contributed to feeling shame and fear of rejection, causing them to avoid or be more cautious of telling others (Lundberg et al., 2021).

In many reported cases, medical professionals contributed to these feelings of shame by operating under a hetero/cis/endonormative essentialist lens which views intersex variations as abnormalities that need to be fixed to conform to social constructs of gender/sex/sexuality (Davis, 2015; Roen & Hegarty, 2018). This often contributes to medical professionals' concealment of information and recommendations for surgery to alter genitals or remove gonads and/or other treatments to "normalize" secondary sex characteristics, often communicated to caregivers and intersex children using pressure, concealment, and scare tactics (Alderson et al., 2004; Davis, 2015; Lampalzer et al., 2021; Roen & Hegarty, 2018). Intersex individuals often described interactions with medical professionals as negative, embarrassing, uncomfortable, and hetero/cis/endonormative, leaving them with inadequate information about their intersex variation or treatment (Alderson et al., 2004; Jones et al., 2016).

Caregivers and medical professionals often communicated hetero/cis/endonormative messages about gender roles and expectations either implicitly or explicitly (e.g., sex is for

pleasing men, you should present in a feminine way; Human Rights Watch, 2017; Jones et al., 2016; MacKenzie et al., 2009). These messages contributed to intersex children's need to monitor their behavior and conform to traditional gender roles and expression (MacKenzie, 2009; Preves, 2003). Comparison to peers and bullying further made intersex individuals aware of their difference and need to cope with being outside the norm (Lampalzer et al., 2021), often by withdrawing from social situations, avoiding disclosing to others their intersex variation, and/or actively working to perform expected gender roles (e.g., lying about having a period, dressing in feminine ways; Lundberg et al., 2021; MacKenzie et al., 2009). Intersex individuals also reported suppressing parts of themselves to spare others. For example, in qualitative interviews of women with androgen insensitivity syndrome (AIS; a common intersex variation; Randjelovic, 2017) in the United Kingdom, participants expressed a desire to talk to caregivers so caregivers could provide empathy and understanding but reported difficulties having these conversations because they wanted to avoid causing parents emotional pain (e.g., making mother feel guilty for passing on AIS to her child; Alderson, 2004). Our study expands on this existing literature by exploring whether these negative experiences reported by intersex individuals in other samples are common among a larger sample of U.S. intersex emerging adults.

Positive Meaning-Making. Socializing agents also have the potential to communicate positive messages about being intersex in the face of a larger interphobic cultural context. In the Jones et al. (2016) study mentioned previously, participants reported they were most likely to have received support and positive responses from a friend, partner, sister, or mother. Similarly, Alderson et al. (2004) reported that family members, partners, and friends provided practical and emotional support that medical professionals were not in a place to provide. Other intersex individuals also cited mental health professionals as well as intersex figures in public spaces and

support groups as important sources of support in navigating intersex-related challenges (Alderson et al., 2004; Lampalzer et al., 2021; MacKenzie et al., 2009). This support was crucial to developing acceptance and pride in being intersex (Jones et al., 2016; MacKenzie et al., 2009; Preves, 2003).

Multiple participants reported they looked to their families for protection and support. For these participants, families were emotionally supportive, accepting, affirming, and fiercely defensive of them if someone made a discriminatory or negative comment about their intersex variation (Davis, 2015; Jones et al., 2016). In a New Zealand sample, intersex individuals reported they initially placed trust in their caregivers to support them and that this trust was strengthened when they had good communication about their intersex variation (Steers et al., 2021). These participants also reported they were strongly affected by how their caregivers responded to learning about their child's intersex variation: "If parents expressed acceptance and unconditional love and framed their child's [intersex variation] as simply being a part of who they were, young people typically felt a sense of acceptance, although this was not always immediate" (Steers et al., 2021, p. 463).

Intersex peers also helped intersex individuals feel less alone, better understood, educated, and empowered and were overall positive socializing agents (Alderson et al., 2004; Jones et al., 2016; Lampalzer et al., 2021; Lundberg et al., 2021; MacKenzie, 2009). In fact, in a study conducted by Davis (2015), nearly all intersex participants expressed the importance of connecting with other intersex people due to positive effects of this peer support. Some intersex individuals also specifically reported positive support from endosex partners and friends in helping them develop self-acceptance (Lundberg et al., 2021; MacKenzie, 2009). Unfortunately, positive socialization experiences with caregivers and endosex peers were less commonly

reported compared to negative socialization experiences across the available literature.. Our study seeks to better understand the positive experiences of meaning-making that have not been thoroughly explored in previous literature in order to provide caregivers of an intersex child with information on what their child may be going through and ideas for how to provide support that is viewed positively.

Effects of Socialization Past Childhood and Adolescence

Many intersex individuals have reported their perceptions of how their key socialization experiences during childhood and adolescence negatively affected their well-being into adulthood (Frank, 2018; Human Rights Watch, 2017; Jones et al., 2016; Lampalzer et al., 2021; Minto et al., 2003; Preves, 2003). Samples of intersex individuals have reported experiencing trauma responses such as dissociation, hypervigilance, avoidance, and difficulty trusting others due to various socialization experiences growing up (Frank, 2018; Human Rights Watch, 2017; Lampalzer et al., 2021; Preves, 2003). One intersex participant shared how it was difficult to be vulnerable with others because of the way their family had subjected them to harmful medical treatments (Human Rights Watch, 2017). Unfortunately, many intersex individuals expressed low self-worth based on their inability to meet society's expectations of sexual and gender performance based on their assigned sex (Frank, 2018), a reflection of hetero/cis/endonormative expectations often communicated by caregivers and medical professionals (Jones et al., 2016; Steers et al., 2021). Many intersex individuals were operated on non-consensually, leaving them to deal with the emotional and physical consequences of these surgeries (e.g., grief, confusion, regret, anxiety, PTSD, dysphoria, life-threatening complications) and the trauma of having no choice in what happened to their bodies (Davis, 2015; Jones et al., 2016).

Specific to sexual behavior, 65% of intersex individuals in one sample reported their desire or ability to engage in sexual activity was impacted by their intersex variation or related treatments with 14% of the sample saying they were unsure or that this varied (Jones et al., 2016). These individuals most commonly reported negative impacts of their intersex variation or related treatments on physical aspects (e.g., lower libido, decreased sensitivity, impaired genital function) and psychological aspects of their lives (e.g., shame, low confidence and self-esteem, fear and worry around engaging in sex; Jones et al., 2016). Participants reported that feelings of abnormality and shame (often exacerbated by caregiver messages; Steers et al., 2021) caused them to avoid sexual interactions so others would not discover their intersex variation, have sex frequently as a way to prove they were “normal,” and/or assume that people with intersex variations simply did not have sex (Human Rights Watch, 2017; Preves, 2003).

Despite the negative impacts of stigmatizing socialization reported by intersex individuals, many developed a positive self-concept by deconstructing and rejecting what society told them was normal and valued. Accepting their intersex variation and celebrating their body without judgment allowed many to find freedom of sexual expression and increased self-confidence after years of isolation and shame (Preves, 2003). In the words of an intersex woman from Australia (Jones et al., 2016): “Nobody looks like the ideal, we’re all a bit hairy, a bit pokey; at least I can enjoy what I have” (p. 112). Participants acknowledged how support from family, friends, professionals, intersex peers, and educational resources helped them make sense of and find acceptance and pride in their intersex identity (Davis, 2015; Lundberg et al., 2021; Mackenzie et al., 2009; Preves, 2003). As this support was crucial for many intersex individuals’ long-term well-being, we aim to better understand specific ways in which caregivers can be

positive influences in their intersex children's journeys of identity development and self-acceptance amidst various socialization messages and experiences.

Recommendations for Caregivers of an Intersex Child

Although a plethora of sources contribute to intersex children's meaning-making around having an intersex variation, caregivers play a unique role as primary socializing agents. Caregivers may be some of the only people who know about their child's intersex variation, are often the first ones to disclose this information to their children (Jones et al., 2016; Lundberg et al., 2021), and can help children navigate interactions with other socializing agents in their lives. Therefore, in this paper, we focus on exploring ways in which caregivers can intervene to provide positive messaging for their intersex children as they navigate various socialization influences and messaging.

Although the authors could find no comprehensive studies that directly addressed what intersex individuals wished their caregivers had communicated with them, of the available literature, we found themes of desires for normalizing messages, open communication, and adult support. Across studies, many intersex individuals expressed desires to feel normal despite the messages from medical professionals that they were not (Alderson et al., 2004; Frank, 2018; Human Rights Watch, 2017; Jones et al., 2016; Preves et al., 2003). Caregivers can be a source of these desired normalizing messages that combat shame (Lampalzer et al., 2021), as one intersex participant's family told her, "I was natural, nothing wrong with me" (Jones et al., 2016, p. 159). In interviews with intersex adolescents and emerging adults in Europe, participants expressed their desires for others to validate their feelings and experiences and to avoid stigmatizing, negative, exotifying, and over conciliatory messages when discussing their intersex identity (Lundberg et al., 2021). This includes prioritizing intersex children's desires for their

bodies and not conducting surgery without the child's consent in non-life-threatening situations (Lampalzer et al., 2021; MacKenzie et al., 2009).

Parental silence around intersex variations only increased feelings of shame, self-blame, fear, inadequacy, and otherness (Human Rights Watch, 2017; Jones et al., 2016; MacKenzie et al., 2009; Preves, 2003). Rather than silence, intersex individuals expressed desires for open discussion about being intersex and praised parents who were open in having these conversations (Jones et al., 2016), although they also stressed the importance of respecting the child's privacy and right to choose when to disclose their intersex variation to others (Lampalzer et al., 2021). In interviews with intersex adults, many participants shared stories from their childhood or adolescence when they needed caregiver support and did not receive it (Jones et al., 2016; Preves, 2003). For example, because of feeling inadequate due to her inability to urinate standing up, one participant assigned male at birth regularly wet her pants at school rather than use the public restroom (Preves, 2003). Some even experienced forms of violence due to their intersex variation; a few individuals reported being physically hit by their caregivers as a means to increase their masculinity and discourage femininity (Jones et al., 2016). This research demonstrates a lack of support, or even maltreatment, by important adults rather than the supportive socialization that intersex individuals desired from their caregivers (Jones et al., 2016).

The Present Study

As most intersex research has focused on biomedical and physiological topics within clinical frames, we have an extreme dearth of knowledge about the experiences of intersex individuals. Research that gives intersex people a voice remains even more rare (Hegarty & Smith et al., 2021; Jones et al., 2016). This dearth only contributes to the silence, shame, and

lack of awareness that harms individuals with intersex variations (Hegarty & Smith, 2021; Human Rights Watch, 2017; Jones et al., 2016; MacKenzie et al., 2009; Preves, 2003). We answer the call for research that utilizes intersex-only samples and aims to “understand [intersex] individuals’ views on their own experiences in more depth” (Jones et al., 2016, p. 29). Specifically, in this study we sought to understand intersex individuals’ key socialization experiences that informed their meaning-making surrounding intersex-related topics growing up and the perceived influence of these experiences. This understanding, accompanied by explicit recommendations from intersex emerging adults, can provide guidance for caregivers on how to best provide support for their intersex children as they navigate various socialization influences and the internalized messages from these sources throughout their life.

Our study contributes to the existing literature we have reviewed in multiple ways. First, by limiting our sample to intersex emerging adults in the U.S., we provide insight into the experience of U.S. intersex individuals as most available studies on the experiences of intersex individuals have been conducted in Europe, Australia, and New Zealand. It is important to give this attention to intersex emerging adults in the U.S. specifically as the U.S. is more religious, sexually conservative, and less accepting of queer identities than other industrialized countries in which intersex individuals’ experiences have been examined previously (Pew Research Center, 2014; 2018). The authors found only two studies which explored intersex individuals’ experiences using solely U.S. samples (Davis, 2015; Human Rights Watch, 2017). Second, utilizing a solely emerging adult sample (a) captures the perspectives of intersex individuals not far removed from their childhood and adolescence when they began to develop meaning-making surrounding their intersex variation and (b) provides insight into the socialization experiences of a younger generation who experienced childhood and adolescence in more recent years. Third,

we explore intersex emerging adults' past socialization experiences with a wide array of sources, including caregivers, extended family, peers/friends, romantic/sexual partners, medical professionals, and other influential adults (e.g., teachers, coaches, religious leaders). This provides a more expansive view of how various people contribute to intersex individuals' meaning-making surrounding their intersex variation. Fourth, although medical intervention and intersex individuals' experiences of maltreatment and abuse from the medical industry is a crucial topic of study and advocacy (e.g., Cannoot, 2021; Human Rights Watch, 2017; Minto et al., 2003; Zeiler & Wickström, 2009), we expand the focus of our study to explore the whole of participants' socialization experiences not limited to interactions with medical professionals. Last, we specifically solicit recommendations for caregivers raising intersex children. Although extremely helpful guides for caregivers have been developed by intersex advocacy organizations (e.g., IGLYO et al., n.d.), our study contributes the recommendations of U.S. intersex emerging adults to the on-going discourse around how to best parent intersex children.

Guided by queer theory with a critical intersex perspective (Holmes, 2009) and social cognitive thought (Bandura, 1986), we used reflexive thematic analysis (Braun & Clarke, 2022) to explore the understudied experiences and perspectives of intersex emerging adults.

Specifically, we aimed to answer the following research questions in a sample of 28 intersex emerging adults in the U.S.:

RQ1: As reported by intersex emerging adults, what were key socialization experiences in developing meaning-making around having an intersex variation growing up?

RQ2: Based on these key socialization experiences, what recommendations do intersex emerging adults have for caregivers of an intersex child?

Chapter 3 - Method

Research Team Positionality Statement

As (a) the positionality and cultural background of researchers inform research design and interpretation of data (Milner, 2007) and (b) our chosen analytic approach (reflexive thematic analysis) centers around the subjectivity and reflexivity of the researchers involved (Braun & Clarke, 2022), we provide insight into the identities of the research team involved in this project. The primary investigator (S.A.) is a cisgender, heterosexual, endosex White woman in her late 20s from a middle-class background whose research focuses on parent-child sexual communication, sexual self-concept, and the role that systems of oppression play in these processes. As an endosex researcher, she has participated in additional trainings and education to increase her understanding of the contextual and cultural factors that largely affect intersex participants' experiences, including completing graduate level courses in Human Sexuality and Gender, Women, and Sexuality Studies; instructing undergraduate level Human Sexuality courses; completing research compliance training in Gender and Sexuality Diversity in Human Research; and independently studying online toolkits provided by #4intersex (2018) and interACT (e.g., Intersex Language Sensitivity Guide, Guide to Covering Intersex Issues, Ally Do's and Don'ts; n.d.; 2017). The secondary investigator (K.A.) is a cisgender, heterosexual, endosex White U.S. Citizen with a Ph.D. in Child and Family Studies who specializes in researching sexual development in adolescence and young adulthood. The third investigator (K.P.) is a White endosex person whose research focuses on sexual communication and sexual norms.

In addition to these investigators, a paid intersex consultant advised throughout every stage of this project. Including an intersex consultant was crucial to the success of this project as

they (a) allowed us to create connections in the intersex advocacy community, (b) raised issues that would not be apparent to non-intersex researchers, (c) evaluated our measures and method from the perspective of our participants, and (d) helped us make sense of findings in the context of the intersex community. This practice is consistent with a critical intersex studies perspective as it centers the voices of the intersex community throughout the design of the project (Holmes, 2009).

Participants

Following IRB approval, 28 intersex emerging adults were recruited to participate in virtual qualitative interviews through social media, snowball sampling, and various existing intersex support groups and networks, both nationally (e.g., interConnect, the Intersex Justice Project, IGLYO, interACT) and locally (e.g., PFLAG Kansas City). Although thematic analysis intentionally does not prescribe adequate sample sizes (Braun & Clarke, 2022), we believe this sample size is appropriate as it meets minimum recommendations for qualitative interviews (Creswell & Poth, 2018) and is in line with sample sizes of similar qualitative research (Mason, 2010). In order to participate, individuals had to (a) identify as intersex or have an intersex variation, (b) be between 18-29 years old, (c) speak English, (d) live in the U.S., and (e) experience effects or symptoms of their intersex variation before age 18. The final criterion allowed us to explore participants' socialization experiences and meaning-making in childhood and/or adolescence. Each participant was compensated \$25 for participating in a 60-90-minute interview conducted via an online video conferencing service (zoom.us). Because participants were taking a risk by disclosing personal information on sensitive and perhaps painful topics to an endosex researcher whom they did not know, we chose this dollar amount to ensure they were being paid fairly and above minimum wage for their time and willingness to share.

The final sample consisted of 28 intersex emerging adults between the ages of 20-29 ($M = 24.04$; $SD = 2.75$). The majority of participants identified as White ($n = 24$; 85.71%) followed by Asian American/Pacific Islander ($n = 3$; 10.71%), other ($n = 3$; 10.71%), and Native American/American Indian ($n = 2$; 7.14%). Five participants identified as Latine (17.86%). The largest portion of participants reported their sexual orientation as bisexual ($n = 9$; 32.14%), followed by queer ($n = 7$; 25.00%), gay/lesbian ($n = 6$; 21.43%), pansexual ($n = 4$; 14.29%), asexual ($n = 2$; 7.14%), and straight ($n = 2$; 7.14%). The largest portion of participants reported their gender as woman/female ($n = 9$; 32.14%), followed by non-binary ($n = 5$; 17.86%), man/male ($n = 4$; 14.29%), transgender ($n = 4$; 14.29%), genderfluid ($n = 3$; 10.71%), femme ($n = 2$; 7.14%), queer ($n = 2$; 7.14%), intergender ($n = 1$; 3.57%), and agender ($n = 1$; 3.57%). See Table 1 for full demographic details with descriptions in participants' own words.

The largest number of participants found out they were intersex between 12-15 years old ($n = 12$; 42.86%), followed by 16-18 years old ($n = 6$, 21.43%), 6-11 years old ($n = 6$, 21.43%), 0-5 years old ($n = 3$; 10.71%), and 19 years old or older ($n = 1$; 3.57%). Only three participants had a parent, primary caregiver, or important adult in their life growing up who was also intersex or had a variation in sex characteristics (10.71%). Most participants were either currently engaged with intersex advocacy groups or participating directly in some form of intersex advocacy ($n = 18$; 64.29%).

Procedure

Advertisements for the study sent via email or posted on social media included a QR code and link that opened to the landing page of the introductory survey in Qualtrics. This page included details about the study's goals, procedure, and primary investigator. After reviewing this content, those who chose to continue were provided with the informed consent form. Those

who gave informed consent were then directed to questions that ensured participants met the inclusion criteria and asked for demographic information (e.g., age, gender). If they did not meet inclusion criteria, they were sent to the end of the survey with an explanation of why they could not be included at this time. In addition to demographic information, eligible participants were asked to answer questions about their sexual self-concept and race/ethnicity that were referenced later in the interview. Participants were also given the opportunity to select a pseudonym we would use when reporting study results and provide contact information we could use to schedule the interview (email) and contact them in case of technical difficulties during the interview (phone number). At the end of the survey, participants were directed to an outside platform (calendly.com) where they could indicate their availability for the interview. The primary investigator then reached out via email to officially schedule a time and date for the interview and provide the participant with the link to join the online video meeting. Participants were contacted one more time via email before the interview to confirm the appointment.

Interviews were conducted by the lead investigator via online video conferencing between May and September 2022. Interviews lasted approximately 60-90 minutes. Participants were welcomed into the online video meeting and provided with introductory information on study procedures and logistics (see Appendix II). With participant consent, interview audio and video were recorded using the online video conferencing software. Because the primary investigator who conducted the interviews does not share an intersex identity with the participants, additional steps were taken to establish trust and rapport with participants and maximize their comfort while participating in the interview. First, we recruited participants through intersex organizations that were willing to show public support for our project (e.g., interACT). Second, we created materials that were posted on the landing page of the introductory

survey that features both the primary investigator and the paid intersex consultant's organization. In these materials, we provided transparent information about why we were conducting this research and how participation of intersex individuals was helpful (DeJonckheere & Vaughn, 2019). We believe that establishing and displaying support from intersex organizations and the intersex consultant helped increase the amount of trust participants brought with them into the interview.

During the interview, the primary investigator engaged in other behaviors to enhance trust and rapport, such as beginning with an introduction of herself and the study's goals and procedures, acknowledging the sensitive nature of the topic, utilizing a relational focus, using a warm and conversational tone, engaging in attentive and nonjudgmental listening, avoiding jargon, encouraging iterative interactions, audio recording the interview, and demonstrating respect for the participants' perspectives and lived experiences (DeJonckheere & Vaughn, 2019; Josselson, 2013). In order to maximize data quality, the primary investigator also used probing techniques (e.g., echo probe, tell-me-more probe; Bernard, 2000), engaged in member checking throughout the interview (Creswell & Poth, 2018), and recorded memos during and immediately after the interview (Birks et al., 2008).

Per recommendations from Seitz (2016), additional steps were taken to ensure the quality of interviews specific to the online video conferencing format. First, in the email confirming the participant's interview time we included recommendations for a more successful interview, including (a) securing a private and quiet location free of distractions, (b) testing out Internet connectivity prior to the interview, (c) and ensuring their device was fully charged or plugged in before the interview. Second, before the interview began, the primary investigator confirmed the participant's phone number and explained that if Internet connectivity failed and prevented the

continuation of the interview via Zoom, she would call that phone number from a Google Voice account in order to continue the interview. The primary investigator also explained that she was happy to repeat questions if the participant did not hear and that it might be necessary for her to ask the participant to repeat questions if the audio lagged.

After the completion of the interview, participants were sent a \$25 gift card via Giftogram.com to the email they used to communicate with the primary investigator. Interview recordings were transcribed by GoTranscript.com. These transcripts were then quality checked against the audio recording by the first author to ensure accuracy before data analysis began.

Measures

Introductory Survey

Demographics and Survey Logistics. Participants were asked to enter their name, gender identity, pronouns, sexual orientation, and what made them intersex using text entry boxes. They were also asked to select their age, country of residence, fluent languages, race, ethnicity, and age when they learned they were intersex from a list of options. Participants were provided with a text entry box to enter their preferred pseudonym (if applicable), email address, phone number, and any questions or concerns about participating in the survey.

Sexual Self-Concept. Nine items from *The Multidimensional Sexual Self-Concept Questionnaire* were included in the introductory survey (Snell, 1998). Each item comes from one of nine subscales: sexual anxiety, sexual depression, sexual fear, sexual consciousness, sexual self-efficacy, sexual self-esteem, sexual assertiveness, sexual satisfaction, and sexual optimism. These items were included in order to help the participant begin to think about their sexual well-being and were referenced in the interview to help the participant reflect on how being intersex plays a role in their sexual well-being. These items were measured on a 5-point Likert scale from

not at all characteristic of me to very characteristic of me. Example items included: “I am very aware of my sexual feelings and needs,” “I expect that the sexual aspects of my life will be positive and rewarding in the future,” and “I feel discouraged about my sex life.” See Appendix I for the full demographic survey.

Interview

Semi-structured interviews addressed how caregivers discussed intersex issues with the participant, how the participant believes this communication could have been improved, and the perceived effects of this communication on the participant’s sexual well-being. We chose to use the loose and flexible structure of semi-structured interviews to allow room to more deeply explore participants’ experiences that we could not anticipate prior to developing the interview questions while still guiding the participants with questions that focused on the research questions of this study. Following a semi-structured format, the interview protocol included ground tour questions, core questions, and planned follow-up questions, while allowing for unplanned follow-up questions (DeJonckheere & Vaughn, 2019). The first interview protocol draft was designed by the primary investigator based on a plethora of stories from intersex adults (e.g., Green, 2017; interACT, 2021; Lindahl, 2019; The Interface Project, 2019) then reviewed and edited by the secondary investigator. After the primary and secondary investigators finalized the draft, they sought feedback from the project’s hired intersex consultant who reviewed the protocol. The investigators then revised the protocol based on feedback from the consultant. See Appendix II for the completed interview protocol.

Analytic Plan

The primary, secondary, and third investigators analyzed interview data using reflexive thematic analysis (Braun & Clarke, 2022). This approach was appropriate and ideal to achieve

the goals of this study for multiple reasons. First, the flexibility and accessibility of reflexive thematic analysis allowed us to develop a rich and in-depth understanding of the range of experiences, realities, and meanings of intersex individuals' socialization (Braun & Clarke, 2006). This aligns with our social cognitive perspective (Bandura, 1986) which highlights the importance of understanding individuals' meaning-making processes. Second, thematic analysis is ideal for research teams in which not all members are trained researchers (Braun & Clarke, 2012), as was the case in our study because we included an intersex consultant in our analysis process. Third, reflexive thematic analysis allows for subjective storytelling, which is congruent with our experiential orientation that validates participants' perspectives and experiences (Braun & Clarke, 2012). Fourth, as thematic analysis is theoretically flexible (Braun & Clarke, 2022), it allowed us to use a combination of inductive and deductive approaches as we coded from the data with the primary focus being on the participants' experiences while also bringing in (a) our previous knowledge from researching intersex stories prior to interview protocol development, (b) our previous knowledge about parent-child sexual communication research and (c) our preconceived notions based on a critical intersex perspective that reject the concept of essential and binary gender and biological sex (Braun & Clarke, 2012; Holmes, 2009).

The coding team followed the six phases of reflexive thematic analysis as presented by Braun and Clarke (2022): dataset familiarization; data coding; initial theme generation; theme development and review; theme refining, defining, and naming; and writing up. First, we familiarized ourselves with the data by reading and rereading interview transcripts while taking notes on potential items of interest. Second, we generated initial descriptive and interpretive codes relevant to the research questions and created a coding sheet to guide team members as we independently coded interview transcripts. Coding was an iterative process: Team members

independently coded 2-3 assigned interview transcripts and then met to compare codes, resolve discrepancies, and update the coding sheet to better capture the data. This process was repeated until 14 of the 28 total interviews were independently coded by each team member and reviewed by the other two team members. At this point, the remaining 14 interviews were divided and coded independently by one team member. A separate team member then reviewed the original coders' codes to check for agreement with and/or identify missing codes. The coding team then met to further update the coding sheet and resolve any discrepancies. Once all interviews were coded, the research team used the codes to construct initial themes, reviewed potential themes, defined themes, and produced the report of our results.

In order to establish trustworthiness of our findings, we employed suggestions from Lincoln and Guba (1985) and Nowell and colleagues (2017) to demonstrate credibility, transferability, dependability, confirmability, and reflexivity. First, in demonstrating credibility, the primary investigator engaged in member checking throughout the interviews to minimize misinterpretations between the participants and the research team. Second, in this report we provided detailed demographic descriptions of our participants so readers can judge the transferability of our findings to the populations with which they work. Third, to increase dependability and confirmability, we kept records of our methodological, analytical, and theoretical decisions using an audit trail. This included “keeping records of the raw data, field notes, transcripts, and a reflexive journal” (Nowell et al., 2017, p. 30).

Table 1. Participant Demographics

Name	Race	Latine	Gender	Sexual Orientation	Intersex Variation
E	White/Caucasian	No	Intersex femme	Queer	Diagnosis of androgen insensitivity syndrome
Anna	White/Caucasian	No	Female	Straight	Androgen Insensitivity Syndrome. Born with Testes instead of ovaries! And an XY chromosome.
Alex	White/Caucasian	Yes	Woman	Bisexual	Complete Androgen Insensitivity Syndrome
Fern	White/Caucasian	Yes	Non-binary Dyke	Queer/Nonbinary lesbian	Complete Androgen Insensitivity
Sarah B	White/Caucasian	No	Female	Bisexual	I am an XY female with complete androgen sensitivity syndrome. I have no female reproductive organs but do have inner testes.
Jade	White/Caucasian	No	AFAB	Lesbian	Complete Androgen Insensitivity
T	White/Caucasian	No	Nonbinary	Pansexual	CAIS
Alyssa	White/Caucasian	No	Gender fluid	Pansexual	CAIS
NC	White/Caucasian	No	Male	Bisexual	Born with partial androgen insensitivity syndrome and born with ambiguous genitalia, went through roughly 6 surgeries, and take testosterone weekly.
Basil	White/Caucasian	No	Complicated but overall male	Homosexual	Partial androgen insensitivity: vaginal and breast development as a male
BA	White/Caucasian	No	Intersex Woman	Queer	I have congenital adrenal hyperplasia (CAH). In simple terms, my body organically makes more testosterone than “normal” in someone who is assigned female at birth.
Vincent	White/Caucasian	No	Intersex FTM	Gay	Congenital adrenal hyperplasia
Sophia	White/Caucasian	Yes	Intersex Femme	Queer/bisexual	I have nonclassic CAH, so around puberty I started growing facial and body hair, my voice dropped, and I have a larger than average clitoris.

JieSi	White/Caucasian, Asian American/ Pacific Islander	No	Trans nonbinary or genderfluid	Queer	I am PCOS with development of sex characteristics from a young age people associate with masculinity (deep voice, increased body/ facial hair, increased sweating, etc)
Jay	White/Caucasian	No	Agender	Bisexual, preference for men	I'm diagnosed with PCOS but may have a different/multiple conditions (currently talking to various doctors). I have an underdeveloped vagina and always experienced pain and bleeding during PIV sex regardless of arousal or lube. My body shape is masculine - I've always had small hips and carried significant weight around my middle.
Elizabeth	White/Caucasian	No	Intersex woman	Gay/lesbian	I was born with 5-alpha reductase deficiency, similar to androgen insensitivity syndrome. Identified intersex at birth, had surgeries early in life.
Sunleaf	White/Caucasian	No	Transgender and genderqueer	Queer	I have hyperandrogenism. I was born with XX chromosomes, a uterus, and ovaries, but during puberty my body changed in unexpected ways, including by developing significant facial and body hair. I later learned that my Anti-Mullerian Hormone levels are 4 times higher than what would be typical for an endosex woman of my age.
Koko	White/Caucasian	No	Nonbinary	Pansexual	I have Turner Syndrome.
Stevie	White/Caucasian	No	Genderfluid	Bisexual	XX Gonadal Dysgenesis
H	White/Caucasian, Asian American/ Pacific Islander	No	Genderfluid	Bisexual	One ovary, internal teste. PMDD.
Hestia Flynn	White/Caucasian	No	Female	Bisexual	I had a "misshapen and undefined" vaginal opening and had a complete vaginoplasty in high school to treat this.
Ellen Jameson	White/Caucasian	No	Trans woman	Asexual	Hypospadias
October	Native American/ American Indian, Alutiiq and Ashkenazi Jewish + Moldavian	No	Intersex man	Asexual	Was born without a defined clitoris or vagina. Have internal ovaries; never had ability to menstruate so never did. Developed minimal breast tissue, but always produce male levels of testosterone through puberty-to this day. Facial hair, thick body hair, male fat distribution. All secondary sex characteristics are masculine.
Guadalupe	Mexican American	Yes	Woman	Lesbian	Variation in external genitalia and hormone production

Sarah A	Samoan/Mexican	Yes	I'm a woman	Bisexual	I have a population of cells in my body that are XXY while the rest are XX. My doctors refer to it as mosaic Klinefelter's.
Vixie	White/Caucasian, Native American/American Indian	No	I am a girl. I have been struggling with this a lot though, as I was designated male at birth.	Mostly lesbian	I am 46 XX/XY. We think that I am chimeric. I have both sets of reproductive organs internally.
Charlie	White/Caucasian	No	Non-binary	Pansexual	I was born XXY
J	Asian American/Pacific Islander	No	I live as male, but I see myself as intergender (gender is respective to my intersex biology)	Mostly straight, I've only dated women but I'm open minded	Karyotype: 47XXY Y:21 Translocation Reproductive organs: internal testes (not fully certain because only seen via ultrasound), uterus, prostate Suspected additional variation (seeking further medical confirmation): the state of my internal reproductive organs implies there may be undetected mosaicism. Lack of detectable DHT in hormone panel and female appearing genitalia at birth that became ambiguous at puberty suggests 5ARD may be primary phenotypical variation

Note. CAIS = Complete Androgen Insensitivity Syndrome; CAH = Congenital Adrenal Hyperplasia; PCOS = Polycystic Ovary Syndrome; PMDD = Premenstrual Dysphoric Disorder.

Chapter 4 - Results

We intentionally report results of our analysis heavily using quotations from participants in order to ensure we are correctly representing their ideas and amplifying their own words. The names associated with participant quotes were chosen by participants.

Key Socialization Experiences

To answer our first research question, we categorized intersex emerging adult participants' descriptions of key socialization experiences into six themes: (a) *We Don't Talk About This*, (b) *We're All In The Dark*, (c) *We Could Use Some Help*, (d) *I Should Be Less Me*, (e) *My Body Isn't Mine*, and (f) *I Feel Supported And Empowered*. See Table 2 for additional information on these themes.

We Don't Talk About This

Participants experienced silence and lack of communication around their intersex variation and related topics. In many cases, not discussing intersex- or sex-related topics was an implicit and unspoken rule in the family; these conversations were simply not initiated: "We didn't acknowledge it at all to really talk about it" (Sarah A); "My parents so obviously, avoided talking about it. Like when I got home from the surgery and they were like lying to people about where I had been I was like, 'Oh, we're not talking about this'" (Hestia Flynn).

Participants described caregivers' avoidance of the topic due to emotional overwhelm or believing communication was unimportant: "My parents honestly did not tell me too much about that and I think they kind of felt like it either wasn't necessary or was something that just they didn't want to bring up" (Basil). According to participants, caregivers also avoided these conversations as a way to help participants feel "normal": "Sophia is different, but we're not going to really talk about it or let her know she's different because we don't want her to feel that

way” (Sophia). Participants also reported their own avoidance of initiating these conversations with caregivers due to fear of caregivers’ responses (e.g., intervening with school administration when participants were bullied, sending them to therapy, parents’ emotional distress, hetero/cis/endonormative reactions), internalized shame, emotional overwhelm (e.g., this is too distressing to talk about or acknowledge; dissociation as a tool to protect oneself), and not seeing initiating these conversations as helpful or relevant.

Even in family cultures where silence on these topics was the status quo, caregivers at times provided participants very small bits of information or advice (e.g., tell doctors you had a period even if you didn’t) or checked in briefly (e.g., “Do you like girls?” [Guadalupe]). In families where communication was limited, caregivers mostly communicated about logistics such as when they would pick up the participant for a doctor appointment or how to manage medication regimens: “All I was told is ‘We’re going to an appointment to talk about what you were born with.’ It’s like, ‘oh, what-what was I born with?’” (Elizabeth).

Participants especially noted a lack of communication about these topics with their fathers. Mothers typically took the lead on managing logistics and communicating with children about intersex-related topics; this was typically due to the mother already being in the primary caregiving role or because fathers were uncomfortable:

I think for my dad, it was just one of those things where it’s like having his kid of what he, you know, perceived to be the opposite sex like he didn’t wanna discuss or think about any of that... That just would have been really weird to him. He just didn’t want anything to do with that. He looked at my mom and said, “Haaaave fun! [chuckles] That’s your job.” (Koko)

In addition to implicit messages that intersex was a topic not to be discussed, caregivers also directly communicated to children that they should not talk with others about their intersex variation or related topics:

There was a strong implication that like, if this information ever got out, it could be catastrophic for my parents' careers, for my family's reputation, for my future and professional career, and my ability to be able to like, get into college even, or whatever. So, it was like pretty clear that it was just not something that I could talk about to anyone or express to anyone. So I didn't (Alex).

Caregivers told participants to never tell others often due to a desire to protect them from negative social consequences: “My mom was terrified for me and she told me, ‘Do not tell anyone that you are intersex. We are proud of you, but we are scared how other people are gonna react’” (Sarah B). Despite any positive intentions, these messages often made participants feel ashamed and internalize the need to hide how their body was different.

This lack of communication typically carried over to other sources such as peers/friends, extended family, siblings, other influential adults (e.g., teachers), and partners. These sources may have known vague or basic information about participants (e.g., they were missing school to see doctors, they were taking medication, or had had surgery), but did not understand the full picture. For similar reasons as avoiding conversations with caregivers, participants chose not to disclose information to others either to protect themselves and/or their families out of fear of others' reactions or simply because they did not think these people needed to know. To illustrate, one participant said, “My lips were sealed. I was like, ‘This is my deep, dark secret’” (Jade). Similarly, another participant emphasized, “It's not really something that I like feel like I need to share with them. It's just like a part of who I am. So, whatever” (T).

Even though they often had access to information about participants' intersex diagnosis and/or characteristics, medical professionals also contributed to limited communication about intersex topics by concealing information and avoiding conversations with participants and their families: "I talked to my mom recently about this 'cause I was wondering if the doctor had said anything to her and not told me. She was like, 'The doctor didn't say anything to me either.' Like, she kept all of this information from us" (Vincent). Some participants also reported doctors explicitly telling them not to tell others about their intersex variation: "The thing my mom and the doctor told me about was like if people know about this, they're gonna make fun of you" (Charlie).

We're All in the Dark

Participants described a context of confusion, isolation, and lack of adequate resources as they navigated intersex-related characteristics, diagnosis/treatment, and identity growing up. This included a general sense of confusion and unawareness both within themselves and from others around them as they worked to make meaning of having an intersex variation.

Most participants described some form of confusion or fear as they worked to connect the dots or put together the puzzle of their intersex body and related social and identity concerns. Many participants reported that they "always knew something was up" (Alex) with their body based on clues from caregivers, peers, siblings, and educational resources. Participants noted that their bodies looked different than peers or siblings (e.g., scars from previous surgeries, differences in genitalia or secondary sex characteristics) and that their body was not going through the changes described in school puberty lessons (e.g., getting a period, growing hair). Although they understood that they were different somehow, many did not yet have an accurate or full explanation as to how or why. Contributing to their confusion, participants reported a

general lack of understanding and education around “typical” puberty, sex development, anatomy, and physiology, whether specifically related to intersex topics or not.

Without a comprehensive explanation for their experiences, participants came to their own conclusions. For example, J said, “the entire time when I was like a teenager, I genuinely just thought that I had like some kind of like a weird infection that wasn't going away... that's what I thought all my urination issues were.” Participants also relied on peer conversations, messages from the media, and lessons in school and church to shape their conclusions, which could be extremely interphobic and fear-inducing. From these sources, participants got the message that biological sex was binary and that intersex was something abnormal and bad. For example, Stevie shared that before their diagnosis,

The only experience or influence that intersex individuals made an effect on my life were only through celebrity rumors, actually. Just being like, ‘Oh, does this person have a penis and a vagina?’... It seemed like a scary topic to broach and no one ever talked about it. And if it was, it was the butt of a joke. So, when I found out about it, it was like, uh, ‘Oh, God. [chuckles] I'm gonna be subjected to so much humiliation.

Even after receiving an intersex diagnosis, many participants reported feeling confused about what their diagnosis meant and what treatment they actually needed (e.g., What happens if I refuse vaginal dilation? Am I going to die? Do I really need surgery?). This feeling was only exacerbated by medical professionals who concealed information or were incompetent at educating participants and their families about the intersex variation. Many participants emphasized that doctors did not share all the details about participants’ intersex diagnosis, accompanying characteristics, and results of or reasons for their lab work. Multiple participants reported not being given all the information about their ability to become pregnant, their genetic

makeup, and predispositions to other health concerns (e.g., diabetes, Hashimoto's). As one participant described,

[The doctor] just said 'You have PCOS' and like left the room. And I was like, 'Please come back and give me some more information.' She was like, 'Oh yeah, don't get diabetes. And if you wanna get pregnant, like you might need some interventions.' And that was it (Sunleaf).

Many participants also reported medical professionals being extremely uneducated about intersex variations (e.g., "I've never heard of that [quoting doctor]" [Jay]), incapable of diagnosing intersex variations and reading or conducting lab work (e.g., looking for organs in ultrasounds that the participant did not have), ignorant of participants' medical histories (e.g., asking when the participant had a period last when their chart clearly stated they did not have periods), and guilty of gross negligence (e.g., leaving stitches in genitals for almost a decade).

Aside from the medical aspects of their intersex variation, participants also reported confusion around what an intersex diagnosis meant for their identity. In this confusion, participants often conflated intersex and other aspects of their identity such as gender identity, gender expression, sexual orientation, race, and ability. Sarah A, who had been questioning her gender before her intersex diagnosis, shared, "All this also made me think like I'm not trans I'm just sick. Like, 'I'm just sick, I don't want to be a boy, I'm just sick.'" Another participant who was assigned female at birth described,

I didn't feel comfortable like calling myself like lesbian because I was kind of like, well, like I knew deep down, like I was like, I don't look like a girl. [laughs] Like I don't really have the right to call myself one. I'm like live action roleplaying as one (J).

At times, figuring out pieces of their identity was made more difficult by gatekeeping in queer spaces which made participants question whether they really could identify as intersex, whether they would be accepted in the trans community, and whether they would be included and represented in LGBTQ advocacy and support groups. For example, Hestia Flynn described,

“My perspective on like the community that I am a part of, the broader like LGBTQIA+ community, is that intersex is still super misunderstood, super underrepresented... Like the places that people are turning for information, they don't even understand. They're like, ‘Are you-- am I looking in the sexuality department? Like where does this live?’”

Caregivers were often just as unaware, uneducated, and unprepared as their children in navigating intersex issues. From participants’ perspectives, caregivers were worried, scared, uncomfortable, confused, and at times upset, annoyed, and frustrated when navigating their child’s intersex-related issues. Participants reported that caregivers did not understand some level of their intersex experience, including a general unawareness of intersex variations and bodies, “typical” puberty and sex development, and identity topics (e.g., distinction between gender vs. biological sex vs. sexual orientation). Even Hestia Flynn, whose father was in the medical profession, noted: “I don't think [chuckles] at any point in [my parents’] lives, did they encounter the idea of intersex characteristics.” This unawareness caused caregivers to not recognize certain signs that would be important to look into (e.g., extremely painful periods, difficulty urinating) and defer to doctors’ authority and recommendations, assuming that doctors knew what was best for their child.

Many participants expressed that even when parents’ decisions had negative impacts on their lives, they knew parents were just doing their best when they were out of their depth:

I do have like compassion and empathy for that because it's like, you know, [my parents] really just had no fucking idea what to do. They had no idea how to handle it. They trusted the doctors, they trusted the medical professionals around them that they were giving them the right advice and doing the right thing (Alex).

Participants also acknowledged how various competing life stressors impacted caregivers' ability to show up to help participants with intersex-related issues. These stressors included other health issues for participants or family members, death in the family, raising multiple children, financial stress, lack of health insurance, language barriers, demanding work schedules, cultural and religious beliefs, lack of community, immigrant stress, and caregivers' own trauma. For example, Elizabeth shared this perspective from her mother: "I was worried you were gonna die from your eating disorder, I couldn't also talk to you about the intersex stuff. I was afraid. I was worried about your life."

Within this larger context of confusion and unawareness, most participants reported feeling isolated and misunderstood by others and many labeled this as an extremely difficult experience. Participants internalized the belief that they had to handle their intersex variation and related issues on their own due to various reasons. First, participants recognized others' lack of understanding and awareness of intersex and related topics: "Well, if no one's talked about this, then no one probably has answers for it. So, there's just no reason to ask 'cause no one's gonna be able to tell me anyway" (Jay). Second, participants recognized others' inability to understand what participants were going through: "I was like, even if somebody else has nipple hairs, I'm just so hairy. Nobody ever is, has ever in the history of the world been as hairy as me. This is never gonna be relatable" (Sunleaf). Relatedly, due to a lack of intersex representation, participants experienced internalized shame and assumed they were the only one with their

intersex characteristics. Existing in interphobic and hetero/cis/endonormative environments only contributed to participants' feelings of isolation:

I think in those formative years like I reached a conclusion about the world that-that nobody is on your side, or at least nobody was on my side 'cause I was so different from everyone else. And I think that, you know, I wish that that didn't have to be the conclusion that I came to, but-- and I think that like on wider level among intersex people, that is a conclusion that most of us have come to, is that even if your family is okay, right? Like they have limited ability to come to your aid, and frequently most of society is against you and they don't care that you couldn't have helped how like you were born physically. Like all they really care is that you're different and you don't belong (J).

Although less commonly reported, it is worth noting that some participants took their medical care into their own hands after realizing that medical professionals were incompetent or unsafe (e.g., removing stitches at home, buying medical equipment to run their own tests at home). For example, Fern shared,

I didn't go back to see the intersex doctors because I was like, 'I know more than you do.' [chuckles] Like, 'I do the research. I talk to like more intersex people than you do, probably. I know what's up with our biology. I read the NIH studies. Like I know what you're doing.' Like, 'I know. I know what's up.' And so I very much just like, 'I don't need these fuckers.'

We Could Use Some Help

Although not all sources provided the support that participants wanted or needed, reaching out to other sources for emotional or educational support was a shared experience for

the majority of intersex participants. Participants and their families often recognized their need to rely on other sources to help them in their confusion, even if only at a very basic level. This included utilizing external resources such as medical professionals, educational materials, and intersex advocacy and support groups.

Most commonly and at the most basic level, participants and their caregivers looked to medical professionals to make sense of their child's symptoms. Whether out of their own concern or at their child's insistence, at some point most participants' caregivers took them to a doctor to address concerns about their bodies (e.g., delayed puberty, "atypical" secondary sex characteristics). Some participants also noted that their caregivers, usually their mothers, did extra work to connect them with specialists and doctors who would give participants better care and provide them with answers about their intersex variation. This often involved participants visiting doctors multiple times, trying out multiple doctors, and involving additional specialists (e.g., pediatricians, dermatologists, endocrinologists, genetic counselors, urologists, gynecologists) even when these visits required traveling long distances. Mothers also assisted in finding new doctors when participants had negative experiences and wished to change providers. Receiving basic medical information and a diagnosis was labeled as helpful; however, participants made it clear that early diagnosis would not have been helpful if it meant they would be forced to undergo non-consensual surgeries or treatments. For example, J wished he had gotten information about his intersex variation earlier in life, but also expressed, "On the flip side, I know other intersex people who are diagnosed like younger, but then they got non-consensually modified by doctors or non-consensually put into case studies, so I don't know if I like dodged a bullet there" (J).

About half of participants reported their caregivers at least attempted to connect them with other resources outside of medical professionals. Most commonly, this included intersex advocacy and support groups that either parents were a part of or that they encouraged their child to join. Stevie shared, “Looking back on it, definitely, it was very much like, wow, [my mom] put like countless hours and hours of researching, connecting with people on Facebook, and saying, ‘Do you experience this?’ Or like, ‘What were your experiences?’” E shared how their mom encouraged them to attend an intersex conference:

I remember going to that like that first meeting and just feeling so anxious and like so uncomfortable and just wanting to go home and being like, ‘Can we try this again, like next year maybe?’ And my mom said, ‘Just do it. Like just, we can leave in an hour, like if you want.’ And of course, I ended up staying like the whole weekend.

Less commonly, some parents offered to pay for therapy, although this was not always something children were interested in. Two participants highlighted that their parents put them in sports hoping it would give them an opportunity to work through emotions and participate in a co-ed activity that simultaneously helped them learn how to stand up to bullies.

In many cases, children and caregivers sought educational resources to learn more about intersex variations and related topics. This primarily included online resources, books, intersex support groups, participants’ medical records, and media mentions of intersex-related topics. For participants, this independent research was at times empowering and at other times a result of isolation. When researching online, participants did not always know what search terms to use and did not always find satisfying answers. For example, Alyssa shared:

[I would] Google late at night when I'd be like up with terrifying anxiety. And I'm like everybody else is getting to live a normal life and I'm like Googling at 4:00 AM like famous intersex people.' And I'm like, 'All right, crickets.' Like, 'What do we got?'

Others had success finding supportive resources (e.g., interACT, Scarleteen) and felt empowered to get answers on their own:

Once I kind of hit high school, I looked like for answers myself through the support group and also through my own like juvenile research, trying to figure out answers for myself. And then I like it came more so like where I turned to other intersex figures in the community and asked them questions as opposed to my mom (Jade).

Although less commonly reported, participants spoke highly of caregivers who also did work to research intersex variations and related topics.

Last, some participants disclosed their intersex variation to friends as a way to get support. E shared that her need for peer support outweighed parents' advice to not tell others about her intersex variation: "It was like 'Okay, this feels like I need support. I need help with this.' And even though I'm feeling like it's kind of wrong, I'm still gonna, like, tell people about it." Others wanted to disclose to peers, friends, or siblings in order to be authentic or get support but ultimately did not because of messages that encouraged secrecy and fostered shame.

I Should Be Less Me

Participants reported a wide range of socialization experiences which communicated to them that they should conform, suppress, or monitor different facets of themselves, whether physical, emotional, or identity-related, because something about them is bad and/or broken. This theme highlights both explicit and implicit pressure to conform to the demands of hetero/cis/endonormativity and to compensate for certain pieces of the self that fall outside of

these expectations. In a context of silence and confusion, hetero/cis/endonormativity became the default and dominant ideology by which participants and those around them measured worth.

This theme also highlights how participants made themselves emotionally smaller in an environment where their feelings and needs were not prioritized.

For some participants, caregivers regularly reminded them that they were “normal,” but these messages led to participants’ concerns being dismissed, led participants to recognize that they must not be “normal” if caregivers are over-emphasizing how “normal” they are, or led to participants not having important information about their bodies:

“[My parents] wanted me to kind of grow up not having to feel so other. And kind of a double-edged sword, I think, in a lot of ways, 'cause it's like I didn't have to grow up feeling like some alien watching all these other kids, but at the same time, I did not know literally anything about like the truth or about myself” (Koko).

Many participants described how their caregivers wanted them to have a “normal” life and feared them being hurt or ostracized for being different. However, most caregivers’ definition of “normal” revolved around meeting hetero/cis/endonormative expectations and traditional standards of beauty (e.g., thinness, women being hairless), often accompanied by Christianity. In the pursuit of this “normalcy,” caregivers, peers/friends, medical professionals, siblings, extended family, and other influential adults implicitly and/or explicitly pressured participants to conform to these standards rather than affirming and celebrating participants’ bodies, emotions, and identities.

Even when not the direct target of queerphobic messaging, almost all participants described receiving indirect messaging by growing up within hetero/cis/endonormative, sex negative, and queerphobic environments. Caregivers, siblings, extended family, peers, and other

influential adults (e.g., teachers, religious leaders) made comments about how being gay, transgender, fat, or falling outside of the gender/sex binary in any way was bad and undesirable: "My first interaction with trans people actually was my mom scoffing and getting insanely angry at a magazine issue in the hospital in 2015, which if you knew that era then that was not a good time" (Basil). Participants described how caregivers' self-deprecating comments about their own bodies and negative commentary about others' bodies sent very clear messages about how they should want to change their own bodies: "A consistent message that I got growing up was having a flat stomach is good and something to be proud of, and having big thighs are bad and something to want to change because those were the ways that [my mom] felt about her body" (Jay).

Participants also received very direct commentary on their own bodies from all sources mentioned. Caregivers, extended family, and medical professionals communicated assumptions and expectations that participants would be cisgender, heterosexual, fit into traditional binary gender roles, and have biological children. These sources told participants directly that they needed to change something about their body (e.g., you have to remove hair, you have to grow breasts, you have to lose weight, you have to wear the "right" clothes) or what they wanted for their life (e.g., you have to want biological children, you have to want penetrative sex):

My family was always wanting to correct my body. Like if I didn't wear a bra, they'd be like, 'You're gonna wear a bra' or like if I have hairy legs or something hairy, they're like, 'You're gonna shave it or not show it off at all (H).

[Your body is] just seen as something that you really, from the medical standpoint, need to kind of like squish into like a binary place that just is like not natural at all (E).

Caregivers also communicated that there was something wrong with participants' bodies by apologizing to children for their genetic role in participants' intersex variations; reacting negatively or uncomfortably to seeing their child's intersex bodies; and expressing their own shame, embarrassment, or fear about their child's intersex variation:

My mom would just cry, would just sob to me when we didn't have periods or we couldn't have children and how she always was like, 'Oh, I'm so sorry.' And all of this stuff. She made me feel I think worse that I didn't have the capability to do certain things. Because she herself felt so bad for like being the reason why I can't do that, you know what I'm saying? Then I didn't feel adequate because I couldn't do certain things that was clearly such a big deal to her so it should be a big deal to me. And then it became a big deal to me... Growing up and just her reactions to things like that just like made me feel less than (T).

Many participants reported verbal bullying from medical professionals, teachers, and caregivers and both physical and verbal bullying from peers related to their bodies and/or gender expression. Participants were made fun of for having a body that was too fat, too hairy, too masculine, or too feminine or for being queer or associated with queerness. These experiences were traumatizing and extremely emotionally difficult, especially when multiple sources were communicating to participants that something was wrong with them that needed to be fixed:

Those comments growing up really impact a growing brain. Like those thoughts aren't normal. And then when I was hearing it from outside peers, such as kids around me, it started making an even bigger impact that my mom was making similar comments about my weight. (Sarah B)

Being bullied for like looking like a boy was when my mom was just like, 'Here's a razor, here's tweezers.' So I got the message that if someone bullies you, that means you have to change so that they stop bullying you. So it's like very victim-blaming for bullying. (Jay)

Participants were also harmed by insensitive comments made by peers, friends, siblings, and partners who did not understand intersex and/or who could not think beyond hetero/cis/endonormativity at the time (e.g., So you're trans? Are you a boy? "Are you a Barbie doll down there?" [T]). Fern describes over-hearing their mom and sister discussing intersex topics:

The way they talked about it was very much eugenics-y... My sister was like, 'Well, I don't wanna give birth to someone like that. I wouldn't wanna do that to a kid.' I think that was one of the bigger moments that really, really broke my heart. That was one of the bigger times that I was like, 'Wow,' you know, 'Even if her kid came out perfectly healthy, you know, like she wouldn't want them to be like me.' And my mom kind of agreed with her, I think she was like, 'I wish this had never happened. I wish someone had never been born.' It was really painful, and they didn't really know that I was listening. That was rough. That was a really hard one.

In addition to pressure from all these sources to conform to hetero/cis/endonormativity, many participants described how parents actively refused to let them transition or even explore their gender identity. Even for parents who were more accepting of diverse sexual orientations, accepting or making room for gender queerness was more difficult. For example, Stevie who was assigned female at birth shared,

[My mom] was just like, “Okay, love who you love, end of topic, end of story” but when it came to the gender... she would say, “Oh, but you were like my little girl like I always wanted a little girl” and it took just a lot of time and patience.

Parents tried to reassure children they were still the gender they were assigned at birth: “You’re just like every other guy, other than that one thing” (Charlie); “No matter how you feel with this beard, you’re still a woman, you know, you’re so beautiful (Guadalupe).” Parents did not ask children about their gender identity and assumed it aligned with the sex they were assigned at birth:

“There was never talk of like, ‘[BA] are you okay being a girl? Do you want to be a girl, do you want to be a boy?’ Like, there was none of that. It was just, yeah. Like I needed to still be a girl and work with that” (BA).

One participant who was assigned female at birth shared their experience coming out to their mom as non-binary and transitioning:

My mom was very much like, ‘What do you mean you’re changing your name? I feel like I’m losing my daughter right now’ ... At that point, it was kind of like I felt very much like she was kind of disgusted with me, is like the way that, uh, she would talk about my gender and she would very much often complain to me about like, ‘Am I ever even gonna be able to have grandchildren?’ And ‘Why are you doing this to us? Why does it have to be about you?’ And just kind of, I think, more angry. It kind of feels like a hurt animal like kind of lashing out (Fern).

In these hetero/cis/endonormative contexts where conversations about intersex and related topics were avoided, participants often internalized shame and guilt surrounding their intersex variation. Participants believed that, because of their intersex variation, they were

broken, defective, freakish, and inadequate for their sex or gender. Participants felt self-conscious and embarrassed, had low self-esteem and self-worth, and believed that no one would love them or be attracted to them because they were different:

My own perceptions of me being defective or that there's something wrong. Or even the fact that I had to like use dilators in order to have like a vaginal canal that would be considered like a normal length. I feel like that just like sent a lot of signals to me about like my body and how other people would value my body (Jade).

I just sort of felt I had part of myself, identity was like, 'I am a freak.' And I was like, 'Okay, because I am a freak that is causing my body to be freakish,' basically. I also felt like that was my fault, that these things were happening to me that didn't seem to be happening to other people (Sunleaf).

One way that participants dealt with this shame and pressure to be “normal” was to attempt to conform to hetero/cis/endonormative expectations. This included changing their body or gender expression (e.g., shaving, wearing makeup, stuffing bras, building muscle), avoiding activities where their body differences could be seen (e.g., changing in locker rooms, swimming, physical intimacy), and hiding or lying about pieces of themselves (e.g., pretending they were straight or cisgender, carrying tampons even when they didn't have a period). For example, Sophia described: “I spent like an hour every morning like tweezing my face 'cause I didn't want anyone to see my hair. I was really in a lot of inner turmoil growing up.” Similarly, NC shared: “If we were changing in locker rooms, I would make sure my back was facing, I was in a corner so no one would see me, notice I was different.” Basil shared how his concern with his physical appearance led him to “starve myself in an attempt to get rid of breast tissue and to try to work out to fit more standard models of what a guy should be. And that was really rough.” Two

participants specifically mentioned achieving in other areas as a way to compensate for what they saw as a deficient body: “I got really good at counting my calories and getting straight A's and doing as many extracurriculars as possible and just like being perfect. Perfect, perfect, perfect. That was like my only goal” (Alyssa).

In addition to messaging about making themselves smaller to fit into hetero/cis/endonormative boxes, participants received messages that they should make themselves emotionally smaller as well. When participants shared concerns with caregivers, medical professionals, religious leaders, and peers, they reported feeling dismissed and their concerns minimized (e.g., if you pray, God will make you fertile; you don't need to question your gender; you're so lucky you don't have periods). For example, when J expressed his concerns about delayed puberty with a doctor, the doctor responded, “From my expertise, I can tell you that Asian women don't have breasts.” J commented on this experience, “I think that if I had been White and presenting with those same symptoms, he would've taken me seriously.” This experience was most commonly reported with caregivers who dismissed their children's concerns in various ways. Caregivers told participants to ignore or change their feelings (e.g., “you'll be fine” [H]) and focus on the positives. Caregivers who were emotionally unavailable or avoidant had a difficult time understanding why participants were concerned about their bodies or bullying: “Your body will normalize. We don't need to pay attention to that. Like you're just a late bloomer” (Jay). In more severe cases, parents directly gaslit or victim-blamed their child. When Vixie told her parents that she had been pregnant, “They were like, ‘That's not possible.’ They're like absolute gaslighting, ‘That's not possible. You're not that. Quit being delusional.’” Jiesi described their father's victim-blaming and gaslighting response to their disclosure of assault:

There was a lot of just like blaming me and being like, ‘Well, you knew blah, blah, blah, blah, blah,’ right? That really affected me. ‘Cause like when I think about like how traumatizing everything was, I think it would have been a lot less traumatizing if I hadn't experienced so much like gaslighting after the fact, right? (Jiesi)

Recognizing the competing stressors and difficult emotions their caregivers were experiencing, multiple participants internalized the belief that their intersex variation was a burden on others. As a result, participants avoided bringing up the topic and did not express their emotions to protect others from stress or emotional overwhelm: “I attempted to monitor myself as much as possible because I didn't want to like say the wrong thing and make [my mom] feel guilty” (Sarah B).

Participants reported still navigating challenges in emerging adulthood as a result of messaging from multiple sources to be less themselves. For many participants, shame and trauma from childhood and adolescence remained present into emerging adulthood which negatively affected their self-worth, relationships, and sexual expression. Participants reported continuously working on unlearning and rejecting hetero/cis/endonormative and sex negative messages, learning to prioritize self, sharing intersex body/identity and needs with others, and building self-worth.

My Body Isn't Mine

Another common socialization experience that was often traumatizing for intersex participants was the loss of autonomy, whether physical, emotional, or identity-related. In these situations, participants were not given a choice about what happened to their bodies, how they expressed themselves, and what their bodies could or could not do.

Participants reported non-consensual practices that took away autonomy, most commonly from caregivers and medical professionals. This included infant surgeries (e.g., gonadectomy, vaginoplasty) that participants could not consent to and forcing children to go through with medical exams, treatments, and later surgeries against their will: “[Parents] were helping the doctors pin me to the bed... Nobody listened. Nobody took me seriously when I said I didn't want to” (Ellen Jameson). Some parents also took away children’s identity-related autonomy by not allowing them to wear types of gendered clothing, wear certain haircuts, and, in one case, even lying to the child about what medication they were taking in order for puberty to progress in the direction that parents desired.

Medical professionals often had their own agenda for participants’ care and made decisions and/or recommendations either directly against the participants’ wishes or without consulting them first (e.g., you have to have surgery, you have to take these hormones, you have to go through puberty this way). During examinations, doctors violated physical boundaries, gave demanding instructions (e.g., “take off your clothes” [Guadalupe]), ignored participants’ pain and protests, and invited other people into the exam room without consent. One participant pointed out the lack of explanations that are key to consensual medical practice:

Invasive medical things where I'm like, ‘Okay, like maybe this wasn't like assault,’ but as a kid, if you're not telling me why this is happening and what's happening to me, like what does this mean? How's it gonna affect me? Then I'm just going to not understand why am I going through this pain, right? And that's traumatic. Especially because the medical system violates your boundaries and dehumanizes you (JieSi).

As mentioned in a previous theme, caregivers’ trust and reliance on doctors for answers contributed to them allowing doctors’ decision to trump their child’s wants and needs: “My

mom's very passive, so she's like 'You know what, they have to check [your genitals].' I'm like 'Do they?' ... She was like 'They know what's good and you don't really know.' So, I was like 'Okay'" (Guadalupe).

Many participants internalized that their body was not their own and experienced intense emotions and trauma responses due to the non-consensual practices and experiences of assault. Participants reported feeling that what other people wanted for their body was more important than what they wanted for their body:

It was pretty clear to me from a young age that it didn't really matter what I wanted for my body or what I thought made sense for my body, because, you know, from all the checkups and the doctor's visits and whatever it was just like, you know, you took your clothes off when they told you to and you let them touch you when they needed-- When they told you to and you let them take blood when they told you that that was what was gonna happen and so on and so forth... you need to contort your body to fit a specific standard of beauty and specific code of what's okay. What you want doesn't matter, my body wasn't mine. (Alex)

With a lack of autonomy over their bodies, many participants turned to self-harm, dissociation, and eating disorders to cope with anxiety, depression, stress, trauma, dysphoria, and dysmorphia.

Quotes from multiple participants illustrate this experience:

I completely rejected and avoided my own body because I was just like, you know, really struggling with suicidal ideation and anxiety because I didn't want this body. I was like, 'This body's wrong, this body's broken. I don't wanna have to try to fix it. I don't wanna have to be on hormones. I don't wanna have to do dilation therapy and go to the doctor every year and get blood work done. (Alyssa)

Having my breasts examined and also the internal ultrasounds were really challenging for me when I was a teen or in middle school. 'Cause like I was already dealing with understanding my gender and my body and having something weird happen medically also just made me feel not connected to my body and like I was just getting it done. So I had to like disassociate a lot (H).

The eating disorder did something to help me change my body. So I liked it and also gave me something to focus on and kind of cope with anxiety and just feeling like I didn't have any control over my life (Elizabeth).

Participants reported that the effects of trauma and non-consensual decisions made for them by caregivers and doctors remained present in their lives (e.g., detachment from body, sexual difficulties, burden of ongoing treatment). Many reported having done and continuing to do difficult work in healing, coping with trauma, and building a positive relationship with their bodies.

I Feel Supported and Empowered

Despite negative socialization experiences described in the preceding sections, participants also described efforts from others that felt supportive, empowering, and/or accepting. This most often included others providing instrumental support, prioritizing and advocating for participants' feelings and choices, communicating openly, and affirming participants' identities. Many of these supportive behaviors contributed to participants' self-acceptance, empowerment, knowledge, and comfort sharing their intersex variation with others in emerging adulthood.

At the most basic level, participants identified support when caregivers, most often mothers, set up appointments with preferred doctors, attended doctor appointments and

procedures, helped participants manage their treatment, and navigated scheduling (e.g., letting school know participant would be out for surgery). For example, to help BA with taking pills regularly, her mom got “the pill caches, I would get like pudding, and Jello, apple sauce like we made it fun. So that was a good experience.” Other participants’ parents did their best to make doctor appointments good experiences. When NC’s family would drive hours into the city to see the doctor “they would take us to a museum or something after. Take us to like a nice lunch. They always tried to make it something positive so we didn’t end the day like just focused on that, sad.” Stevie’s mom “even invested in a little self-care bag for me to bring with stuff for sensory and coloring books and just things to help ground me again and I really did appreciate that so much.” Participants also identified basic instrumental support from doctors who were knowledgeable about intersex topics and could diagnose and order tests correctly, extended family members who physically showed up at the hospital or intersex events to show support, and siblings and school staff who provided physically safe spaces for participants to spend their time.

Caregivers, peers, partners, extended family, medical professionals, and other influential adults were labeled as supportive when they prioritized and advocated for child’s feelings and choices. Caregivers advocated for their children’s wants with doctors and encouraged children to advocate for themselves with doctors as well:

As soon as I got home from my diagnosis and from marching band practice, I was like, ‘I wanna start hormones because I’m a female. I’m going to present as female for the rest of my life.’ So immediately that night, my parents emailed my pediatric OB-GYN and told her that I want to start hormones. She started me on the lowest dose, and then my dad

called every single pharmacy going, ‘My daughter needs hormones, she cannot produce it herself. Let's get it going. (Sarah B)

Caregivers also fostered participants’ body autonomy by allowing them to choose their own interests, gender expression (e.g., clothing, haircut style), and refusing surgery before the participant was old enough to consent. Other sources advocated for participants by standing up for them when others were making jokes or queerphobic comments and intervening to prevent bullying (e.g., teachers changing seat assignments).

In general, education around intersex topics and development from different sources was labeled by participants as supportive and often empowering. Participants felt supported when caregivers did their own research in order to be able to advocate for and educate them. Stevie’s mom did extensive research and was

very open and honest about what was going on without the scare factor that a lot of the doctors would try and instill in us... She would basically be my go-between between the doctors and just make sure she tells me in a way that I can understand and process easier and was just my best advocate for that.

Participants also appreciated caregivers’ willingness to provide basic sex education about consent, puberty, anatomy, and reproduction, even when it was not intersex- or queer-inclusive. Fern shared how her mother and siblings established a “really good foundation and then I just built a gay house on top of it. I had to do a lot of that on my own, but my family, my sister, and I started talking about sex very early.” Similarly, participants appreciated when doctors took the time to answer their questions and educate them about their diagnosis and what it means for their identity. For example, Sarah B’s doctor told her “Gender is fluid. You get to choose how you want to present yourself” and it did kind of soothe some nerves.” A few participants also noted

that it was helpful when teachers acknowledged intersex topics: “I had one teacher who was just like, ‘Oh, yeah, it's a common thing in humans and animals and plants.’ And I'm just like, ‘No way! [excited and interested]’” (Stevie).

Open and honest communication was an important way that most sources showed support to participants. Conversations in which others were willing to learn, able to listen, and emotionally validating were extremely helpful for participants:

Pretty much every single family member who's ever said, “If you need me, if you ever need to talk about this, if you need anything,” they backed it up. Even if it was difficult for them or strange for them, or they didn't understand, or my grandfather would sit there playing solitaire and very clearly zoning out while this ADHD child is bouncing off the walls, ranting at him. You know, they always at least listened to me talk. (October)

Being able to talk with others about shared experiences (e.g., genital surgery, intersex diagnosis, infertility, identity exploration) was also helpful for participants. This was especially helpful with queer and intersex friends. For example, Hestia Flynn shared:

My immediate friend group, very receptive, super liberal, probably didn't hurt that we were all like weird orchestra and theater kids, so everybody's weird and has their weird stuff. But they were super cool and I think, because again, people conflate like gender identity and sexual orientation, everybody was really, at that point, in my friend group trying to figure themselves out from a sexual orientation perspective and I think because they confused it, they were like, ‘Sure, yeah, you know, Will made out with a guy last week, you had your genitals surgically altered, like sure!’ And so everybody was like, ‘Yeah, whatever and then we moved on.

Three participants in our sample had siblings who also had confirmed intersex variations and found it helpful to share experiences with their sibling, even if their experiences weren't always the same:

I'm glad that I have that like bond. I feel like I would've felt so much more alone if it was just me. Like even not having the exact same experience, still having someone there to turn to if need be was extremely comforting. (T)

Even when not perfect, the efforts of caregivers, peers, extended family, siblings, other influential adults, and partners to affirm and make room for queerness was seen as supportive. Sources unconditionally accepted and celebrated participants' gender identity, sexual orientation, and intersex identity and used participants' correct name and pronouns:

[My parents] were like, "No matter what you choose, no matter what gender you choose, we're gonna be here for you. We're gonna support you no matter your gender or later on in life if you come out as bisexual, lesbian." They were happy to just have me. And it was very reaffirming that my parents were supportive of how I was going to live my life as an intersex individual. (Sarah B)

Even when siblings and caregivers were not always supportive of participants' queer and/or intersex identity growing up, many participants noted that their family members have grown to be more understanding and supportive over time, even if they still may not fully understand.

With or without the support and acceptance of those around them, many participants came to embrace and become more empowered about various facets of their intersex variation in childhood and adolescence. Participants rejected shaming, victim-blaming, queerphobic, fatphobic, sex negative, and hetero/cis/endonormative messaging and accepted their body and their identities. The following examples illustrate this shared experience:

While on paper, it should have been really hurtful to hear like your mom be like, “You're gonna die alone because you won't learn how to put mascara on.” In reality, I was like, “I'm in a three-year relationship and you're the one whose like husband left you. And I don't understand why you're giving me advice on attracting people to be with me. My friends like me even though I wear these clothes and my boyfriend's attracted to me even though I've never worn makeup in front of him.” I think the messages coming from [my parents] contrasted so much with my experience of reality. And being surrounded by supportive people who were like cool with me the way I was that I wasn't super impacted (Hestia Flynn).

I had to become very cool with myself very early because I didn't really have an option. I couldn't have hidden whatever it is, I love to call it queer magic or something. It was not a thing that I physically was able to not do and it was innate... I think it just made it a lot easier because I had already been like, “Screw you, I'm the nerdy lesbian.” And like, “I don't really care what you think.” And like, “I'm gonna do whatever I want,” and very much was like gay superiority complex at like a very young age. Like just like, “I'm gonna do what I'm gonna do and that's it” (Fern).

With CAIS, having like less body hair and really clear skin, really thick hair on your head, no body odor, it was like, “Oh, okay.” Like I was really excited about all of those things, plus like not having a period and not having to go through with like cramps and PMS. I was like, “Wow, this is kind of like great.” All my friends are like really going through it every month and I feel like I won the lottery. (Alyssa)

As participants developed self-acceptance and awareness of their intersex variation, many felt empowered to come out, educate others, and advocate for intersex rights. This included

advocating for their own rights, as described by October: “Sometimes you'll see a doctor and eventually just have to go, ‘I'm shutting this conversation down, and if you don't let me, I'm walking out of my appointment.’” Sarah B even described advocating for her needs with her mother who had made negative comments about her weight in the past:

I found out about my diagnosis, I was like, “Mom, this is how you impacted me when I was younger on my weight. We cannot have that same thing happen with my genetics because this is now a big part of my life and I need a support system because this is not normal. Even though it's a lot more common than we think, but it's not normal for anyone around us. So I need that support system because if we don't have that, I won't be happy with how I'm presenting myself, I won't have good mental health, and I really need you to recognize that I just need a positive impact throughout this entire experience.”

Table 2. Themes of Key Socialization Experiences

Theme	Description	Illustrating quotes
<i>We Don't Talk About This</i>	Experiences of silence and lack of communication around intersex and related topics for various reasons	<p>“If you have sex with somebody, they'll find out you're intersex.’ And it like became this thing that like I needed to keep hidden. And like I had this false perception of like, I can't tell anybody about this because I'm going to be socially ostracized.” (Jade)</p> <p>“I was told repeatedly not to tell anybody... [My mom] had so much resistance about me-me even coming out as intersex because she didn't want the stigma and she didn't want people to know.” (Alyssa)</p> <p>“My parents and I have no conversations about it. We avoid it like it's COVID.” (J)</p>
<i>We're All in the Dark</i>	Experiences of feeling lost, isolated, and/or under-resourced as they navigate intersexness (e.g., diagnosis, identity)	<p>“For a long time in my life, I just kind of thought that [my intersex characteristics were] disability-related, which like it kind of is, but like, it just affects me in a different way than I was thinking about before” (JieSi).</p> <p>“The specialists were like, ‘Oh, we don't really owe you an-an explanation for your body.’ They literally just said, ‘it's like bad feng shui,’ which is like Chinese for ‘you just got unlucky.’” (J)</p> <p>“Me not having the language or the vocabulary to put my body into in an intersex body, you know, and like, see its differences. Like, it was all the same thing. It was all like, ‘I'm gay and my body's different.’” (Guadalupe)</p> <p>“I am the only fucking freak in the entire world.” (Sunleaf)</p>
<i>We Could Use Some Help</i>	Experiences of reaching out to other sources for emotional and educational support	<p>“My mom was like the best person ever back then and she delved into research with all my symptoms and looking into what kind of variations I may have... She went in [to doctor appointments] informed with printed sheets of articles she had found, all my CT scans-- I had a whole portfolio that she had made just on her own.” (Stevie)</p> <p>“I feel very privileged to have them find out so early so that way they could actually make sure that I had all of the medical care that I needed, even though not all of those doctor experiences are wonderful.” (Alyssa)</p> <p>“I did enjoy how like my mom, when I really felt insecure, like 15 years old and stuff, my mom found like a support group and she found like, interACT or whatever. And that's then how I like got to go to the intersex conferences and meet people. And I'm really happy that she included me in that community because I felt like I didn't have a community. So they did a really good job with like, just introducing me to others.” (T)</p>
<i>I Should Be Less Me</i>	Experiences which communicated to participants that they should conform, suppress,	<p>“When I was a kid, there was just kind of like, my parents would look at me regardless of how I was dressing or like what I was doing. They would just look at me with like this like pained expression all the time. Like, they would like look at me doing something masculine or they would like, or whatever else I was doing. They'd be like [makes pained expression].” (Vincent)</p>

or monitor different facets of themselves, whether physical, emotional, or identity-related, because something about them is bad and/or broken.

“Guadalupe: Because of the culture that is already so misogynistic and homophobic and fatphobic and all the phobics, I feel like I never got a message of like loving your body or accepting your body. It was just more like ‘You're beautiful no matter what. You're still pretty.’ But it was like, ‘If you're fat, you need to lose weight,’ or it was like, ‘Don't wear boy clothes or things like that.’

Interviewer: Hmm. Yeah. The ‘You're beautiful, no matter what, but fix these things.’

Guadalupe: Yeah ‘but look like a girl.’ (Guadalupe)

“Interviewer: What did you take away from the conversations that you did have or when [your family] referred to [your intersex variation] as like the family ‘mutant gene?’

NC: I mean that never made me feel very good, as you can imagine, 'cause even the connotation of that word, they always meant it like jokingly, but it definitely wasn't great for the self-esteem.” (NC)

My Body Isn't Mine

Experiences of loss of autonomy whether physical, emotional, or identity-related

“I didn't cooperate at all. I was having to be restrained, like held on the bed by adults. I kicked one of the nurses in the eye. And I'm not violent. I've never been violent, I've never attacked anyone, nor would I ever, but I thought I was fighting for my life. I didn't know what's going on. I was involuntarily sedated a few times, maybe once or twice. And then I just sort of thought that, ‘Yeah, that was me being a kid and me not cooperating 'cause I'm scared.’ But finding out I had every right to be like that and that I should have fought harder and knowing that what was done was horrible and unnecessary, just that context in my memory is- I just shut down.” (Ellen Jameson)

“I always felt like I just had no kind of control of going [to the doctor]. I mean, I really, a lot of times didn't wanna go 'cause I had medical trauma and anxiety undiagnosed and it just made it worse that my parents really didn't give me an option not to go and I could have used their kind of support with that.” (Elizabeth)

“Vixie: When I found out, ‘Oh, soy increases estrogen,’ you know, there was a thing going on back then, I started chugging soy milk. Meanwhile, my parents were giving me testosterone supplements.

Interviewer: Did you know they were?

Vixie: No, they said it was for my brain.” (Vixie)

I Feel Supported and Empowered

Experiences of efforts that were supportive, empowering, and/or accepting

“What is important is your health, is that you're happy, that you can support yourself, that you have a home, that you've got what you need to live, that you do the things you love, that you are an artist like you wanna be, that you're a writer like you wanna be. If you wanna do singing, you do singing, whatever you want to do, go do what-- You wanna get a tattoo. You wanna get a piercing, you wanna dye your hair, you wanna cut it, you wanna grow it out, don't care, go do it. That was always more important.” (October)

“My mom was in the room with me [during a medical exam] and she didn't know what was happening because I was just trying to suck it all in, so to speak, and it wasn't until I started sobbing from the pain that she jumped in and was immediately like, ‘No, you're done. Get your hands off of them.’” (Stevie)

Recommendations for Caregivers

To answer our second research question, we categorized intersex emerging adult participants' recommendations for caregivers of an intersex child into four themes: *Make it Okay to Talk About*; *Get Informed and Connected*; *Center Your Child's Choices and Feelings*; and *Disrupt Systems of Oppression*. See Table 3 for additional information on these themes.

Make It Okay to Talk About

Participants recommended that caregivers of an intersex child create environments where open, direct, honest communication about intersex topics is normalized and supported for both the caregivers and child. This communication should be clear and frank with age-appropriate information caregivers can build upon as the child ages. Participants also wanted caregivers to initiate conversations to check in on their child's feelings and wants. For example, when asked what she would have done differently if she were raising a younger version of herself, Sophia replied,

I would have just had much more like direct conversations. Like, "Do you want to have hair on your face? If you don't, I can show you some ways to get rid of it. If you do, here's some ways to combat what people are gonna say to you. Because that might happen." You know, that sort of thing. (Sophia)

Participants emphasized that caregivers should not treat their child's intersex variation as a secret or as a taboo topic; they also noted the complicated nature of secrecy vs. privacy messages. Multiple participants retrospectively understood parents' protective intentions behind messages to not tell others about their intersex variation, but wished parents had framed this message as "be cautious who you tell" rather than communicating a shame-based message of "you can't tell anyone":

I would probably stress like, 'Be really mindful who you would tell this to because, uh, it might not end up the way that you want it to,' or 'Friends aren't forever.' And it's so cute when you're in middle school and you really, you got that matching BFF necklace, you think that shit's locked for life. Like, I don't even remember those girls' fucking names, but I would just remind them like, 'This is not secret information.' I'm a very spiritual person. I'd be like, 'This is sacred information. This is something that like, you hold close to your heart and you don't need to disclose it to anybody if you don't want to, but also, like, it's nothing to be ashamed of. It's sacred. It's not a secret, it's sacred (Alyssa).

When having open conversations about intersex and related topics, Koko emphasized that caregivers should recognize that this is just part of their child's life and not the defining feature:

The main takeaway I said 10 million times: Talk about it. Please. I mean, it doesn't have to be all at once either. 'Cause I recognize that it's a lot to figure out. And I think it doesn't have to be at once. 'Cause it would be a lot for you and for your kid, but like, find a way to integrate it into their life because it is a part of their life... Talk about it and make it a part of life without making it their life (Koko).

Get Informed and Connected

Next, participants recommended that caregivers of an intersex child help themselves and their child become more educated and connected to resources. This was especially important in a context where caregivers lacked important information on intersex and related topics.

Participants emphasized the importance of caregivers doing their own work to become educated about intersex variations, social issues relevant to intersex individuals, common experiences among intersex individuals, and other related topics (e.g., trauma, sexuality) rather than accepting what doctors and other people tell them:

I wish [my parents] just had information or encouraged me to seek out information... There are people you can talk to who are in the community who are knowledgeable. There are doctors who do work with the community who are knowledgeable. Just research, go online, ask somebody to go online, go to your local library, try to seek information at a big medical facility (October).

This recommendation included pushing for information from doctors who were not always forthcoming about participants' intersex variation: "I wish that [my parents] had looked into it a bit more or asked more questions or made me feel comfortable asking more questions. 'Cause, it's insane that I still don't have the full picture like 10 years later (Sarah A)."

As caregivers educate themselves, they can pass their knowledge onto their child. Participants recommended that caregivers educate their intersex child about a wide array of topics. These topics included general education on both endosex and intersex bodies, covering anatomy, puberty, and reproduction. Participants wanted information that would help them better understand their different identities, such as the differences between biological sex, gender identity, gender expression, and sexual orientation. Participants also wished that caregivers had educated them about topics that would help them navigate their own experiences, including concerns, treatments, body changes, and options relevant to the child's specific intersex variation; consent (including advocating for themselves with doctors); and dealing with discrimination in a variety of settings. Participants wanted this education to be inclusive of queer relationships and identities.

In addition to attaining more education on intersex and related topics, participants highly recommended that caregivers connect their children with other intersex individuals, intersex advocacy organizations and communities, mental health resources, and competent and non-

coercive medical professionals. Participants especially emphasized the healing power of intersex peer support:

If parents can allow their intersex kids to connect with each other and just generally feel like they're not the only one who's experiencing this and that they can have friends who are like them, not that they only socialize with other intersex kids, but having that connection I think helps a lot. (J)

Even if my mom didn't know anything but knew enough to like connect me with other people, that could have changed a lot of things in my life because growing up, part of the reason why it felt so isolating was because I didn't know anyone else who had disabilities like me or queer stuff like me, or, you know, just like the experience of their body that I had. And if I had known people growing up like that, I think I would've been like a lot better off, even if my mom knew just enough to like connect me to those people, right? (Jiesi)

Jade also highlighted the importance of giving children the opportunity to get connected with resources, even if it was not something they wanted at that time: “Go out of your way to like get involved in those communities, present opportunities to your child. Even if they don't wanna take them, make sure you know about what those opportunities are.”

Center Your Child's Choices and Feelings

Participants also recommended that caregivers of an intersex child prioritize, accept, and value their child's choices, bodies, and feelings. According to participants, the child's choice should be the focus and take priority over the choices, wants, and comfort of others. For example, participants emphasized the importance of respecting intersex children's body autonomy. This included no surgery or medical treatments without the child's consent or without

the child being fully informed about their options and the associated consequences. As Anna said, “Let's talk about why we need surgery. Okay, that helps me decide if I need it or not. You know, versus ‘I need surgery,’ having those kinds of discussions.” In the case of infant surgeries, participants recommended waiting until the child was old enough to make the decision for their body, unless there was a life-threatening situation (e.g., salt-wasting). Vincent shared his gratitude for being able to make decisions for his body: “I feel very happy and very fortunate to have grown up as a like, fully intact intersex person until I chose to start taking hormones for my choice. I would want every intersex child to have that option for sure.” Caregivers should also advocate for their child’s wishes with doctors and help the child voice these desires with medical professionals: “Make sure their choice is considered and taken care of. If they want things removed, advocate for them. If they want medications or they don't want medications, advocate for them. Just advocate with doctors, because a lot of doctors suck” (H).

Fostering children’s body autonomy also included letting them make decisions about their gender identity, gender expression, sexual orientation, and other aspects of their identity:

Don't force them into one group. Let them choose for themselves. I have you know, gender being an open discussion. Take me for example. I had boobs. I was forced to be a boy. That was uncomfortable as shit going through school like that. I was always forced to change in a stall in the bathroom. Don't do that. It's up to them if they wanna tell people, but don't force them to do anything. (Vixie)

Participants encouraged caregivers to accept and support their intersex child’s decisions and identities. This included showing and communicating unconditional love and acceptance and providing a safe and affirming environment for their child to explore their various identities:

I think if I was a parent to intersex kid, it was just like the body autonomy, the full acceptance and just giving them all the information to explore. Because I think the harm was that I love to explore and I wasn't allowed to... Experience all the things and go to rallies and educate yourself so that you know. I don't think anyone's ever will ever know who they really are, but at least get a better grasp of it. (Charlie)

Validating and valuing intersex children's feelings is an important piece of understanding what children want for their bodies. Participants recommended that caregivers believe and validate children's feelings without dismissing, gaslighting, or minimizing them:

Believe your kids, right? I think that kids, sometimes they don't have all the language for everything and so they may not say something that is like 100% accurate, but that doesn't mean that they're wrong... believe them and like try and figure out what they're actually saying even if they don't know how to like- even if they don't know the words to use, right? (Jiesi)

Participants shared that caregivers should listen to their child when they express concerns, share experiences, and show emotions but also check in with the child regularly and pay attention to how they may be feeling: "I would say just listen to your children, like listen to their fears, and listen to their wants and how they feel about their body" (H). Ellen Jameson shared the importance of paying attention to and prioritizing the child's feelings and wants:

Just listen to me. And when I was trying to like physically escape the building, maybe just notice that it's not worth it. Like at what point does the trauma that I'm getting outweigh worrying about sitting to pee for the rest of my life?... I would much rather be forced to sit down forever and not have trauma and nightmares and stuff. I'd much rather that. It's just not worth it, for like a few seconds of convenience. (Ellen Jameson)

Being able to talk openly and process complicated feelings with a caregiver was also an important piece of valuing the child's feelings:

When your child wants to do something so stupid, sometimes, you just gotta support them and get them through it. And I would say that mentality when someone learns about their identity and has this, you know, crisis of thought of 'Who am I?' It's really important to identify that and be like, 'Okay, like, yeah, oh, you're feeling that way. Sure. Let's do it. Let's talk about it. Let's get through this together. (Anna)

For many caregivers, serious emotional work is required to be able to be supportive of their child's feelings and autonomy in these ways. Participants identified the necessity of parents doing emotional work to overcome their own guilt, shame, and worry related to their child's intersex variation so that they do not project these feelings onto their child. For example, T's mom often shared with them her own feelings of guilt for genetically contributing to T's intersex variation. Commenting on these experiences, T said,

I definitely would've kept that to myself. Like my child does not need to be my therapist for something that's literally their identity. You know what I'm saying? I feel like I would've not shown all those emotions and all those thoughts and all those feelings to my kid, maybe to like my spouse, or even just like to a therapist or somebody. I would be secure in myself so I could be there for my kid... I would definitely make sure that I took care of my mental and emotional needs so that I could take care of-- 'cause I just feel like that wasn't really happening.

Disrupt Systems of Oppression

Last, participants recommended that caregivers take action to combat systems of oppression that may harm their intersex child. The majority of participants recommended that

caregivers normalize diversity for their child. Participants wished they had been taught that intersex bodies are normal and part of natural variation in human sex development: “Present them with the fact that their body is a natural expression of having a body. You know, sex characteristics aren’t bimodal. There are people in the middle. And that's just the way nature does things and always has” (Jay); “If that had been a part of [the sex talk] too, like, ‘You know, this is a penis, this is a vagina. And there's also this array of other characteristics you can have,’ that would've made a huge difference to me” (Hestia Flynn). Along with normalizing the existence of intersex bodies, participants wanted caregivers to help prepare their child to navigate an interphobic society where others will see their body as abnormal. This included recognizing and deconstructing hetero/cis/endonormative and interphobic expectations and assumptions:

There's nothing wrong with being intersex. It's completely a natural thing that occurs, but a lot of people in society don't recognize that. And you just kind of need to be there for your child to help them with that. And to help kind of deconstruct these ideas of like normalcy and what a guy should be or what a woman should be, you know? (Basil)

I wish that there had been more acknowledgment that like sometimes your body will do things that don't match up with what people say your body should do. I think that having intersex development be a part of sex ed would be like a really great change. And just an overall acknowledgment that like, if your body isn't doing these things or it's doing other things, that's not actually a problem with your body, it's just like the idea of being different being okay (Jay).

Participants also wished for messaging that normalized a wide array of identities and choices, including gender identity, gender expression, sexual orientation, relationships, family structures, and life choices (e.g., having children or not having children):

You need to like know that there are people out there that are on this whole spectrum of gender that are born this way or identify this way or are attracted to this or attracted to that. And it's just, it's normal and it's a beautiful, amazing rainbow experience (Alyssa). I just wish from a young age that I had more models of like, 'Life isn't one thing, and it doesn't look like one thing, and you can make whatever decision makes the most sense for you.' There's more than one model of how to be happy and how to have a healthy relationship (Alex).

As one tool to normalize diversity, participants recommended that caregivers locate representation of intersex and queer adults for their child. For example, Hestia Flynn described how her parents were really good at showing her representation of empowered women, but expressed that "somewhere between Annie Oakley and Sacagawea, it would've been really cool if I had seen somebody who had an experience with like gender diversity or sexual orientation that wasn't heteronormative. I didn't get to see any of that." She emphasized the importance of exposing children to queer and intersex people so they can see happy and successful role models:

Look, this adult was successful. Not this adult who looks like me got assassinated, but represents something good. But this adult actually went on and did things that you might wanna do and like lived their life openly and wasn't like oppressed the entire time.

In addition to normalizing diversity, participants wanted caregivers to directly confront queerphobia and interphobia through advocacy. This included advocating for school policies that support trans and intersex children (e.g., gender neutral spaces), confronting other adults' queerphobic comments or behaviors, and protecting their child's right to explore outside of hetero/cis/endonormative boundaries. For example, Alyssa shared,

We just need to like foster a safe environment for kids to be whoever the fuck they wanna be and really stand up for them. If any parents are like, 'Why is your kid doing this?' It's like, 'Cause they fucking are.

In order for caregivers to disrupt systems of oppression in these ways, they need to do their work to overcome their own queerphobic and hetero/cis/endonormative ideas. Elizabeth offered this advice to caregivers of an intersex child:

Don't make being intersex seem like something weird. 'Cause kids are really smart and intuitive and if parents handle things anxiously, I think children are obviously gonna kind of do the same. So I think a lot of the way parents think about it is how the children kind of end up thinking about it. So model good behavior, model good thinking about sex and gender. Even if you're super religious conservative parents for the sake of the future of your kid, try to be more open.

Similarly, Sunleaf shared:

Sunleaf: I guess you can't undo the life experiences of intersex adults, but there's still a lot that parents can do to get over their own internalized queerphobia and transphobia and how they raise their intersex children. And there's a lot that I just think everybody, literally everybody, no matter what they do needs more education about intersex people, 'cause so a few people have any level of awareness or-or competency. And that includes trans people. Like I'm really tired of people being like, 'Ah, yes, LGBTQIA+' and then like not including or understanding intersex in any way.

Interviewer: Mm-hmm. Yeah. So even just like breaking down all of these, like, binaries, and, like, transphobia, queerphobia for parents of both like intersex, trans, and cis kids,

like, it just feels like it would make the whole world a better place regardless of who your kid is and who you are.

Sunleaf: Yeah, absolutely.

Table 3. Themes of Recommendations for Caregivers

Theme	Description	Illustrating quotes
<i>Make It Okay to Talk About</i>	Recommendations for parents to create environments where open, direct, honest communication about intersex topics is normalized and supported for parents and child	<p>“I would say don't hide it, but like maybe give them the opportunities to talk about it, work through it. Don't think it's something you have to wait to talk about until they're older... To the extent that the child can obviously handle it, but yeah, just being able- being something that you can talk about that it's okay.” (NC)</p> <p>“I needed [my parents] probably not to just like make it this huge, big, bad secret. I think that would have been the best thing. Made it so that I could talk to people about it or that my mom would check in with me about it more often or really just start using age-appropriate terms at a younger age for me.” (Elizabeth)</p> <p>“A little bit more awareness without alienation- to at least have had a little bit more awareness, and to not have had to grow up with the notion and feeling inadvertently that this was something that had to be kept hush-hush and under wraps and that like, ‘Oh, well, it's not obvious, so better to just not talk about it, so you don't have to go through all that and like, be made to feel weird around, you know, other people.” (Koko)</p>
<i>Get Informed and Connected</i>	Recommendations for caregivers to help themselves and their child become more educated and connected to resources	<p>“Educate yourself about sexuality. In the process of like having an intersex kid, you can also liberate yourself from so much... It has liberated my family and the way that people talk about sexuality, it has changed my-- just educate yourself, find the resources out there. And if there aren't, ask the community, get involved with the community, talk to older intersex and trans people. Know that you're going to make mistakes and be as committed as you can to learning with as open of a mind as you can. And think first, talk later because eventually, you will probably never be an expert on this, but there are experts out there because there are people who've lived it and like they have some of the answers and it's more important to get your kid in part of that community. And there's people all over that community of all different political backgrounds of all different races, religions, genders, all of the above. Find someone who is knowledgeable and ask them and read the books that we've already published. Read Georgian Davis's book, read Christina Cherkeizie's, read Herculine Barbin, the analysis by Foucault, read-- Go to interACT, go to the conferences, be involved, take charge of it. The more afraid you are, the more you miss out on a beautiful opportunity.” (Fern)</p> <p>“One thing I would have liked probably would have been maybe to talk about it more or even go to therapy and be able to like really understand it. I feel like a lot of the time I was just confused. Yeah, like I knew something was wrong, but not what, 'cause I never got into like the nitty gritty of it... just being able to work through it all, 'cause I kind of did that on my own.” (NC)</p> <p>“I would probably force them to go to therapy and force them to go to all the conferences and support groups and meetups. I would be like, ‘Bitch, suck it up. I know you're so traumatized and so ashamed that you don't even wanna talk to fucking people, but you need to.’ I would be like toxic parent in that department. I'd be like, ‘You have to.’ It's not a when you're ready because the healing that I found from finding people like me has just expedited and transformed everything in my life that I'm like, ‘Had I had at least like one little intersex pen pal at 11 years old I think I would've like ended up slightly less fucked up.” (Alyssa)</p>

*Center Your
Child's Choices
and Feelings*

Recommendations for caregivers to prioritize, accept, and value child's choices, bodies, and feelings

“Are you teaching [your intersex child] to maintain the ability to give consent or not consent to people, including doctors, to do different things to their bodies? And are you teaching them to love and feel ownership of their bodies in every other way you can? Even if they have to go through a lot of these procedures.” (Sunleaf)

“Try not to do anything without your child's informed consent. I think that's like number one up there. Unless it is literally going to endanger your child's life in some way, it's probably not necessary. If you think about it, there are children who are born with malformity or deformities, things like holes in their hearts, that if they can be operated on, they need to be operated on. But then there are also children who are born with things like atrophy disorders or they may be missing a limb or their limb may not have formed correctly or they may be born deaf or blind. And even if surgery exists for these children, you are probably going to wait until that child is older and better developed and their body has developed and can handle that surgery if they even need it.” (October)

“I wish I could just go back and just be like, ‘Tell them no, tell them it hurts. Tell them this makes you uncomfortable.’ And just, I don't know, I guess instill a little more self-advocacy... I would just be like, ‘Speak up. Speak up little [Stevie]. Tell them what's going on.’” (Stevie)

“If you can just accept and embrace your kid exactly the way they are, they will grow up to be equipped with the tools they need to advocate for themselves, and find themselves in a situation where they're safe, loved, and successful.” (Hestia Flynn)

*Disrupt Systems
of Oppression*

Recommendations for caregivers to disrupt systems of oppression that may harm their intersex child

“I think the main thing I would tell [caregivers of an intersex child] is to practice going out into the world, observing and interacting with people without gendering them. And if you teach yourself how to do that, it will allow you to recognize people's humanity without having to first filter them through the lens of a binary sex and gender. And that's something that most people do not know how to do, because they have not learned, but it is possible to do. I've taught myself to do it. I've known other people who can do it. And I think that that's one of the most important things that they can do for their kid.” (Sunleaf)

“For upcoming parents, I would definitely say, be prepared for it to be an eventuality. Because if you're going to have a kid, there's a chance they could be intersex. Like they could. And you don't control that. Neither do they. It's the way people are born and just be prepared for that eventuality. I would say if you're not willing to have a kid who is intersex, then probably don't have kids.” (Koko)

"I saw this video of this kid in somewhere like Washington State and their parents are raising them like to be the nonbinary intersex kid of their dreams and like they interviewed the kid. And they're just like- the kid is just like the happiest, most well-adjusted kid. And I just--[crying] I want every kid to have that experience because they deserve it. And I don't want it to be just like rich, White kids because kids like me deserve that too." (Alex)

Chapter 5 - Discussion

By conducting and analyzing interviews with 28 intersex emerging adults, we identified six themes of key socialization experiences that contributed to these individuals' meaning-making around having an intersex variation growing up: (a) *We Don't Talk About This*, (b) *We're All In The Dark*, (c) *We Could Use Some Help*, (d) *I Should Be Less Me*, (e) *My Body Isn't Mine*, and (f) *I Feel Supported And Empowered*. These themes highlighted the shared experiences of silence around intersex and related topics; confusion, isolation, and a lack of resources; reaching out to other sources for support; pressure to conform to hetero/cis/endonormative expectations and suppress emotions; lack of autonomy in multiple areas; as well as support and empowerment. Supported by social cognitive theory (Bandura, 1986), participants' stories emphasized the influence of explicit and implicit messages that they received from multiple influential sources in their lives as they worked to make meaning around their intersex variation and other identities. Both explicit and implicit messages from an interphobic and hetero/cis/endonormative societal context considerably contributed to negative meaning-making around having an intersex variation.

Based on these experiences, our sample of intersex emerging adults provided recommendations for caregivers of an intersex child, which we summarized in four themes: (a) *Make it Okay to Talk About*; (b) *Get Informed and Connected*; (c) *Center Your Child's Choices and Feelings*; and (d) *Disrupt Systems of Oppression*. These themes highlighted the importance that intersex emerging adults in our sample placed on open and honest communication about intersex and related topics; accessing educational and community resources; valuing intersex children's autonomy and feelings enough to let them make choices; and challenging interphobia and hetero/cis/endonormativity in multiple contexts. These findings show the importance of

caregivers as proximal socialization sources who have the potential to challenge and reject hetero/cis/endonormativity and interphobia and model how to do so for their intersex child (Bandura, 1986; Holmes, 2009). Even in the face of these systems of oppression, through a social cognitive perspective (Bandura, 1986), receiving intersex-inclusive and -positive messages from one source could positively affect one's meaning-making around having an intersex variation, emphasizing the importance of caregiver support.

Across their responses, participants showcase their personal adherence to principles of queer theory (Morland & Willox, 2017), critical disability studies (Malatino, 2019), and a critical intersex perspective (Holmes, 2009). On the whole, participants as emerging adults had deconstructed the idea of binary biological sex; rejected the idea that intersex bodies are abnormal and require intervention; rejected hetero/cis/endonormative essentialist ideas of sex, gender identity, gender expression, and sexual orientation; prioritized bodily autonomy; and celebrated bodily diversity. However, it was clear that this was not always the perspective they held growing up. Accepting tenets of these theories was labeled as helpful in combating shame and self-hating messages from an interphobic society. This perspective informed the importance that participants placed on caregivers disrupting systems of oppression, protecting their child's body autonomy, and affirming their child's choices.

Participants' stories highlighted how their other intersecting identities (e.g., gender, ability, race, ethnicity, immigrant status, socioeconomic status) influenced their experiences growing up with an intersex variation and their recommendations for caregivers. For example, participants whose families spoke English, presented as White, had health insurance, and were financially stable were better able to access medical care and were taken more seriously by medical professionals. Participants who were transgender, disabled, or a racialized minority in

addition to having an intersex variation reported grappling with these multiple layers of their identity and experienced forms of discrimination that their cisgender (or those who passed as cisgender), able-bodied, and White peers did not (e.g., “For a long time it was like, “I cannot be like broke, Latina, intersex, and bi. That’s just too fucking much.”[Alex]). These stories highlight the importance of the aims of the second wave of the intersex movement which focuses on understanding intersex in conjunction with other social identities (Rubin et al., 2022) and provide numerous directions for future research.

These findings considerably contribute to our understanding of intersex individuals’ experiences and perspectives in the U.S. Our findings support those from other U.S. samples (Davis, 2015; Human Rights Watch, 2017) which document experiences of shame, parents’ lack of understanding, and hetero/cis/endonormativity, with the need for caregivers to openly communicate and provide normalizing messages for their intersex child. Our findings also echo those of samples in Europe, Australia, and New Zealand which highlighted intersex individuals’ experiences of silence, confusion, shame, hetero/cis/endonormative pressures, harmful doctor experiences, need to monitor or suppress aspects of self, as well as support and acceptance from friends and family (Alderson et al., 2004; Frank, 2018; Gough et al., 2008; Jones et al., 2016; Lampalzer et al., 2021; Lundberg et al., 2021; MacKenzie, 2009; Pasterski, 2014; Preves, 2003; Randjelovic et al., 2017; Steers et al., 2021; Zeiler & Wickstrom, 2009). Our sample and samples outside of the U.S. agree on recommendations that caregivers normalize diversity in sex development, validate and prioritize child’s feelings and choices, and break the silence on intersex and related topics (Alderson et al., 2004; Frank, 2018; Jones et al., 2016; Lampalzer et al., 2021; Lundberg et al., 2021; MacKenzie, 2009; Preves, 2003). Although intersex individuals

and their experiences are not a monolith, these similarities suggest that many of these experiences and recommendations are common across various contexts.

Our study provides a novel contribution to existing intersex literature by directly soliciting recommendations for caregivers from intersex emerging adults. Although not all intersex emerging adults' recommendations are the same, this allowed us to organize recommendations from 28 intersex young adults into four common themes. These themes align with those of international human rights organizations. For example, in a guide for caregivers of an intersex child, IGLYO, OII Europe, and EPA (n.d.) advised that caregivers delay surgical intervention until a child can consent, minimize shame, normalize body diversity, provide unconditional love and acceptance, openly communicate about intersex topics, connect to resources for both themselves and their child, and advocate for their child with others. Similarly, in interACT's brochure *What We Wish Parents Knew*, they advised caregivers of an intersex child to connect their child to resources (e.g., therapy, support groups), get support for themselves as a caregiver (e.g., education about intersex topics, help working through emotional distress), listen and check in with their child's feelings, initiate and normalize conversations about intersex and related topics, advocate for their child with other sources (e.g., teachers, doctors), and prioritize their child's body autonomy (interACT, n.d.).

Our findings also bring to light experiences and recommendations for caregivers not commonly reported in previous literature. Most notably, our participants discuss feelings of support and empowerment that came from others providing instrumental support, prioritizing and advocating for their feelings and choices, communicating openly, and affirming their identities. These experiences bring focus to positive aspects of intersex young people's experiences, contributing a perspective of queer joy to intersex stories that are often overshadowed by

experiences of oppression, discrimination, and stigma. As proclaimed by the leaders of The Queer Joy Project (2019, para. 2):

[LGBTQIA+ folx] deserve to hear more stories than we have been told. We deserve narrative plentitude—so many stories that no single story or person has to serve as representative for the whole. We deserve to not just feel joy, but to share the infinite ways we have experienced it.

We hope that highlighting intersex emerging adults' stories of support and empowerment in this study contributes to this mission. Further, our participants' stories of support and empowerment showcase the potential for the positive impacts that others can have in the lives of intersex young people in the face of an interphobic world.

Last, our findings represent experiences with a wide array of influential figures in the lives of intersex young people, including caregivers, peers, friends, extended family, siblings, partners, medical professionals, and other influential adults (e.g., teachers, coaches, religious leaders). Unexpectedly, we were able to categorize the socialization experiences that intersex emerging adults had with all of these sources into six themes. Although each source had a unique relationship with participants (e.g., doctors in a position of authority, peers in shared social positions), they contributed in different ways to the same socialization experiences of silence, confusion/isolation, help-seeking, self-monitoring, shame, lack of autonomy, support, and empowerment. Therefore, our findings have important implications for not just one source, but a number of influential sources in the lives of intersex children; this includes recommendations for how caregivers can provide support for intersex children when dealing with other sources. Relatedly, we explored a variety of social situations and issues in the lives of intersex emerging adults, providing additional context to a body of literature that has often focused on intersex

surgeries (e.g., Cannoot, 2021; Human Rights Watch, 2017; Minto et al., 2003; Zeiler & Wickström, 2009). Although this is a crucial topic of study, surgeries and medical treatment do not represent the whole of intersex individuals' experience. By exploring a variety of social settings and socialization influences, our study provides additional context to the stories of intersex emerging adults by including their experiences of surgeries and medical treatments without limiting our study to just this one facet of their experience growing up as an intersex person.

Implications

Our findings have numerous implications for all sources with which intersex children and adolescents interact. First, caregivers and influential adults in intersex children's lives should work to educate themselves about intersex topics, deconstruct and challenge their own hetero/cis/endonormative beliefs, be open to conversations about intersex and related topics, and center the child's feelings and choices. This advice applies to all caregivers and adults who influence the lives of children, as (a) many intersex variations go undiagnosed well into adolescence and adulthood and (b) many intersex children do not disclose their diagnosis with others. As many individuals in our sample were significantly positively impacted by the support of just one or few affirming adults, increasing the number of adults who can provide support in these ways is an important step in improving the lives of intersex young people.

For caregivers, incorporating these suggestions requires a significant amount of self of the parent work (see Astle et al., 2022). This includes caregivers working through their own emotional distress that prevents open parent-child communication about intersex and related topics as well as emotional distress about their child existing outside of hetero/cis/endonormative assumptions and binaries. This includes deconstructing the idea that fathers cannot be involved

in the medical care and emotional experience of intersex children. Many participants in our sample expressed gratitude that their fathers were not involved in these aspects of their life due to fathers' interphobia and general queerphobia; this suggests that fathers especially should work to examine and challenge queerphobic and interphobic beliefs in order to provide additional support for their intersex child. Caregivers will also need to work to develop emotional competency so they can check in with and validate their child's feelings as recommended by participants in our sample. Parent education programs can help caregivers strengthen their emotional skills and deconstruct hetero/cis/endonormative beliefs. Parent education resources specific to caregivers of an intersex child can educate them on general intersex topics, including medical, identity, and social issues, and connect them to resources they can recommend to their intersex child.

Nearly all participants in our sample reached outside of their family for support in various ways. Therefore, improving the support that doctors and educational resources can provide intersex children and adolescence are important intervention points. First, in order to protect the body autonomy of intersex children, policies and laws must be set in place to prevent non-consensual surgeries, especially those done on infants. This is something for which intersex advocacy organizations have been fighting for decades and continue to do so (e.g., Human Rights Project, 2017; IGLYO et al., n.d.; interACT, 2021; Intersex Justice Project, 2021). As many participants reported incompetent medical professionals lacking knowledge of intersex development and queer identities in general, medical schools and training programs for medical professionals should provide comprehensive intersex- and queer-inclusive education, including education about queerness in general and how to affirm patients' identities and choices. Studies like this one can inform medical professionals about what intersex children and adolescents may

be going through as they learn about and navigate their diagnosis (e.g., confusion, shame, silence) so that medical professionals can be more aware of and attuned to potential needs of their intersex patients. Medical professionals should be made aware of the importance of providing adequate information at the time of diagnosis for intersex patients, including information on the distinctions between sex vs. gender identity vs. gender expression vs. sexual orientation. This requires medical professionals to do their own self of the medical professional work to challenge their own hetero/cis/endonormativity and be emotionally competent to center their patients' feelings and choices. Finally, medical professionals can provide important connections for intersex patients and their families to intersex resources, terminology, information, and advocacy groups.

Next, there is need for an increase in trustworthy and affirming intersex resources. This includes ensuring that existing sex education, biology, humanities, and any related courses are intersex-inclusive and intersex-positive. By acknowledging the reality of intersex bodies in positive ways, these existing educational resources can work to stop the erasure of intersex bodies and individuals. Sex education programs that help students confront hetero/cis/endonormativity can help students better support their intersex and queer peers and prepare students for a potential future as a caregiver of an intersex child. Increasing positive intersex resources also includes ensuring that existing LGBTQ advocacy spaces are intersex-inclusive. These organizations should seek to make it clear that intersex people and the unique issues they face will be represented and centered in their organization rather than ignored. As Sunleaf said in our interview, "I'm really tired of people [and organizations] being like, 'Ah, yes, LGBTQIA+.' And then not including or understanding intersex in any way." By improving the resources to which intersex children and adolescents have access, we can hopefully decrease the

shame, confusion, isolation, and silence that our participants reported for future generations of intersex children.

Relatedly, many intersex adults are working to cope with and heal from trauma they experienced in childhood and adolescence from silence, shame, confusion, and loss of autonomy. Creating resources specifically for intersex emerging adults navigating this healing process is crucial as existing resources are often centered on intersex children without consideration for challenges they may face in emerging adulthood (e.g., academic/career barriers due to poor school performance because of bullying, fighting for accurate legal gender and sex markers, inability to afford medical care). As J shared in our interview, “It's not like we perish at the age of 18. I think that there's remarkably little resources for intersex young adults... these are people who grow up and they're trying to participate into society and there's a lot of barriers.”

Last, as members of a society and culture that uphold the gender/sex binary and seek to erase intersex individuals and bodies, every person reading this study, whether personally connected to intersex experiences or not, can contribute to normalizing diversity in sex characteristics, educating others about the existence of intersex bodies and individuals, making space for queerness in their personal circles, and advocating for intersex-inclusive policies. As Pidgeon Pagonis recently stated in an interview published in *Transgender Studies Quarterly*, “Our contempt cannot rest on the shoulders of intersex people. We need a more radical display of solidarity beyond intersex people and their parents. We need everyone out there” (Rubin et al., 2022, p. 191). We especially recommend individuals consult interACT and the Intersex Justice Project to learn more about how to contribute in big or small ways to the intersex advocacy movement. We hope this movement will help create a more aware and inclusive world in which

intersex children and adolescents do not have to grow up in the dark, in silence, in shame, and without autonomy.

Limitations and Future Research

The contributions of our study to extant literature must be contextualized within its limitations. First, although our sample was diverse in terms of gender and sexual identities, the majority of our sample was White with a limited number of participants who identified as Latine, Asian American, Pacific Islander, or Native American, and no participants who identified as Black or African American. Future work should strive to amplify the voices of intersex individuals with minoritized racialized identities as “intersex people, especially those affected by multiple forms of marginalization are vulnerable to medical mismanagement, discrimination, stigmatization, and potential malpractice” (Wolff et al., 2022, p. 144). Representation in intersex advocacy spaces remains largely White (Rubin et al., 2022), highlighting the importance of intersex advocacy organizations that center people of color such as the Intersex Justice Project (2021). Future research should work to support the second wave of the intersex movement focusing on connecting intersex with other social identities (Rubin et al., 2022). Second, our sample does not represent the opinions of all people with variations in sex characteristics, especially those who do not use the label “intersex.” Although we advertised our study with language intended to include both (“identify as intersex and/or have a variation in sex characteristics”), we acknowledge that even associating this study with the word “intersex” may have deterred individuals with variations in sex characteristics who do not wish to be associated with that term. Future research should explore the experiences and recommendations for caregivers of individuals with variations in sex characteristics who do not identify as intersex and instead prefer to use other terms (e.g., disorder of sex development). Related, although there are

over 30 distinct medical terms for combinations of intersex variations (see interACT, 2016b and Randjelovic, 2017), our sample includes individuals with less than half of these variations. Certain variations are over-represented in our sample, with nearly half of participants having been diagnosed with androgen insensitivity or congenital adrenal hyperplasia. This highlights the need for future research with intersex individuals with a wide variety of variations and sex characteristics. Relatedly, as 18 of 28 participants reported being currently involved in a support group or advocacy organization for intersex individuals or individuals with a variation in sex characteristics, our work may not be representative of the opinions and experiences of intersex individuals who are not associated with these kinds of groups. Overall, future research should continue to explore experiences and needs of intersex individuals with a wide variety of backgrounds, intersex variations, cultural contexts, and identities.

Conclusion

This study is part of an ongoing movement to amplify the voices of intersex individuals and call attention to their needs in a society that erases and dehumanizes them. By interviewing 28 intersex emerging adults, we found that in the face of silence, confusion, isolation, shame, and autonomy loss, intersex emerging adults benefitted from and/or wished they had open and honest communication about intersex and related topics, supportive resources that challenged hetero/cis/endonormativity, and autonomy to make choices about their bodies and identities. As important influential figures in the lives of children, caregivers especially should work to provide these forms of support for their intersex child. Alyssa summed up our findings and their implications best in her interview when she advised caregivers of an intersex child: “Support the shit out of them.”

References

- #4intersex. (2018). *Educate yourself*. <https://4intersex.org/#yourself>
- Alderson, J., Madill, A., & Balen, A. (2004). Fear of devaluation: Understanding the experience of intersexed women with androgen insensitivity syndrome. *British Journal of Health Psychology*, 9(1), 81–100. <https://doi.org/10.1348/135910704322778740>
- Arnett, J. J. (2006). Emerging adulthood in Europe: A response to Bynner. *Journal of Youth Studies*, 9(1), 111-123. <https://doi.org/10.1080/13676260500523671>
- Arnett, J. J. (2014). *Emerging adulthood: The winding road from the late teens through the twenties*. Oxford University Press.
- Astle, S., McAllister, P., Emanuels, S., Rogers, J., Toews, M., & Yazedjian, A. Just be open about it or turn up the radio: A qualitative analysis of parent-child sexual communication experiences in adolescence. *Sexuality Research and Social Policy*, 1-14. <https://doi.org/10.1007/s13178-020-00530-1>
- Astle, S., McAllister, P., & Pariera, K. (2022). Self of the parent: An expanded social cognitive perspective on parent–child sexual communication. *Journal of Family Theory & Review*, Advance online publication. <https://doi.org/10.1111/jftr.12452>
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Prentice-Hall.
- Bernard, H. R., & Bernard, H. R. (2013). *Social research methods: Qualitative and quantitative approaches*. Sage.
- Birks, M., Chapman, Y., & Francis, K. (2008). Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*, 13(1), 68–75. <https://doi.org/10.1177/1744987107081254>

- Blackless, M., Charuvastra, A., Derryck, A., Fausto-Sterling, A., Lauzanne, K., & Lee, E. (2000). How sexually dimorphic are we? Review and synthesis. *American Journal of Human Biology*, 12(2), 151–166. [https://doi.org/10.1002/\(SICI\)1520-6300\(200003/04\)12:2<151::AID-AJHB1>3.0.CO;2-F](https://doi.org/10.1002/(SICI)1520-6300(200003/04)12:2<151::AID-AJHB1>3.0.CO;2-F)
- Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological*. (pp. 57–71). American Psychological Association. <https://doi.org/10.1037/13620-004>
- Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. Sage publications. <https://doi.org/10.53841/bpsqmip.2022.1.33.46>
- Canoot, P. (2021). Do parents really know best? Informed consent to sex assigning and ‘normalising’ treatment of minors with variations of sex characteristics. *Culture, Health & Sexuality*, 23(4), 564–578. <https://doi.org/10.1080/13691058.2020.1785012>
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches*. Sage publications.
- Davis, G. (2015). *Contesting intersex: The dubious diagnosis*. NYU Press.
- DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: A balance of relationship and rigour. *Family Medicine and Community Health*, 7(2), 1-8. <https://doi.org/10.1136/fmch-2018-000057>
- Flores, D., Docherty, S. L., Relf, M. V., McKinney, R. E., & Barroso, J. V. (2019). “It’s almost like gay sex doesn’t exist”: Parent-child sex communication according to gay, bisexual,

- and queer male adolescents. *Journal of Adolescent Research*, 34(5), 528–562.
<https://doi.org/10.1177/0743558418757464>
- Frank, S. E. (2018). Intersex and intimacy: Presenting concerns about dating and intimate relationships. *Sexuality & Culture*, 22(1), 127–147. <https://doi.org/10.1007/s12119-017-9456-4>
- Gough, B., Weyman, N., Alderson, J., Butler, G., & Stoner, M. (2008). ‘They did not have a word’: The parental quest to locate a ‘true sex’ for their intersex children. *Psychology & Health*, 23(4), 493–507. <https://doi.org/10.1080/14768320601176170>
- Green, J. (Host). (2017). *Finding intersex* [Audio podcast].
<https://www.podomatic.com/podcasts/findingintersex>
- Harvey, L. (2015). Beyond member-checking: A dialogic approach to the research interview. *International Journal of Research & Method in Education*, 38(1), 23–38.
<https://doi.org/10.1080/1743727X.2014.914487>
- Holmes, M. (Ed.). (2009). *Critical intersex*. Routledge.
- Human Rights Watch. (2017). *I want to be like nature made me: Medically unnecessary surgeries on intersex children in the US*. <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us#>
- IGLYO, OII Europe, & EPA. (n.d.) *Supporting your intersex child*. <https://www.iglyo.com/wp-content/uploads/2018/10/Supporting-Your-Intersex-Child.pdf>
- interACT Advocates for Intersex Youth. (2016a). *interACT Statement on Intersex Terminology*.
<https://interactadvocates.org/interact-statement-on-intersex-terminology/#:~:text=interACT%20believes%20that%20people%20born,of%20people%20with%20intersex%20traits.>

interACT Advocates for Intersex Youth. (2016b). *Intersex definitions*.

<https://interactadvocates.org/intersex-definitions/#:~:text=Intersex%20is%20an%20umbrella%20term,organs%20like%20testes%20or%20ovaries.&text=Intersex%20people%20can%20have%20any%20gender%20identity%20and%20sexual%20orientation>.

interACT Advocates for Intersex Youth. (2017). *Covering the intersex community*.

<https://interactadvocates.org/wp-content/uploads/2017/01/INTERSEX-MEDIAGUIDE-interACT.pdf>

interACT Advocates for Intersex Youth. (2021). *Stories*.

<https://interactadvocates.org/category/intersex-stories/>

interACT Advocates for Intersex Youth. (n.d.) *Working with intersex people*.

<https://interactadvocates.org/working-with-intersex-people/>

interACT Advocates for Intersex Youth. (n.d.). *What we wish our parents knew*. [https://live-](https://live-interact-advocates.pantheonsite.io/wp-content/uploads/2015/12/BROCHURE-interACT-Parents-final-web.pdf)

[interact-advocates.pantheonsite.io/wp-content/uploads/2015/12/BROCHURE-interACT-Parents-final-web.pdf](https://live-interact-advocates.pantheonsite.io/wp-content/uploads/2015/12/BROCHURE-interACT-Parents-final-web.pdf)

Intersex Justice Project. (2021). *Intersex Justice Project*. <https://www.intersexjusticeproject.org/>

Jones, T., Bonnie, H., Carpenter, M., Ansara, G., Leonard, W., & Lucke, J. (2016). *Intersex:*

Stories and statistics from Australia. Open Book Publishers.

<https://doi.org/10.11647/OBP.0089>

Josselson, R. (2013). *Interviewing for qualitative inquiry: A relational approach*. Guilford Press.

Kim, J. L., & Ward, L. M. (2007). Silence speaks volumes: Parental sexual communication

among Asian American emerging adults. *Journal of Adolescent Research*, 22(1), 3–31.

<https://doi.org/10.1177/0743558406294916>

- Lampalzer, U., Briken, P., & Schweizer, K. (2021). ‘That decision really was mine...’. Insider perspectives on health care controversies about intersex/diverse sex development. *Culture, Health & Sexuality*, 23(4), 472–483.
<https://doi.org/10.1080/13691058.2021.1892828>
- LGBTQ+ Primary Hub (2022). *Heteronormativity & cisnormativity*.
<https://www.lgbtqprimaryhub.com/heteronormativity-cisnormativity>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage publications.
- Lindahl, H. (2019, October 25). *Young people on how they found out they are intersex*. Teen Vogue. <https://www.teenvogue.com/gallery/young-people-on-how-they-found-out-they-are-intersex>
- Lundberg, T., Roen, K., Kraft, C., & Hegarty, P. (2021). How young people talk about their variations in sex characteristics: making the topic of intersex talkable via sex education. *Sex Education*, 1-16. Advance online publication.
<https://doi.org/10.1080/14681811.2021.1911796>
- MacKenzie, D., Huntington, A., & Gilmour, J. A. (2009). The experiences of people with an intersex condition: A journey from silence to voice. *Journal of Clinical Nursing*, 18(12), 1775–1783. <https://doi.org/10.1111/j.1365-2702.2008.02710.x>
- Malatino, H. (2019). *Queer embodiment: Monstrosity, medical violence, and intersex experience*. University of Nebraska Press.
- Martin, K. A. (2009). Normalizing heterosexuality: Mothers’ assumptions, talk, and strategies with young children. *American Sociological Review*, 74(2), 190–207.
<https://doi.org/10.1177/000312240907400202>

- Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research, 11*(3), 1-19. <https://doi.org/10.17169/fqs-11.3.1428>
- McAllister, P., Astle, S., & Vennum, A. (2021). Sex feelings: A mediated group path analysis of the association of perceptions of parent communicated sexual values with sexual attitudes and outcomes in emerging adulthood. *The Journal of Sex Research, vol. #*, 1-10. <https://doi.org/10.1080/00224499.2020.1869143>
- Milner IV, H. R. (2007). Race, culture, and researcher positionality: Working through dangers seen, unseen, and unforeseen. *Educational Researcher, 36*(7), 388-400. <https://doi.org/10.3102/0013189X07309471>
- Minto, C. L., Liao, L. M., Woodhouse, C. R., Ransley, P. G., & Creighton, S. M. (2003). The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study. *The Lancet, 361*(9365), 1252-1257. [https://doi.org/10.1016/S0140-6736\(03\)12980-7](https://doi.org/10.1016/S0140-6736(03)12980-7)
- Morland, I., & Willox, D. (2017). *Queer theory*. Bloomsbury Publishing.
- Negy, C., Velezmoro, R., Reig-Ferrer, A., Smith-Castro, V., & Livia, J. (2016). Parental influence on their adult children's sexual values: A multi-national comparison between the United States, Spain, Costa Rica, and Peru. *Archives of Sexual Behavior, 45*(2), 477–489. <https://doi.org/10.1007/s10508-015-0570-9>
- Newcomb, M. E., Feinstein, B. A., Matson, M., Macapagal, K., & Mustanski, B. (2018). “I have no idea what’s going on out there:” Parents’ perspectives on promoting sexual health in lesbian, gay, bisexual, and transgender adolescents. *Sexuality Research and Social Policy, 15*(2), 111–122. <https://doi.org/10.1007/s13178-018-0326-0>

- Nokoff, N. J., Palmer, B., Mullins, A. J., Aston, C. E., Austin, P., Baskin, L., ... & Wisniewski, A. B. (2017). Prospective assessment of cosmesis before and after genital surgery. *Journal of Pediatric Urology*, *13*(1), 28.e1-e6.
<https://doi.org/10.1016/j.jpuro.2016.08.017>
- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), 1-13. <https://doi.org/10.1177/1609406917733847>
- Open Society Foundations. (2019, April). *What are intersex rights?*
<https://www.opensocietyfoundations.org/explainers/what-are-intersex-rights#:~:text=Intersex%20people%20often%20experience%20prejudice,genitalia%2C%20face%20abandonment%20and%20violence>.
- Pasterski, V., Mastroyannopoulou, K., Wright, D., Zucker, K. J., & Hughes, I. A. (2014). Predictors of posttraumatic stress in parents of children diagnosed with a disorder of sex development. *Archives of Sexual Behavior*, *43*(2), 369-375.
<https://doi.org/10.1007/s10508-013-0196-8>
- Pew Research Center. (2014, April 15). *Global morality*.
<https://www.pewresearch.org/global/interactives/global-morality/>
- Pew Research Center. (2018, July 31). *Americans are far more religious than adults in other wealthy nations*. <https://www.pewresearch.org/fact-tank/2018/07/31/americans-are-far-more-religious-than-adults-in-other-wealthy-nations/>
- Preves, S. E. (2003). *Intersex and identity: The contested self*. Rutgers University Press.
- Randjelovic, K., Kumwenda, R., Macauley, J., Mladenovic, N., & Konstantinov, B. (2017). *Intersex research study: Albania, Bosnia and Herzegovina, the former Yugoslav Republic*

- of Macedonia and Serbia*. United Nations Development Programme. <https://www.lgbti-era.org/sites/default/files/pdffdocs/Intersex%20Research%20Study-ENG.pdf>
- Roen, K., & Hegarty, P. (2018). Shaping parents, shaping penises: How medical teams frame parents' decisions in response to hypospadias. *British Journal of Health Psychology*, 23(4), 967–981. <https://doi.org/10.1111/bjhp.12333>
- Rubin, D. A., Wolff, M., & Swarr, A. L. (2022). Creating intersex justice. *TSQ: Transgender Studies Quarterly*, 9(2), 187–195. <https://doi.org/10.1215/23289252-9612823>
- SOAS University of London (2022). *SOAS trans, non-binary & intersex inclusion guidance for those supporting students*. <https://www.soas.ac.uk/sites/default/files/2022-11/PHUM-TNBI-StG-001.pdf>
- Seitz, S. (2016). Pixilated partnerships, overcoming obstacles in qualitative interviews via Skype: A research note. *Qualitative Research*, 16(2), 229–235. <https://doi.org/10.1177/1468794115577011>
- Snell, W. E. (1998). The multidimensional sexual self-concept questionnaire. In T. D. Fisher, C. M. Davis, W. L. Yarber (Eds.), *Handbook of sexuality-related measures* (pp. 521–524). Routledge. <https://doi.org/10.4324/9781315881089>
- Solebello, N., & Elliott, S. (2011). “We want them to be as heterosexual as possible”: Fathers talk about their teen children’s sexuality. *Gender & Society*, 25(3), 293–315. <https://doi.org/10.1177/0891243211403926>
- Steers, D. M., Andrews, G. L., Wiltshire, E. J., Ballantyne, A. J., Collings, S. C., & Stubbe, M. H. (2021). Young people with a variation in sex characteristics in Aotearoa/New Zealand: Identity, activism and healthcare decision-making. *Culture, Health & Sexuality*, 23(4), 457–471. <https://doi.org/10.1080/13691058.2020.1863472>

- The Interface Project. (2019). *Stories*. <https://www.interfaceproject.org/stories>
- The Queer Joy Project. (2019). *The Queer Joy Project*. <https://www.thequeerjoyproject.com/>
- Thisisintersex.org. (2023). *What is intersex? This is intersex!*
<https://thisisintersex.org/advanced/interphobia/>
- UCSF Lesbian, Gay, Bisexual, and Transgender Resource Center. (2023). *General definitions*.
<https://lgbt.ucsf.edu/glossary-terms>
- Wolff, M., Rubin, D. A., & Swarr, A. L. (2022). The intersex issue. *TSQ: Transgender Studies Quarterly*, 9(2), 143–159. <https://doi.org/10.1215/23289252-9612767>
- Zeiler, K., & Wickström, A. (2009). Why do ‘we’ perform surgery on newborn intersexed children?: The phenomenology of the parental experience of having a child with intersex anatomies. *Feminist Theory*, 10(3), 359–377.
<https://doi.org/10.1177/1464700109343258>

Appendix A - Introductory Survey and Informed Consent

Start of Block: Introduction to Survey

Q25 Welcome- you're in the right place! Click ahead for more details about participating in this project.

**INTERSEX
YOUNG ADULTS
WE WANT TO
HEAR FROM YOU**

**THANKS FOR YOUR
INTEREST IN OUR PROJECT!**

WE ARE INTERVIEWING INDIVIDUALS WHO

- Are between 18-29 years old
- Identify as intersex and/or have a variation in sex characteristics
- Experienced effects or symptoms of their variation in sex characteristics/intersex variation before age 18
- Live in the U.S.

PARTICIPANTS WILL EARN A \$25 GIFT CARD

OUR PROJECT GOALS

We want to understand intersex young adults' experiences with caregivers related to being intersex and how these experiences affect their identity and sexual well-being as a young adult.

WE HOPE THIS RESEARCH CAN INFORM CAREGIVERS ON HOW TO BE BETTER SUPPORTS FOR THEIR INTERSEX CHILDREN

Intersex individuals deserve better sex ed from birth. Unfortunately, there is very little research on how caregivers can be better supports. I hope this project will amplify intersex voices to help caregivers of intersex children provide the shame-free education & acceptance their children deserve.

- Shelby Astle, M.S.,
Lead researcher

Funding for this project provided by the Society for the Study of Emerging Adulthood with consulting services from InterACT Advocates for Intersex Youth

Ssea InterACT Advocates for Intersex Youth

Page Break

Q26 Here's how we define intersex for this study. You can learn more at interACT's [website](https://www.interactadvocates.org).

WHAT WE MEAN BY INTERSEX

INTERSEX



is an umbrella term for unique variations in reproductive or sex anatomy, compared to the two usual paths of human sex development. Variations may appear in a person's chromosomes, genitals, or internal organs like testes or ovaries. Some intersex traits are identified at birth, while others may not be discovered until puberty or later in life. - **interACT Advocates for Intersex Youth**

NOT EVERYONE

with a variation in sex characteristics identifies as intersex, but lots of people do. If you have a variation in sex characteristics but don't identify as intersex, you're still welcome to participate in our interviews!

Learn more at
[interactadvocates.org](https://www.interactadvocates.org)

SOME COMMON VARIATIONS IN SEX CHARACTERISTICS

Turner syndrome (TS)
Klinefelter syndrome
Gonadal dysgenesis
Hypospadias and epispadias
Mayer-Rokitansky-Küster-Hauser (MRKH)
Congenital adrenal hyperplasia (CAH)
Androgen insensitivity syndrome (AIS)
5 alpha reductase-3 deficiency



End of Block: Introduction to Survey

Start of Block: Informed Consent

Q14 Get to know the [lead researcher](#) behind this project and what participation in this study would look like:

A NOTE FROM THE RESEARCHER

My name is Shelby Astle and I am a PhD student who studies how caregivers can provide the best support for their children as they teach them, either verbally or nonverbally, about sexuality, bodies, attraction, identity, and more. As I was doing my research, I found that we were missing the voices of intersex people and what they needed from caregivers when they were growing up to help them develop a healthy relationship with themselves and their sexuality. We've partnered with **interACT Advocates for Intersex Youth** in creating this research project and are beyond grateful for their support.



The goal of this project to (a) understand intersex young adults' experiences with caregivers related to being intersex and (b) how these experiences affect identity and sexual well-being as a young adult. By sharing your experiences and thoughts with me, you will be providing valuable information about sexual well-being and caregiver-child communication that we can use to help educate caregivers and professionals about the best ways to support intersex children. The information you provide is critical in amplifying the experiences and needs of intersex children and young adults. If you complete both the intro survey here on Qualtrics and an hour-long interview, we will be compensate you with a **\$25 gift card** as we know your time is valuable.

In order to participate, you have to (a) identify as intersex and/or have a variation in sex characteristics, (b) be between 18-29 years old, (c) learned you were intersex or had a variation in sex characteristics before age 18, and (d) live in the U.S. We've used both of the terms "intersex" and "variation in sex characteristics" since not everyone with a variation in sex characteristics identifies as intersex. If you meet these criteria, you'll be able to complete the intro survey here in Qualtrics. Once you complete the survey, you'll be directed to a website where you can select available times for the interview. I will then reach out to you via email to officially schedule a time for the interview which will take place via online video conferencing.

In interviews, I will ask questions about how your caregivers did (or didn't) talk about intersex-related topics, what support you would have liked to receive, and how you feel these interactions may affect you today. Because we want to understand how childhood experiences affect sexual well-being in young adulthood, we will be asking questions about sexuality. Know that it is your right to skip a question or take a break at any time throughout the interview. You can also **reach out to me at prolific.query@gmail.com** if you have questions or concerns about the interview questions we'll be asking.

I know that sharing your life experiences is a choice and I take my responsibility of ethically conducting research very seriously. Throughout this process, **your well-being is my priority** and I promise to treat the information you share with me with absolute care and respect. Your personal identifying information will not be shared with anyone besides me & you will have the choice to use a pseudonym in the final report of results.

Funding for this project provided by the Society for the Study of Emerging Adulthood with consulting services from interACT Advocates for Intersex Youth



Q27 If you'd like to sign up to participate, click on the arrow below to start the intro survey.

Page Break

Q8

PARENT-CHILD SEXUAL COMMUNICATION AND INTERSEX EMERGING ADULTS' SEXUAL WELL-BEING

APPROVAL DATE: 3/13/22

EXPIRATION DATE OF PROJECT: 3/12/25

LENGTH OF STUDY: 60-90 minutes

PRINCIPAL INVESTIGATOR: Kristin Anders

CO-INVESTIGATORS: Shelby Astle

CONTACT FOR ANY PROBLEMS/QUESTIONS: Shelby Astle, prolific.query@gmail.com

IRB CHAIR CONTACT INFORMATION: Rick Scheidt, Chair, Committee on Research Involving Human Subjects, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224; Cheryl Doerr, Associate Vice President for Research Compliance, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224. **PROJECT SPONSOR:** The Society for the Study of Emerging Adulthood

PURPOSE OF THE RESEARCH: The goal of this research project is to understand intersex young adults' experiences with parents/caregivers related to being intersex (e.g., how you communicated or didn't communicate about intersex topics). We also want to understand how these experiences with parents/caregivers affect identity and sexual well-being as a young adult.

PROCEDURES OR METHODS TO BE USED: We will collect your contact information, screen eligible participants, and collect information that will be referenced in the interview (e.g., sexual self-concept, race/ethnicity) using this online survey. The lead researcher will then contact you to set up a time for an interview conducted through online video conferencing. Interview will last approximately one hour and will include questions about (a) the communication you had (or did not have) with your caregivers and other important adults related to being intersex and (b) current pieces of your identity and sexual well-being. We realize your time is valuable, but the information you provide is critical in amplifying the experiences and needs of intersex young adults.

RISKS OR DISCOMFORTS ANTICIPATED: The possible risk to your participation is psychological discomfort from revisiting past events and interactions that might have been negative. To minimize the potential for discomfort, you can skip any questions you are not comfortable answering or end your participation in the study at any point in time. However, if you do experience discomfort, the following resources might be helpful: interACT provides online resources for connecting with intersex individuals and educational resources about intersex topics (<https://interactadvocates.org/>).

BENEFITS ANTICIPATED: If you complete both the online demographic survey and the interview, you will receive a \$25 gift card. You will also be providing valuable information about sexual well-being and caregiver-child communication that we can use to help educate caregivers and professionals about communicating about intersex topics.

EXTENT OF CONFIDENTIALITY: Data will be stored electronically on password protected

computers. The lead researcher will have access to your identifying information that will be used to communicate with you about scheduling an interview time and send you compensation for your participation. An audio-only recording of your interview will be sent to a third-party service for transcription. However, you may request instead that the lead researcher transcribes the interview. The report of the research findings will be in summary form, reflecting the general responses of participants. You will have the choice to use a pseudonym in place of your real name in the report of these results.

Q9 By clicking on the “I Agree” button at the bottom of the page, you are indicating that you understand the information provided above and have decided to consent to participate in the study. You also understand that if you decide to participate in this study, you may withdraw consent at any time and stop participating without explanation, penalty, or loss of benefits to which you may otherwise be entitled. We recommend that you print a copy of this consent form for your records. Thank you in advance for your willingness to help us out on our project.

- I Agree (1)
- I Disagree (2)

End of Block: Informed Consent

Start of Block: Inclusion Criteria: Current Age



Q18 What is the best email address to contact you at? (this will be the email used to schedule your interview and send you your \$25 gift card at the end of the interview, so please use an email you check regularly)

Q4 What is your age (in years)?

- 18 (1)
 - 19 (2)
 - 20 (3)
 - 21 (4)
 - 22 (5)
 - 23 (6)
 - 24 (7)
 - 25 (8)
 - 26 (9)
 - 27 (10)
 - 28 (11)
 - 29 (12)
 - Not listed (please specify): (13)
-

End of Block: Inclusion Criteria: Current Age

Start of Block: Inclusion Criteria: Age at Finding Out

Q39 Were you born intersex and/or with a variation in sex characteristics? This could involve variations in gonads, internal organs, external genitalia, hormone production or response, chromosomes, or secondary sex characteristics.

- Yes (1)
 - No (2)
 - Unsure (please specify): (3)
-

Q1 How do you describe what makes you intersex (i.e., your variation in sex characteristics)?

Q33 About how old were you when you learned that you were intersex or had a variation in sex characteristics?

- 0-5 years old (1)
- 6-11 years old (2)
- 12-15 years old (3)
- 16-18 years old (4)
- 19 years old or older (5)

End of Block: Inclusion Criteria: Age at Finding Out

Start of Block: Inclusion Criteria: Language and Country

Q35 What country do you live in?

- United States (1)
 - Outside of the U.S. (please specify): (2)
-

Q36 What languages are you fluent in? Check all that apply.

- English (1)
- Spanish (2)
- French (3)
- Tagalog (4)
- Mandarin (5)

End of Block: Inclusion Criteria: Language and Country

Start of Block: Demographics

Q2 Please indicate your race (mark all that apply).

- White/Caucasian (1)
 - Black/African American (2)
 - Asian American/Pacific Islander (3)
 - Native American/American Indian (4)
 - Not listed (please specify) (5)
-

Q3 Do you identify as Latinx or Hispanic?

- Yes (1)
 - No (2)
-

Q6 How would you describe your gender identity?

Q15 What are your pronouns?

Q7 How would you describe your sexual orientation?

Page Break

Q26 Are you currently involved in any support groups or advocacy organizations for intersex individuals or individuals with a variation in sex characteristics?

- Yes (please specify): (4) _____
- No (5)
-

Q41 Growing up, did you have a parent, primary caregiver, or important adult in your life who was also intersex or had a variation in sex characteristics?

- Yes (1)
- No (2)
- Unsure (please specify): (3)
- _____

End of Block: Demographics

Start of Block: Sexual Self-Concept

Q22 The next items in this questionnaire refer to people's sexuality. We're asking these questions so we can learn more about the pieces of your current sexual well-being.

Please read each item carefully and decide to what extent it is characteristic of you. Give each item a rating of how much it applies to you.

	Not at all characteristic of me (1)	Slightly characteristic of me (2)	Somewhat characteristic of me (3)	Moderately characteristic of me (4)	Very characteristic of me (5)
I feel anxious about the sexual aspects of my life. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel discouraged about my sex life. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a fear of sexual relationships. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm not very direct about voicing my sexual needs and preferences. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have the capability to take care of my own sexual needs and desires. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel good about the way I express my own sexual needs and desires. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am very aware of my sexual feelings and needs. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with the sexual aspects of my life. (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I expect that the sexual aspects of my life will be positive and rewarding in the future. (9)

End of Block: Sexual Self-Concept

Start of Block: Questions or concerns

Q20 To ensure your anonymity and confidentiality when reporting the results of these interviews, we offer the option of using a pseudonym instead of your real name. Would you like us to use a pseudonym when sharing the results of this study?

- Yes; please use a pseudonym (1)
- No; please use my real name (2)

Display This Question:
If To ensure your anonymity and confidentiality when reporting the results of these interviews, we o... = Yes; please use a pseudonym

Q5 Which pseudonym would you like to us to use for you?

Page Break

Q19 What is the best phone number to contact you at? (this will only be used to communicate with you if the Internet fails during our interview video call)

Q11 What questions or concerns do you have about participating in this study? Anything you want us to know?

End of Block: Questions or concerns

Start of Block: Scheduling Interview

Q12 Thank you for answering the previous questions!

Please click the arrow below to submit your answers and to be redirected to the Calendly.com, a scheduling service where you can select dates and times that you are available for your interview. After selecting your availability, our lead researcher will reach out via email (using the email you entered in this survey) to officially schedule your interview time.

End of Block: Scheduling Interview

Appendix B - Interview Protocol

Introduction

My name is Shelby and I am the lead researcher on this project. Everyone on this project appreciates your time and willingness to speak with me today. We hope that hearing the experiences of yourself and others interviewed for this project will increase intersex visibility and help caregivers of intersex children better understand how to provide the support their children need.

The goal of this conversation is to understand your experiences growing up with parents/caregivers related to being intersex, including how you communicated or didn't communicate about intersex topics and what support you received or would have liked to receive. We also want to understand how these experiences with parents/caregivers and other people in your life affect your identity and sexual well-being as a young adult. There are no right or wrong answers, we are just interested in your opinions and experiences.

We will be keeping everything that you say here today confidential. In fact, if you feel more comfortable turning off your camera during the interview, that is totally ok. Your responses will be only shared [anonymously/with your first name only] and I will be the only one who has access to your personal identifying information. It looks like you have chosen "X" as the pseudonym you'd like us to use when reporting these results, is that correct?

As stated in the informed consent at the beginning of the intro survey, I will be recording our conversation so we don't have to slow down this process to write everything down, although you will also see me taking notes throughout to help guide the interview. An audio-only recording will then be sent to a third-party service for transcription to help us record your answers. Before we begin, I just want to confirm that we have permission to record this conversation and transcribe your interview in this way.

Participation is completely voluntary so you can leave at any time, skip a question at any time, or ask that we take a break at any time. We will be covering topics that can be emotionally difficult (e.g., sexuality, childhood experiences), so please let me know if you need to take a break, skip a question, or access additional resources. If we experience technical difficulties and lose the ability to communicate via Zoom, I will email you at [confirm email from introductory survey] with instructions on how to continue our interview using a phone call.

Before we begin, what questions do you have for me about myself, this project, or the interview process? [answer any questions]

I will start the recording now.

<< Start recording >>

Background

Let's start with some background information about yourself and your life growing up. This will help me get a better sense of the important adults in your life we will be discussing throughout the interview.

- What language would you like me to use when referring to your intersex variation (e.g., intersex, name of variation, etc.)?
-
- Tell me about the important adults or caregivers in your life growing up. Who do you consider your primary caregiver/s or the main people who took charge of raising you?
- What was your experience growing up intersex or finding out you were intersex?
 - Possible probes: How did you find out you were intersex? [reference age listed in demographic survey]

Parent-Child Communication

Now, I'd like to talk about the ways that your parents/caregivers communicated with you about being intersex and some other topics.

- Did parents/caregivers talk with you directly about being intersex?
 - **Yes:** What were those conversations like? What do you remember about what they said, how they said it, and how you felt? What did you take away from these interactions?
 - **No:** Do you think things would have been different if your parents/caregivers had talked to you about these topics? Why do you think they didn't talk to you?
- Did you ask your parents/caregivers questions about being intersex?
 - **Yes:** How did they respond? What do you remember about what they said, how they said it, and how you felt? Did you feel like you could ask them more questions?
 - **No:** Why not?
- What indirect messages did you get from your parents/caregivers about being intersex (e.g., body language, tone, things they avoided discussing, etc.)?
 - How did parents/caregivers make you feel about being intersex?
 - What emotions do you remember picking up from your parents/caregivers (how they were feeling) about you being intersex?
- What messages did parents/caregivers send you (either directly or indirectly) about...
 - a. Gender and sexuality (sex, sexual orientation, sexual feelings, sexual attraction)
 - b. Anatomy/puberty
 - c. Body autonomy, self-love, & acceptance
 - d. Discrimination/oppression
 - **Talked about these:** What did you take away from these conversations?
 - **Didn't talk about these:** What would have been different if your parents/caregivers had talked to you about these topics? Do you feel like they could

have?

- Overall, looking back on conversations or messages from parents/caregivers about intersex or related topics, what do you wish they had said or done differently (timing, context, topics, values)?
- Growing up, did you feel like parents/caregivers advocated for you? What about looking back on it now?
 - Were there specific instances when you felt your parents/caregivers advocated for you?
 - **Yes:** What did that mean to you?
 - **No:** What do you wish they would have done to advocate for you? What would that have meant to you?
- Do you have conversations about intersex with your parents/caregivers now? Would you? What is that/would that be like?
-

Parents & Others

Thanks for everything you've shared so far. Now, we're going to talk about what it was like growing up intersex in different social groups.

- Other than your parents/caregivers, did you get social support, messages, or seek info about being intersex from other important adults in your life? Did you have access to other intersex adults?
 - What was that like? What direct or indirect messages did you receive from them about being intersex? What did that mean to you?
 - Could you share with them about being intersex and what that was like for you?
- Other than your parents/caregivers, how did you navigate being intersex around other family members or members of your household (e.g., siblings, extended family)?
 - Did parents/caregivers provide support to you in dealing with these interactions?
 - Did you ever tell or try to tell your parents/caregivers about what was going on with other family members or members of your household (e.g., your emotions, what they were saying)? Why or why not?
- How did you navigate being intersex around your friends or peers? How did friends or peers respond to you being intersex (if they knew)?
 - Did parents/caregivers provide support to you in dealing with peer interactions related to being intersex?
 - Did you ever tell or try to tell your parents/caregivers about what was going on with friends/peers (e.g., your emotions, what they were saying)? Why or why not?
- How did you navigate being intersex around other adults (e.g., doctors, teachers, religious leaders)? How did they respond to you being intersex (if they knew)?
 - Did parents/caregivers provide support to you in dealing with these interactions?

- Did you ever tell or try to tell your parents/caregivers about what was going on with other adults (e.g., your emotions, what they were saying)? Why or why not?

Overall Retrospective

My next couple of questions ask you to think about what it might have been like for your parents/caregivers.

- What do you think was going on for your parents/caregivers as they parented you?
- If you were in charge of parenting yourself, what would you have done differently?

Sexual Self-Concept in EA

Now, we're going to transition to talking about your current identity and relationship with sexuality. We're hoping to get a better understanding of how early life experiences may or may not contribute to sexual well-being for intersex young adults. I know this can be difficult to talk about and want to remind you that you can take a break or skip a question at any time.

- What does being intersex mean for you in your current stage in life?
 - How did learning about being intersex affect how you see yourself? What was that journey like?
- How would you describe your relationship with your sexuality? (i.e., How do you feel about your sexual self? How do you see yourself sexually? What is your view of yourself as a sexual being?)
 - In the intro survey, you marked that [SSC]. Could you tell me more about that?
- How does being intersex play a role in how you see yourself as a sexual being?
 - How did the way your parents/caregivers talked with you (or didn't talk with you) play a role in shaping this part of your life?
- How does being intersex play a role in your romantic and/or sexual relationships now?
 - How did the way your parents/caregivers talked with you (or didn't talk with you) play a role in shaping this part of your life?

Emerging Adulthood & Identity

Thank you so much for sharing what you have with me – some of that can be really hard to talk about. My last questions will focus on your identity, future, and any final reflections you have about the interview topic and process.

- How does intersex fit into your identity now?
 - How does that piece of your intersex identity play a role in your future dreams, goals, or plans?
- Do you feel like being [race/ethnicity] has affected your experience of being intersex? If so, how?

- Based on your life experiences, what would you say to parents/caregivers of intersex children today?

-

Debriefing

- Is there anything else you'd like to add about what we've talked about today?
- How did you feel about the interview process? Was there anything that made you feel comfortable or that you would change?

<< Stop recording >>

Concluding Instructions

Thank you so much for your time. Everyone on this project appreciates your willingness to share with me today. I will be emailing your \$25 gift card along with a list of intersex resources. In the future, we will also be emailing you the final results of this study.

If you know of anyone who would be interested in participating in these interviews, please feel free to share the link to our introductory survey with them.