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"I wouldn't want anything that would change who he is." The relationship between perceptions of identity and attitudes towards hypothetical gene-editing in parents of children with autosomal aneuploidies

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ABSTRACT

Attitudes towards hypothetical somatic and germline gene-editing technologies for those who are directly impacted by genetic conditions are of increasing importance as these potential therapeutics are developed. This study is a secondary analysis of 27 semi-structured interviews conducted with parents of children with Trisomy 13 (N = 9), Trisomy 18 (N = 8), or Trisomy 21 (N = 10) that aimed to explore the relationship between perceptions of identity as it relates to the trisomy within the family and parental attitudes towards gene-editing. A codebook was developed using both deductive and inductive approaches. All transcripts were coded and every third was adjudicated to consensus. Identity themes that emerged were integrated into a framework that conceptualized the relationship between participants' perceptions of identity and their attitudes towards somatic and germline gene-editing. Participants varied in the degree to which they incorporated their child's trisomy into their perception of their child's identity (from *a series of medical features* to *"who the child is"*) and their identity as a parent (from *a barrier to expected adult and parenting experiences* to *a catalyst for personal, parental, and social change*). Participants who viewed the trisomy as separate from identity were more likely to favor gene-editing as a restorative therapy, while participants who conceptualized their child's trisomy as fundamental to identity were more likely to oppose gene-editing as an unwelcome cure. Participants who had discrepant views about the incorporation of the trisomy into their child's identity and their own identity had more complex attitudes towards gene-editing. Considering perceptions of identity as it relates to genetic conditions and its role in attitudes towards potential therapeutics is important for researchers, policy makers, and practitioners who will develop, regulate, and implement gene-editing technologies.

1. Introduction

Gene-editing technologies, such as CRISPR-Cas9, are currently being explored as potential therapeutics for genetic conditions. Clinical trials for somatic gene-editing for several monogenic conditions, including inherited retinopathies and sickle cell disease, are underway (Bacci et al., 2022; Frangoul et al., 2021), and a group of biomedical scientists controversially employed germline gene-editing in human subjects (Normile, 2018).

Such research developments have led to the expectation that somatic gene-editing may soon emerge as conventional treatment (Hsu et al., 2014). The scientific and bioethical communities have generally supported human somatic gene-editing but opposed germline gene-editing on ethical grounds (Andorno et al., 2020; Ormond et al., 2017; Howard et al., 2018), or at least urged caution and ongoing deliberation (The Royal Society, 2020; World Health Organization, 2021). However, increased engagement from diverse stakeholders is needed to align the scientific goal of ameliorating or preventing disease with the goals of those with genetic conditions who will be directly impacted (Allyse et al., 2019).

Studies have reported attitudes towards gene-editing treatments from individuals affected with several monogenic conditions (Hoffman-Andrews et al., 2019; Hollister et al., 2019; Persaud et al., 2019). Yet, more research is needed to characterize the complexity of perspectives on gene-editing throughout the genetic disability community, including conditions that feature intellectual disability and a broader range of

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medical severities.

Trisomy 21 (T21), commonly known as Down Syndrome, is caused by the presence of a third chromosome 21. T21 is the most common autosomal aneuploidy and genetic cause of intellectual disability (de Graaf et al., 2017); Trisomy 18 (T18), caused by a third chromosome 18, and Trisomy 13 (T13), caused by a third chromosome 13, are the next two most common autosomal aneuploidies. Individuals with T21, T18, and T13 present with phenotypic diversity including varying medical concerns and degrees of cognitive impairment (Mai et al., 2013). These conditions are congenital and have no targeted treatment. Although gene-editing technologies aimed at "silencing" the extra chromosome are being researched, the efficacy of these technologies remains low (Akutsu et al., 2020; Zuo et al., 2017). Consequently, the somatic and germline CRISPR-Cas9 technologies discussed in this paper are not available to parents of children with trisomies. Rather, those affected by these conditions represent an interesting and important stakeholder in the conversation about attitudes towards potential therapeutics for parents of children with genetic intellectual disability.

Studies have begun to explore the perspectives of parents of individuals with autosomal aneuploidies on hypothetical gene-editing (Snure Beckman et al., 2019; Michie & Allyse, 2019; Riggan et al., 2020). Snure Beckman et al. (2019) found that parents of children with T21, T18, and T13 have complex perspectives on both somatic and germline CRISPR-Cas9 technologies. Parents of children with T18 and T13, conditions associated with high morbidity and mortality, were more open to gene-editing as a life-saving treatment. Parents of individuals with T21 emphasized gene-editing as a potential tool for increasing communication and independence as a way to improve quality of life for their children. However, many parents were conflicted about genetically altering their child's personality or identity.

This study builds upon the work of Snure Beckman et al. (2019) to further characterize how concepts of identity relate to attitudes towards gene-editing in this population, including parents of children with T13 and T18, who are under-represented in the literature. This paper also goes beyond the current literature to explore how parental identity, as it relates to the childs' disability, interacts with their view of their child's identity to contribute to attitudes on gene-editing.

1.1. Concepts of identity

Identity can be defined simplistically as "who a person is" (Chadwick, 2001). However, identity is a complex and multidimensional concept. Kelly and Millward (2004) built upon Erikson's (1968) theory of psychosocial development to study identity in the context of health. They conceptualized identity as having two components: personal identity and social identity. Personal identity is a manifestation of how one views themself (self-concept) as influenced by many aspects of one's life, including genetic information and disability status (Forber-Pratt et al., 2017). Social identity aligns with postmodernist theory that suggests that identity is constructed in relation to others within their social context (Stets & Burke, 2000). This socially-constructed understanding of identity is central in the literature that explores how individuals with disabilities and their parents incorporate disability into identity (Darling, 2003; Johnson, 2020).

The interaction between attitudes towards treatment and identity is documented in the disability studies literature. Individuals who view their own disability as a positive element of their personal identity and as a tie to their community are less likely to desire treatment or cure. Conversely, individuals who view their disability as a medical problem separate from identity with a negative impact on quality of life are more likely to desire treatment or cure (Boardman et al., 2018; Hahn & Belt, 2004; Hoffman-Andrews et al., 2019).

Parental identity is described by Galinsky (1987) as a reflexive process. A child's lived experience influences parental identity as parents evolve to meet the demands of their growing child. Parents of children with severe impairments have reported increased stress, exhaustion, and interference with expected parental activities; yet they also report that their children provide them with "direct benefits" of increased confidence, strength, and skills (Green et al., 2016). Parents of children with disabilities have also described "straddling the border between ability and disability" as not just an ally of their disabled child but also as an extension of their child (Johnson, 2020; Ryan & Runswick-Cole, 2008). The way that parents personally experience their child's disability has been shown to influence their approach to the process of adaptation including desire for treatment (Darling, 2003; Green et al., 2016; Inglis et al., 2014; Johnson, 2020).

2. Materials and methods

This study is a secondary analysis of interviews conducted as part of a primary study that explored stakeholders' views of hypothetical gene-editing (Snure Beckman et al., 2019). Stanford University's Institutional Review Board granted ethical approval of all aspects of both the primary study and secondary analysis (protocol #46984), and all participants provided informed consent.

2.1. Primary study

2.1.1. Participant recruitment

There were 27 interviews conducted with parents of living or deceased children diagnosed with full or mosaic (some but not all of the individual's cells harbor the aneuploidy) T21, T18, or T13. The participants were recruited using purposive sampling (Giacomini & Cook, 2000) according to the genetic diagnosis of the child. The participant recruitment of this study has been previously reported in greater detail (Snure Beckman et al., 2019). Briefly, parents of individuals with T21 were recruited through the Mayo Clinic GIFTED study, a mixed-methods study that explored attitudes toward potential genetic therapeutics in this population (Michie & Allyse, 2019). Parents of children with T13/T18 were recruited through the Support Organization for Trisomy 18, 13, and Related Disorders (SOFT).

2.1.2. Materials and data collection

A team of genetic counselors and bioethicists with clinical experience, qualitative research experience, and gene-editing content expertise created an interview guide for the primary study. The interviews included short educational segments to uniformly inform participants about the hypothetical technologies being discussed (see Supplemental File S1 from the primary study Snure Beckman et al., 2019). Participants were asked to comment on their overall experience having a child with a trisomy, their attitudes toward hypothetical somatic and germline gene-editing, and factors that contributed to these attitudes. Although participants were not asked to directly comment on perceptions of identity, this was a recurring topic. These semi-structured interviews were conducted by a single interviewer (ESB) between October 2018 and January 2019 using a secure video conferencing platform. Participants received a $15 gift certificate after the interview. The interviews were recorded and transcribed verbatim with names and identifiers removed.

2.2. Secondary analysis

This secondary analysis can theoretically be understood as a supplemental analysis, aimed at exploring themes of identity as it relates to attitudes towards gene-editing that were not fully characterized in the primary study (Heaton, 2008). The first author of this secondary analysis (KE) was not part of the primary study; however, the research team included researchers who conducted the primary study (ESB, KEO) to provide important contextual understanding of the dataset for the secondary analysis (Heaton, 2008).

The 27 de-identified transcripts were uploaded to Dedoose qualitative analysis software v8.3.45 (Dedoose Version, 2021). A preliminary codebook for the secondary analysis was created by the first author (KE).

Codes related to identity were inductively determined through descriptive open-coding to capture diverse concepts related to child, parental, and family identity formation (Gibbs, 2018). Codes related to attitudes towards gene-editing were deductively adapted from the primary study (Snure Beckman et al., 2019). Four researchers (KE, NA, ESB, KEO) independently coded a transcript using the preliminary codebook and discussed discrepancies until agreement was reached to develop an intermediate codebook. This process was repeated three times until the codebook was stable (MacQueen et al., 1998). The first author then excerpted and coded all 27 interviews; every third interview was independently coded by a co-coder (NA) and underwent adjudication until 100 percent negotiated agreement was reached. This process was completed to ensure limited bias was introduced throughout the coding process (Campbell et al., 2013).

After completing coding, the research team (KE, NA, ESB, KEO) conducted a thematic analysis using a grounded theory approach paired with an iterative review of the data both within and across individuals (Corbin & Strauss, 2014). The first author (KE) composed a list of emerging identity themes, which spanned two independent identity spectra: parental identity as influenced by having a child with a trisomy, and parental perceptions of the child's identity. The first author then conceptualized the spectra as a series of x and y axes. Each participant was plotted in one of the four resulting quadrants according to their perceptions of identity (Supplementary Fig. S1). Finally, each participant's attitudes towards somatic and germline gene-editing were assessed to explore the relationship between perceptions of identity and attitudes towards gene-editing. From these emic interpretations of the data four interrelated typologies (quadrants) emerged, which summarize the intersection of parents' views on identity and gene-editing (Fig. 1). The first author re-reviewed all transcripts to gain a broader appreciation for the nuances present in the data and refine the typologies. The research team used identity and disability models described in the literature to interpret the results.

3. Results

3.1. Sample characteristics

Demographics of the parent participants and their children, evenly distributed between the three conditions and phenotypically diverse, are described in Supplementary Tables S1 and S2. All children with T21 and seven children with T18/T13 were living at the time of the interviews (5 months - 40 years old). Ten children with T18/T13 were deceased (stillborn - 35 years old). Parents were primarily mothers (82%) who were highly educated with high household income (>55% reported household incomes over $100,000/year).

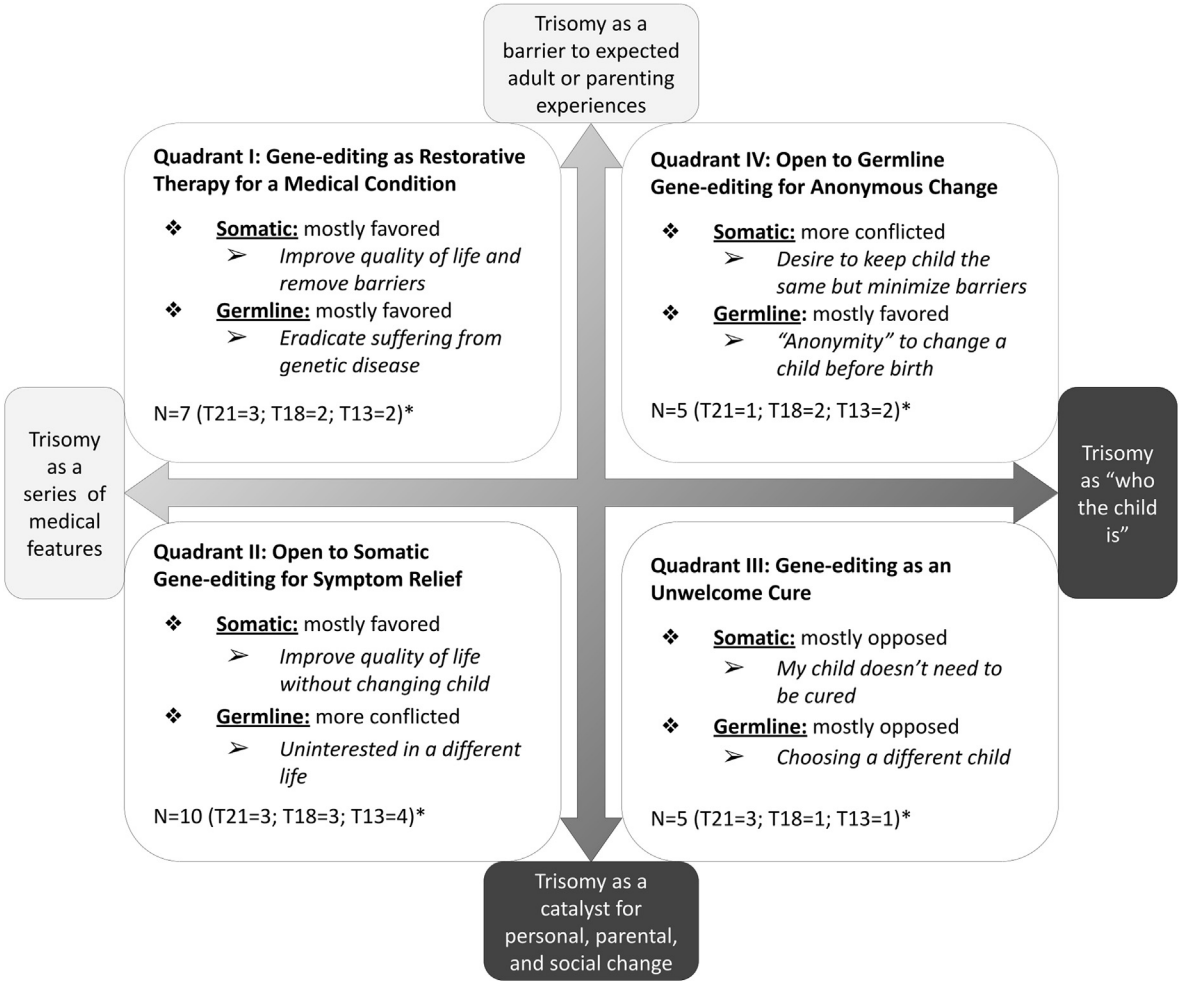

Fig. 1. Incorporation of Trisomy into Identity is Related to Attitudes Towards Gene-Editing.
*The number of participants that are represented by each quadrant are outlined (N) to demonstrate the prevalence of the themes that emerged. However, participants' perceptions of identity existed along the entire continuum of each of the spectrums, and consequently aligned with the emerging themes in the quadrants to differing degrees.

3.2. Findings

Participants' perspectives toward hypothetical gene-editing technologies were related to how they incorporated their child's trisomy into their perception of their child's identity (hereafter referred to as "child's identity") and how they believed the experience parenting a child with a trisomy influenced how they saw themselves (interpreted as "parental identity"). Participants' perceptions of their child's identity ranged from a medical identity (i.e. a series of symptoms or medical features separate from the child's fundamental identity) to a fundamental identity characteristic (i.e. "who the child is") (Table 1). Some parents expressed a more moderate view or struggled with the degree to which they felt the trisomy defined their child's identity. While not universal, participants with children with T21 were more likely to view their child's trisomy as fundamental to their child's identity, and conversely parents of children with T13 and T18 were more likely to view their child's trisomy as a series of medical features (Supplementary Table S3).

Table 1
Major identity themes and representative quotes.

Identity Theme	Representative Quote
Incorporation of trisomy into child's identity	
Trisomy as a series of medical features	"I don't see Down syndrome as like who my kid is. Like it's … I kind of look at it like as if he had diabetes or something like that" *(Parent of a young child with T21)*
Trisomy is the child's fundamental identity	"The thing that's difficult for me with the name of "gene-editing" is because Trisomy 18 was [CHILD W/T18]. It was in his DNA. It's impossible to separate the two. He is Trisomy 18." *(Parent of a child with T18 that passed in infancy)*
Incorporation of trisomy into parent's identity	
Parenting a child with a trisomy as a catalyst for personal, parental, and social change	"I think the experience of having her just taught me, it definitely changed me. I think that she, that having her made me, I think, a better person. It made me a better mom for the children I had after her. I think it helped me in understanding what kind of a parent I wanted to be in the future." *(Parent of a child with T18 that passed in infancy)* "For me, it's been a real eye opener to what's important in life I feel. My faith in God has grown substantially." *(Parent of a young child with T13)* "[CHILD W/T21] has introduced me to about 6000 other moms, all who have children, under age six, with Down syndrome who are all across the country. And these women are like my sisters, all of them, we're really tightly connected online. I have a parent support group, for anything that I'm going through. " *(Parent of a young child with T21)*
Parenting a child with a trisomy as a barrier to expected adult or parenting experiences	"It's definitely more challenging, in that I think it's hard because it is like each stage is kind of prolonged. Like you know, the babyhood stage lasted longer, the toddler stage lasts longer and it's very exhausting sometimes just how ways that a typical four-year-old would be more independent he is not still. He requires much more care." *(Parent of a young child with T21)* "The negative aspects were, how much time we had to spend in the hospital her first year, set my career back a little bit, then she's got a lot more medical appointments than a typical needs child." *(Parent of a young child with T18)* "It has seriously restricted my social life. […] Very hard to date or be in a serious relationship because I can't just simply leave him alone and go away on a weekend or a vacation with someone. And you know, they want the freedom to travel and do things and I don't have that." *(Parent of an adult child with T21)*

Participants also differed in how their parental identity was influenced by having a child with a trisomy. Some viewed having a child with a trisomy as a catalyst for positive change, describing themselves as a "better person" due to increased patience, redefined values, a stronger religious identity, and improved empathy. Social changes included inclusion in parental support groups or improved relationships with those already in their life as a result of having a child with a trisomy. Other participants described having a child with a trisomy as a barrier to expected adult or parenting experiences. This included increased time and energy parenting, grieving the loss of a child, difficulties with the medical community, social stigmatization, and stress. These challenges sometimes led to stalled professional development, interfered with relationships, or were a barrier to fulfilling family goals (Table 1). Many participants shared that parenting a child with a trisomy was both a positive catalyst and a barrier (Supplementary Table S3).

3.2.1. The interaction between child's identity and parental identity

Participants' attitudes towards hypothetical gene-editing was related to their incorporation of the trisomy into their perception of identities (Fig. 1 and Supplementary Table S3). It is important to note that participants' nuanced perspectives are not fully represented by the themes in a single quadrant of the framework (Fig. 1); rather the framework aims to capture the emerging concepts.

3.2.2. Quadrant I: Gene-editing as restorative therapy for a medical condition

When participants described their child's trisomy as a series of medical features separate from their child's fundamental identity and as a barrier to typical adult or parenting experiences, they were more open to somatic and germline gene-editing.

3.2.2.1. Somatic gene-editing: improve quality of life and remove barriers. Participants who conceptualized their child's trisomy as a series of medical features (left side of the figure) tended to view somatic gene-editing as similar to other medical treatments, therapeutics, or interventions with the potential to resolve symptoms or cure disease.

> "I think [somatic gene-editing] could be helpful. Because I know in a lot of cases, if one or two of the symptoms could have been reduced or fixed altogether that could have impacted the whole outcome. Like our baby, our main concern was her missing cerebellum. And if they could have got to her and could have done something to maybe alter her brain growth or something a little bit more. You know she would have had more of a chance of not living a normal life, but not being as dependent on machines." (*Parent of a child with T13 that was stillborn)*

Many parents believed that using somatic gene-editing would lead to improved quality of life by reducing physical pain and helping their medically fragile children live healthier or longer. Other participants described the potential of somatic gene-editing to improve quality of life beyond symptom relief.

> "I don't think it would be trying to change him. I think some people think that it would be [..] but my personal belief is that it wouldn't be, that it just kind of takes away the obstacles so that he could just be himself." (*Parent of a young child with T21)*

Some parents commented on the potential for somatic gene-editing to improve their parental quality of life; for example, a treatment that helped the child would reduce parental worry or improve connection with their child.

> "For us there's certainly gonna be physical handicaps most likely, but the biggest one, the most painful one for us as a parent is seeing your child not being able to have the intellectual capacity either to relate to

others or … that's kind of the, I don't say it in a selfish way, but that's the one thing that we want more than anything is to be, to have an emotional connection with our child. That would be the first thing [to use somatic gene-editing for]." (*Parent of an infant with T18)*

3.2.2.2. Germline gene-editing: Eradicate suffering from genetic disease. Participants in this quadrant often voiced support of germline gene-editing technologies as a way to reduce barriers and suffering.

"I don't think [germline gene-editing] would change him, who he is, I think it just would kind of help him in the areas that are hard for him." *(Parent of a young child with T21)*

Many of these participants preferred germline over somatic gene-editing because removal of the additional chromosome at conception leading to typical development was seen as preferable to waiting to treat symptoms after birth.

"Certainly, the positive aspect [of germline gene-editing] would be being able to, on a level previously unattainable, to cure these diseases at the source. Rather than just simply treating symptoms." *(Parent of a child with T13 that passed away in infancy)*

Germline gene-editing was also conceptualized as a way to remove parenting barriers and fulfill family goals in future pregnancies.

"I think it would be too hard to have two kids with two disabilities, it would be too hard. I don't think that I would be able to give myself as much to two kids with disabilities. I think I miss out on certain things by having a child with Down syndrome and one of them is hope … in specific things like the hope for grandchildren, I don't have that right now. [CHILD W/ T21] won't be able to have kids and I want that. I want that in having a typical child. So, if I could be assured [through germline gene-editing] of having that experience, the typical experience, certain hopes that I don't have with [CHILD W/ T21] then yeah I would take it in a heartbeat." *(Parent of a young child with T21)*

3.2.3. Quadrant II: Conflicted but open to somatic gene-editing for symptom relief

Some participants perceived their child's trisomy as a series of medical features separate from their child's fundamental identity, but unlike those in Quadrant I, they conceptualized their child's diagnosis as central to their own parental identity. These parents expressed mostly favorable views towards somatic gene-editing but reservations about germline gene-editing.

3.2.3.1. Somatic gene-editing: improve quality of life without changing the child. Similar to the parents in Quadrant I, participants in this quadrant were generally open to somatic gene-editing as a way to fix the medical problems caused by the trisomy. However, they were overall more indecisive about the degree to which the trisomy influenced their child's identity. As such, they often expressed some internal conflict about using somatic gene-editing.

"If there were something that oh, we think that this would 99% or 90% cure pretty much all of her ailments, well, of course. You always want your child, regardless of the situation, if you have a child with any kind of medical issue, you want to try and make it all better. If there was something that was going to completely change who she is, that I wouldn't want. But if there was something that could change the impact on her body and lessen her medical issues and lessen some of the difficulties she has, I would totally be for that, absolutely." *(Parent of a young child with T13)*

These participants generally prioritized their child's circumstance over their own experience. They recognized the positive effects of having a child with a trisomy on their personal identity formation, but still favored the use of somatic gene-editing to improve their child's life.

"There's some benefit to having a child with a disability. It teaches you more compassion, and patience, but I wouldn't necessarily say eliminate. It's hard. For my daughter, specifically, I would do anything to help her improve her health and her cognitive abilities, and her muscle tone." (*Parent of a young child with T18)*

3.2.3.2. Germline gene-editing: Uninterested in a different life. Participants in Quadrant II expressed that germline technology may have the potential to improve quality of life by preventing disease. However, they were often more hesitant than participants in Quadrant I due to concerns about eliminating the trisomy altogether.

"I'm more optimistic and excited for changing a child after they're here. Not like genetically maneuvering them before they arrive but helping them after they do get here." *(Parent of a child with T13 that passed away in adulthood)*

When parents discussed their own experience as a catalyst for positive personal or family growth, they similarly expressed internal struggle about the use of germline gene-editing.

"If [CHILD W/ T18] hadn't been born with Trisomy 18, there are a lot of things we would have missed out on as well. The things she's gone through have made us stronger as a family, stronger as people, really good advocates for her, and then also just made us more patient, and accepting as individuals, and those are all things that we've benefited from personally having a child with Trisomy 18. That's why I'm torn." (*Parent of a young child with T18)*

Additionally, participants who expressed parental acceptance and adaptation were less interested in germline gene-editing, as they felt comfortable and confident parenting a child with a disability.

3.2.4. Quadrant III: Gene-editing as an unwelcome cure

Some participants viewed their child's trisomy as inseparable from their child's identity (right side of the figure), and viewed their own identity as positively influenced by their experience parenting a child with a trisomy. These parents tended to be less open, or actively opposed, to both somatic and germline gene-editing.

3.2.4.1. Somatic gene-editing: My child doesn't need to be cured. These participants were less likely to view their child's trisomy as an impairment or disability and did not feel that their child needed to be fixed or cured.

"I wholeheartedly reject that my son's genetic condition is a disease that needs a cure. […] My son is a person that begins with his body and his body begins with his cells and his cells begin with the genetic code that makes him up, so it turns my stomach to think that the solution in our society to a person who is differently abled and therefore is a strain on us, whether it's financial or socially or systematically in our society that we think of it as, 'hey we could cure this' because what that means is we should change my son's being." *(Parent of a young child with T21)*

Parents of children with T21 who were minimally or moderately impacted by the trisomy were more likely to view their child's trisomy as fundamental to their child's identity, as compared to parents of very affected children with T21 or those with T18/T13. Some parents of children with T21 explicitly expressed that they felt that their child was healthy, making the trisomy fundamentally different from other genetic conditions.

"For me, I think the bottom line, anything that will, if it can take the place of a pill or surgery then, gee […] here's a family that has history of maybe some sort of a heart problem, or aneurysms, but there's a

gene that you can turn off that would keep this family from having aneurysms, that I'm all for. I think that's great. But then when you decide [to use somatic gene-editing on] somebody, because they are Down Syndrome, to me, because he is Down Syndrome that's like saying, 'Oh, he's black'. That's a problem. Because that's his whole person. That's who he is." *(Parent of an adult child with T21)*

These participants felt that editing the trisomy would not alleviate suffering but rather it would change the child's fundamental identity. However, some were open to somatic gene-editing as a therapy for other medical conditions or for specific medical features associated with the trisomy.

"One piece that I guess I could clearly say that I'd be all over would be things that would make speaking easier and more clearly so that people could understand an individual with Down syndrome easier. […] So if it was easier for him to express his ideas and his thoughts then that would certainly make life easier so that would probably be something I'd be a little bit more open to than other pieces." *(Parent of an older child with T21)*

The desire to help children communicate was common to almost all parents of children with T21, including some who opposed the use of somatic gene-editing technologies more broadly. In this way, they supported hypothetical somatic gene-editing as a potential treatment for symptoms as long as the goal was not to cure the child of the trisomy altogether.

3.2.4.2. Germline gene-editing: Choosing a different child. These participants viewed germline gene-editing as choosing to not have their child at all, and therefore expressed opposition.

"It's a super loaded question 'cause I can't picture the world without [CHILD W/ T21], and all of the uniqueness that he brings to it." *(Parent of an older child with T21)*

"This whole germline editing is the same thing as them asking me if I wanted to send my son to an institution. No I wouldn't." *(Parent of an adult child with T21)*

Some parents acknowledged that while they would not use the technology themselves, they did support it being available to other prospective parents similarly to prenatal or preimplantation genetic diagnosis. Other participants expressed concern that germline gene-editing would eradicate trisomies and the beneficial diversity that comes with them.

3.2.5. Quadrant IV: Conflicted but open to germline gene-editing for anonymous change

Participants who viewed their child's trisomy as "who their child is", similar to Quadrant III, but who conceptualized the experience of parenting a child with a trisomy as more of a challenge tended to be opposed to somatic gene-editing and favorable to germline gene-editing.

3.2.5.1. Somatic gene-editing: desire to keep child the same but minimize barriers. Participants in this quadrant viewed their child's trisomy as central to their fundamental identity. But unlike Quadrant III, these participants were more likely to be parents of children with T13/T18 who were more severely affected both medically and cognitively. As a result, these parents expressed more internal conflict about the utility of somatic gene-editing; they were interested in its use to reduce barriers but were wary of 'changing the child.'

"When it comes to his developmental delays, his cognitive and intellectual and social emotional delays, it's like part of that is just who he is so I'm not sure how much I would really want to change that, but on the flip side, I also want him to be able to achieve the most he can." *(Parent of a young child with T13)*

Similar to participants in Quadrants III, some participants described specific medical features they would be comfortable using somatic gene-editing as a treatment for:

"I wouldn't want anything that would change who he is. Which, I don't think you're saying that that's what this is. But, like, just his personality or his physical qualities. I would mostly want to focus on anything that would cause him pain or something that could help him walk easier, talk easier. But even those things are secondary to just him being able to live and being not in pain." *(Parent of a child with T18 that passed away in infancy)*

Most participants were open to using somatic gene-editing as a life-saving technology, but even this use felt in conflict with their acceptance of their child.

3.2.5.2. Germline gene-editing: "Anonymity" to change a child before birth. Participants who perceived their child's trisomy as core to the child's identity expressed concern and guilt about gene-editing after they already had an established relationship with their child. Unlike Quadrant III, these participants were more open to germline gene-editing to alleviate suffering prior to meeting the child.

"The [somatic] gene therapy to me that's hard. It's like […] a parent saying, "I want to fix who my child is." That's sad in a way. Whereas the germline is like there's an anonymity to that … I don't know if that's the right word, but you don't even know what you're dealing with so you're just kind of like mechanically fixing something." *(Parent of a young child with T13)*

"I have much more interest to use […] the embryonic one, because it's before you know the child. I don't see where people could possibly do the other gene editing when the child is already grown on you and has a personality, I think it would be really hard to suddenly have to change it and be a different person, that would be tough." *(Parent of an adult child with T21)*

Parents believed this approach to gene-editing would allow for a higher quality of life for the child and family. Like parents in Quadrant I, some participants described germline gene-editing as a way to fulfill family goals.

"Having a healthy child, one that doesn't have to struggle, and also being able to fulfill your family goals and dreams. You're having a child that is complex, it derails a lot of what your hopes and dreams are. […] Not that I don't think that what we've experienced hasn't been great but it definitely throws your thinking about your future." *(Parent of a young child with T13)*

4. Discussion

This study found that parents of children with autosomal aneuploidies have diverse attitudes towards both somatic and germline gene-editing that are related to perceptions of identity. Participants incorporated their child's trisomy into their child's identity along a spectrum from a medical identity to the child's fundamental identity. Participants' perception of their child's identity was often based on the degree to which they felt that having an extra chromosome influenced the child's personality or that the child would not be the same if they did not have the trisomy. Parental identity mapped along a separate spectrum based on the degree to which participants conceptualized parenting a child with a trisomy as a positive growth opportunity or as a barrier to expected adult and parenting experiences. When these spectrums are conceptualized as axes, each participant loosely falls in one of four quadrants (Supplementary Fig. S1), in which participants tend to have similar attitudes towards hypothetical gene-editing. The resulting framework (Fig. 1) captures the relationship between perceptions of

child and parental identities and attitudes towards gene-editing that can be understood best through the lens of different "models" of disability: the *Medical Model of Disability* (Shakespeare, 2006), the *Affirmative Model of Disability* (Swain & French, 2000), and the *Disability as an Interaction Model* (Green et al., 2016).

The *Medical Model of Disability* (Quadrant I) considers disability to be an impairment, either physical or mental in origin. Disability is perceived as something that requires fixing, either through cure or adaptation of the individual with the disability to their environment (Green et al., 2016; Shakespeare, 2006). Participants in Quadrant I were more likely to be parents of children with T13/T18 and children more severely affected medically and cognitively per parent report. This is consistent with other studies of parents of children with T21 which found a correlation between parents' desire for pharmacologic interventions and views of T21 as burdensome to participants' children and/or families (Michie & Allyse, 2019; Riggan et al., 2020). Parents of children that were deceased were also more likely to have views that aligned with the left side of the figure (Quadrants I and II). This suggests that the death of a child makes parents more likely to separate the trisomy from the child's fundamental identity, and increases parents' support of gene-editing as a life-saving technology to reduce suffering for the child and family.

The *Affirmative Model of Disability* (Quadrant III) posits that disability is both a positive personal and social identity (Swain & French, 2000). Participants in Quadrant III generally expressed that their children did not "need to be fixed," aligning with the idea that disability and impairment are not problems that inherently require solving. Participants across studies with a range of congenital conditions, even when clinically severe and/or presenting with intellectual disability, often report being both healthy and disabled and struggle to separate the condition (and the subsequent impairment) from their fundamental identity. This is less commonly noted in individuals whose conditions onset later in life (Boardman, 2021; Boardman & Clark, 2022; Hoffman-Andrews et al., 2019). The nature of the condition, including age of onset and associated features, has been documented in the literature as a major factor that influences perceptions of identity and attitudes towards treatment. Participants with congenital conditions are likely to cite high quality of life and frequently reject the notion that technologically mediated reproduction or "cure" would reduce suffering (Boardman, 2021; Boardman & Clark, 2022; Hahn & Belt, 2004; Hoffman-Andrews et al., 2019; Inglis et al., 2014). Parents in Quadrant III, and parents of children with genetic intellectual disability in other studies, who view the condition as inseparable from personhood often report hesitation regarding treatment for fear of negatively impacting their child's personality or changing who their child is altogether (Boardman, 2021; Inglis et al., 2014; Riggan et al., 2020).

In the current study, some participants in Quadrant III described "exceptions", specific features of the trisomy or other genetic conditions, for which they believe gene-editing may have utility. These exceptions included life-threatening conditions, physical conditions with no cognitive impacts, or adult-onset conditions that they conceptualize as impairments that can be separated from identity. In this way, these parents align with the *Affirmative Model of Disability* with regards to their children but remain open to the development of these therapeutics for features or conditions that they view as more medical.

The perceptions of identity that are seen in Quadrants I and III, and the corresponding views of gene-editing as largely welcome or unwelcome respectively, are similarly described by studies that explored attitudes of individuals with other conditions towards curative technologies (Boardman & Clark, 2022; Boardman & Hale, 2018; Hahn & Belt, 2004; Hoffman-Andrews et al., 2019).

The perceptions of identity represented by participants in Quadrants II and IV are more aligned with the *Disability as an Interaction Model,* which recognizes both the biological and social aspects of disability and the ways in which these elements interact (Green et al., 2016). These parents focused more on the differences between somatic and germline gene-editing and the nature of the change that would result from each.

In Quadrant II many participants struggled with the extent to which they believed that their child's personality was determined by the trisomy. Most parents ultimately expressed that they saw their child's trisomy as a series of medical features that had an influence on, but did not define, the child's identity. Many expressed that somatic gene-editing would be preferable as germline gene-editing would lead to an entirely different child or parenting experience. These perspectives can be understood in the context of the work of Chadwick (2001) which states that changing some key part, or a large enough proportion, of genetic material could lead to changes to identity. However, changing certain features may be permissible if these smaller changes would not lead to changes to one's fundamental identity. As such, somatic gene-editing may be conceptualized as similar to organ transplantation. However, germline gene-editing may be conceptualized as a global change that could reach the threshold capable of altering identity (Chadwick, 2001). This perspective is also described by members of the disability community who have interest in treatment for the biological aspects of their disabilities, but who oppose curative technologies that would eliminate the condition altogether (Hollister et al., 2019; Persaud et al., 2019).

The consequential distinctions between somatic and germline gene-editing that are highlighted by the participants in this study, and others in the disability studies literature, are fundamentally different from the distinctions that are central to the bioethical arguments supporting somatic gene-editing but opposing germline technology (Ormond et al., 2017; Howard et al., 2018). Concerns about the heritability of germline alterations and threats to the autonomy of future offspring were not brought up as factors influencing these participants' attitudes towards germline gene-editing. This discrepancy may in part be due to the fact that individuals with autosomal aneuploidies typically do not reproduce, and therefore parents of these individuals may not be focused on this potential impact of germline gene-editing.

Participants in Quadrant II were also more likely to cite their own parental identity as a reason that they opposed gene-editing. This same view has been expressed by other parents within the disability community. In Andrew Solomon's book "Far From the Tree: Parents, Children and the Search for Identity" (2012), when asked about a hypothetical cure a mother of a child with T21 comments:

> "For [CHILD W/ T21], I'd cure it in an instant; but for us [his parents], I wouldn't exchange these experiences for anything. They've made us who we are, and who we are is so much better than who we would have been otherwise." (p.219)

Participants in Quadrant IV, who felt that the trisomy was fundamental to the child's identity but viewed the trisomy as a barrier to expected parental experiences, tended to view both somatic and germline gene-editing as a change that would be significant enough to change the child's fundamental identity, similar to views in Quadrant III. However, parents in this quadrant felt earlier correction of the biological elements of the condition, represented by the prospect of germline gene-editing, was acceptable as it would lead to higher quality of life for the child and family without changing the child after the child's identity was formed. Another study similarly found that parents' views of "cure" are influenced by the temporal nature of the application of the treatment. Some parents expressed support of treatment early in life due to suspected increased efficacy, while others commented that limited personality development earlier in life made earlier editing more desirable (Inglis et al., 2014).

5. Limitations

As a secondary analysis, this study was limited by the content present in the transcripts. The interviews were not originally conducted to specifically assess perceptions of identity, and not all participants discussed perceptions of identity as central to their attitudes towards gene-editing. However, the nature of a secondary analysis allowed the research team to

assess perceptions of identity organically within the context of a conversation about attitudes towards gene-editing. The original interview guide was designed to encourage narrative accounts of parenting a child with a trisomy, and the interviewer followed up when participants raised concepts of identity to allow for the emergence of identity themes.

The study participants were highly educated, mostly came from high socioeconomic backgrounds, and there was an overrepresentation of mothers. Additionally, the population was sampled through support groups and related studies, which may represent a biased sample that is more integrated into the disability community. As such, these results may not be representative of all individuals within this stakeholder group.

Future research in larger and more diverse cohorts is needed to better elucidate how specific factors influence the incorporation of the child's trisomy into parent's perceptions of their child's identity (e.g. perceived medical and cognitive severity) and their identity as a parent (e.g. loss of a child). Such studies, as well as studies with individuals that represent other genetic conditions, are also required to more fully characterize the relationship between parental identity, perceptions of child's identity, and attitudes toward gene-editing technologies.

Finally, this study did not include individuals with trisomies themselves. Parents of children with disabilities have been documented to have different perspectives on treatment and cure than individuals with the disability (Darling, 2003). It is important for the perspectives of both of these stakeholder groups to be assessed and elevated in future research.

6. Conclusion

Perceptions of identity, as it relates to a genetic condition, are complex. For parents of children with autosomal aneuploidies, perceptions of their child's identity and their own parental identity are influenced by the child's trisomy. These perceptions of identity are central to how these individuals perceive cure and the degree to which they desire treatment for their children. For researchers and policy makers, the broad clinical application of gene-editing requires an established set of guidelines for when this kind of technology is appropriate for use. However, creating such regulations requires that there is a consensus about the kinds of disabilities that warrant correction (Shakespeare, 2015). For clinicians, who will be offering and administering therapies for genetic conditions, concepts of identity should be assessed as an important factor for decision-making. Parents of children with trisomies, as a proxy for their children, are an important stakeholder group that will be directly impacted by gene-editing. Their voices, among others in the disability community, must be central in the conversation as these potential therapeutics are developed.

Ethics statement

This study is a secondary analysis of interviews conducted as part of a primary study that explored stakeholders' views of hypothetical gene-editing (Snure Beckman et al., 2019). Stanford University's Institutional Review Board granted ethical approval of all aspects of both the primary study and secondary analysis (protocol #46984), and all participants provided informed consent.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ssmqr.2022.100151.

References

Akutsu, S. N., Fujita, K., Tomioka, K., Miyamoto, T., & Matsuura, S. (2020). Applications of genome editing technology in research on chromosome aneuploidy Disorders. *Cells, 9*, 239. https://doi.org/10.1186/s13059-017-1354, 10.3390/cells9010239.

Allyse, M., Bombard, Y., Isasi, R., Michie, M., Musunuru, K., & Ormond, K. E. (2019). What do we do now?: Responding to claims of germline gene editing in humans. *Genetics in Medicine, 21*, 2181–2183. https://doi.org/10.1038/s41436-019-0492-3

Andorno, R., Baylis, F., Darnovsky, M., Dickenson, D., Haker, H., Hasson, K., Lowthorp, L., Annas, G. J., Bourgain, C., Drabiak, K., Graumann, S., Grüber, K., Kaiser, M., King, D., Kollek, R., MacKellar, C., Nie, J.-B., Obasogie, O. K., Fang, M. T., Werner-Felmayer, G., & Zuscinova, J. (2020). Geneva statement on heritable human genome editing: The need for course correction. *Trends in biotechnology, 38*, 351–354. https://doi.org/10.1016/j.tibtech.2019.12.022

Bacci, G. M., Becherucci, V., Marziali, E., Sodi, A., Bambi, F., & Caputo, R. (2022). Treatment of inherited retinal dystrophies with somatic cell therapy medicinal product: A review. *Life, 12*, 708. https://doi.org/10.3390/life12050708

Boardman, F. K. (2021). Attitudes toward population screening among people living with fragile X syndrome in the UK: 'I wouldn't wish him away, I'd just wish his fragile X syndrome away. *Journal of Genetic Counseling, 30*, 85–97. https://doi.org/10.1002/jgc4.1355

Boardman, F. K., & Clark, C. C. (2022). What is a 'serious' genetic condition? The perceptions of people living with genetic conditions. *European Journal of Human Genetics, 30*, 160–169. https://doi.org/10.1038/s41431-021-00962-2

Boardman, F. K., & Hale, R. (2018). How do genetically disabled adults view selective reproduction? Impairment, identity, and genetic screening. *Molecular & Genetics Genomic Medecine, 6*, 941–956. https://doi.org/10.1002/mgg3.463

Boardman, F. K., Young, P. J., & Griffiths, F. E. (2018). Impairment experiences, identity and attitudes towards genetic screening: The views of people with spinal muscular atrophy. *Journal of Genetic Counseling, 27*, 69–84. https://doi.org/10.1007/s10897-017-0122-7

Campbell, J. L., Quincy, C., Osserman, J., & Pedersen, O. K. (2013). Coding in-depth semistructured interviews: Problems of unitization and intercoder reliability and agreement. *Sociological Methods & Research, 42*, 294–320. https://doi.org/10.1177/0049124113500475

Chadwick, R. F. (2001). Genetic interventions and personal identity. In H. ten Have, & B. Gordijn (Eds.), *Bioethics in a European perspective, international library of ethics, law, and the new medicine* (pp. 339–349). Dordrecht: Springer Netherlands. https://doi.org/10.1007/978-94-015-9706-7_11.

Corbin, J., & Strauss, A. (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. SAGE Publications.

Darling, R. B. (2003). Toward a model of changing disability identities: A proposed typology and research agenda. *Disability & Society, 18*, 881–895. https://doi.org/10.1080/0968759032000127308

Dedoose Version. (2021). *Dedoose Version 8.3.45, web application for managing, analyzing, and presenting qualitative and mixed method research data*. Los Angeles, CA: SocioCultural Research Consultants, LLC. www.dedoose.com.

Erikson, E. H. (1968). *Identity: Youth and Crisis*. W. W. Norton & Company.

Forber-Pratt, A. J., Lyew, D. A., Mueller, C., & Samples, L. B. (2017). Disability identity development: A systematic review of the literature. *Rehabilitation Psychology, 62*, 198–207. https://doi.org/10.1037/rep0000134

Frangoul, H., Altshuler, D., Cappellini, M. D., Chen, Y.-S., Domm, J., Eustace, B. K., Foell, J., de la Fuente, J., Grupp, S., Handgretinger, R., Ho, T. W., Kattamis, A., Kernytsky, A., Lekstrom-Himes, J., Li, A. M., Locatelli, F., Mapara, M. Y., de Montalembert, M., Rondelli, D., … Corbacioglu, S. (2021). CRISPR-Cas9 gene editing for sickle cell disease and β-thalassemia. *New England Journal of Medicine, 384*, 252–260. https://doi.org/10.1056/NEJMoa2031054

Galinsky, E. (1987). *Six stages of parenthood*. Addison-Wesley Pub. Co.

Giacomini, M. K., & Cook, D. J. (2000 Jul 19). Users' guides to the medical literature: XXIII. Qualitative research in health care A. Are the results of the study valid? Evidence-Based Medicine Working Group. *JAMA, 284*(3), 357–362. https://doi.org/10.1001/jama.284.3.357. PMID: 10891968.

Gibbs, G. R. (2018). *Analyzing qualitative data*. SAGE.

de Graaf, G., Buckley, F., & Skotko, B. G. (2017). Estimation of the number of people with Down syndrome in the United States. *Genetics in Medicine, 19*, 439–447. https://doi.org/10.1038/gim.2016.127

Green, S. E., Darling, R. B., & Wilbers, L. (2016). Struggles and joys: A review of research on the social experience of parenting disabled children. In *Sociology looking at disability: What did we know and when did we know it, research in social science and disability* (pp. 261–285). Emerald Group Publishing Limited. https://doi.org/10.1108/S1479-354720160000009013.

Hahn, H. D., & Belt, T. L. (2004). Disability identity and attitudes toward cure in a sample of disabled activists. *Journal of Health and Social Behavior, 45*, 453–464. https://doi.org/10.1177/002214650404500407

Heaton, J. (2008). Secondary analysis of qualitative data: An overview. *Hist. Soc. Res. Historical Social Research Historische Sozialforschung, 33*, 33–45.

Hoffman-Andrews, L., Mazzoni, R., Pacione, M., Garland-Thomson, R., & Ormond, K. E. (2019). Attitudes of people with inherited retinal conditions toward gene editing technology. *Molecular & Genetics Genomic Medecine, 7*, Article e00803. https://doi.org/10.1002/mgg3.803

Hollister, B. M., Gatter, M. C., Abdallah, K. E., Armsby, A. J., Buscetta, A. J., Byeon, Y. J. J., Cooper, K. E., Desine, S., Persaud, A., Ormond, K. E., & Bonham, V. L. (2019). Perspectives of sickle cell disease stakeholders on heritable genome editing. *CRISPR J, 2*, 441–449. https://doi.org/10.1089/crispr.2019.0034

Howard, H. C., van El, C. G., Forzano, F., Radojkovic, D., Rial-Sebbag, E., de Wert, G., Borry, P., & Cornel, M. C. (2018). One small edit for humans, one giant edit for humankind? Points and questions to consider for a responsible way forward for gene editing in humans. *European Journal of Human Genetics, 26*, 1–11. https://doi.org/10.1038/s41431-017-0024-z

Hsu, P. D., Lander, E. S., & Zhang, F. (2014). Development and applications of CRISPR-cas9 for genome engineering. *Cell, 157*, 1262–1278. https://doi.org/10.1016/j.cell.2014.05.010

Inglis, A., Lohn, Z., Austin, J. C., & Hippman, C. (2014). A 'cure' for Down syndrome: What do parents want? *Clinical Genetics, 86*, 310–317. https://doi.org/10.1111/cge.12364

Johnson, B. J. (2020). Daily life in National Disability Insurance Scheme times: Parenting a child with Down syndrome and the disability politics in everyday places. *Qualitative Social Work, 19*, 532–548. https://doi.org/10.1177/1473325020911691

Kelly, M. P., & Millward, L. M. (2004). Identity and illness. In *Identity and health* (pp. 13–30). Routledge.

MacQueen, K. M., McLellan, E., Kay, K., & Milstein, B. (1998). Codebook development for team-based qualitative analysis. *CAM J, 10*, 31–36. https://doi.org/10.1177/1525822X980100020301

Mai, C. T., Kucik, J. E., Isenburg, J., Feldkamp, M. L., Marengo, L. K., Bugenske, E. M., Thorpe, P. G., Jackson, J. M., Correa, A., Rickard, R., Alverson, C. J., & Kirby, R. S. (2013). Selected birth defects data from population-based birth defects surveillance programs in the United States, 2006 to 2010: Featuring trisomy conditions. *Birtish Defects Research A Clinical Molecular Teratology, 97*, 709–725. https://doi.org/10.1002/bdra.23198

Michie, M., & Allyse, M. (2019). Gene modification therapies: Views of parents of people with Down syndrome. *Genetic Medicine Official Journal of American College of Medical Genetics, 21*, 487–492. https://doi.org/10.1038/s41436-018-0077-6

Normile, D. (2018). Shock greets claim of CRISPR-edited babies. *Science, 362*, 978–979. https://doi.org/10.1126/science.362.6418.978

Ormond, K. E., Mortlock, D. P., Scholes, D. T., Bombard, Y., Brody, L. C., Faucett, W. A., & Young, C. E. (2017). Human germline genome editing. *The American Journal of Human Genetics, 101*, 167–176. https://doi.org/10.1016/j.ajhg.2017.06.012

Persaud, A., Desine, S., Blizinsky, K., & Bonham, V. L. (2019). A CRISPR focus on attitudes and beliefs toward somatic genome editing from stakeholders within the sickle cell disease community. *Genetics in Medicine, 21*, 1726–1734. https://doi.org/10.1038/s41436-018-0409-6

Riggan, K. A., Nyquist, C., Michie, M., & Allyse, M. A. (2020). Evaluating the risks and benefits of genetic and pharmacologic interventions for Down syndrome: Views of parents. *American Journal on Intellectual and Developmental Disabilities, 125*, 1–13. https://doi.org/10.1352/1944-7558-125.1.1

Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society, 23*, 199–210. https://doi.org/10.1080/09687590801953937

Shakespeare, T. (2006). The social model of disability. *The disability studies reader, 2*, 197–204.

Shakespeare, T. (2015). Gene editing: Heed disability views. *Nature, 527*, 446. https://doi.org/10.1038/527446a, 446.

Snure Beckman, E., Deuitch, N., Michie, M., Allyse, M., Riggan, K., & Ormond, K. E. (2019). Attitudes toward hypothetical uses of gene-editing technologies in parents of people with autosomal aneuploidies. *CRISPR Journal, 2*, 324–330. https://doi.org/10.1089/crispr.2019.0021

Solomon, A. (2012). *Far from the tree: Parents, children and the search for identity*. Simon and Schuster.

Stets, J. E., & Burke, P. J. (2000). Identity theory and social identity theory. *Social Psychology Quarterly, 63*, 224–237. https://doi.org/10.2307/2695870

Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability & Society, 15*, 569–582. https://doi.org/10.1080/09687590050058189

The Royal Society; National Academy of Sciences; National Academy of Medicine. (2020). *Heritable human genome editing, the national academies collection: Reports funded by national institutes of health*. Washington (DC): National Academies Press (US). International Commission on the Clinical Use of Human Germline Genome Editing.

World Health Organization. (2021). *Human genome editing: Recommendations*. Geneva: World Health Organization.

Zuo, E., Huo, X., Yao, X., Hu, X., Sun, Y., Yin, J., He, B., Wang, X., Shi, L., Ping, J., Wei, Y., Ying, W., Wei, W., Liu, W., Tang, C., Li, Y., Hu, J., & Yang, H. (2017). CRISPR/Cas9-mediated targeted chromosome elimination. *Genome Biology, 18*, 224. https://doi.org/10.1186/s13059-017-1354-4