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Views of Genetics Professionals in Canada on Human Gene Editing

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ABSTRACT

CRISPR has initiated an ethical debate surrounding human gene editing (HGE). Somatic gene editing (SGE) is advancing through clinical trials, while germline gene editing (GGE) remains controversial. Stakeholder perspectives suggest GGE may be acceptable for severe conditions. However, what constitutes a severe condition remains unclear. In a Canada-wide qualitative study, we explored genetics professionals' views on what kind of conditions, if any, should qualify for GGE, as well as ethical implications of HGE overall. Participants (n = 12) expressed support for SGE, while GGE was associated with safety and ethical concerns. Participants characterized GGE as a "Pandora's box," as it may lead to irreversible societal changes. Despite concerns, participants supported GGE for "severe" conditions. To classify severity, participants suggested referencing preimplantation genetic diagnosis (PGT-M) guidelines. This study provides insights into the acceptability of HGE and a novel need for the development of Canadian PGT-M guidelines, which currently do not exist.

Introduction

Since the discovery of the CRISPR-Cas9 system, human gene editing (HGE) has been placed at the forefront of medical research, with the promise of preventing and treating human disease [1-2]. There are two types of HGE: somatic gene editing (SGE) and germline gene editing (GGE). SGE refers to the editing of somatic cells, where the changes are contained to the individual (i.e., offspring are unaffected). GGE refers to the editing of germ cells or an early-stage embryo, where the changes are heritable [3]. While SGE appears to have been accepted by the medical community, patients, and the public with clinical trials underway, GGE remains controversial [4-9]. Ethical and safety concerns include off-target effects (i.e., unintended genomic changes), altering the human gene pool (i.e., the notion of "playing God"), misuse of the technology for non-therapeutic purposes, issues of accessibility, and issues of human dignity (i.e., eradicating a condition in future persons through GGE may undermine the value of those currently living with the condition) [3].

Countries vary in their regulatory approach towards GGE [10]. The United States (US), United Kingdom (UK), and China are particularly active in the global debate on GGE. While no country permits GGE for reproductive purposes, China and the UK permit GGE for the purpose of research. The US also permits GGE for research purposes, but not with the use of federal funds [10]. In Canada, GGE for any purpose, including research, is a criminal offense; it is punishable by up to 10 years in prison and a fine of up to $500,000 [11]. This policy is currently under pressure from some members of the scientific community, citing concerns about limitations on research [12].

In order for policies on HGE to be realistic, effective, and ethical, it is crucial to assess the views of stakeholder groups. The views of patients, the public, and the medical community on HGE have been assessed by several studies. Overall, the results indicate clear support for SGE for both research and therapeutic purposes. In contrast, support for GGE seems to primarily be in the context of research, with moderate support for future therapeutic applications [13-23]. In 2020, the National Academy of Sciences, National Academy of Medicine, and the Royal Society issued a report on heritable human genome editing, which stated its use may be permissible for severe conditions [24]. However, what constitutes a severe condition remains unclear (i.e., the criteria) and as such, several studies have noted the need to clarify these criteria [22-23]. To address this gap in the literature and contribute to the growing work on stakeholder perspectives, this study aimed to explore the views of genetics professionals in Canada on criteria for GGE, as well as the overall ethics of both SGE and GGE.

Materials and Methods

Design

This was a qualitative study utilizing interpretive description methodology [25]. Semi-structured interviews with Genetic Counsellors (GCs) and Medical Geneticists (MGs) in Canada were conducted to understand their views on the ethics of HGE and criteria for GGE. This methodology was chosen to elucidate an in-depth understanding of participants' perspectives on a complex ethical topic and uncover themes that could aid the development of GGE criteria [25].

Research ethics approval was obtained through the Hospital for Sick Kids Research Ethics Board (REB# 1000079839). Participants provided written consent.

Setting, Sample, and Recruitment

This study sought to recruit a geographically diverse sample of GCs and MGs from across Canada. Eligible participants were proficient in English and currently practicing in Canada. As we sought to explore a diverse set of perspectives, participants were included from any specialty type, with a range of years of work experience. Potential participants were recruited through the mailing lists of the Canadian Association of Genetic Counsellors (CAGC) and the Canadian College of Medical Geneticists (CCMG). A single invitation email was sent and those who were interested contacted the study team directly and underwent eligibility screening. In addition, a subset of participants was identified via convenience sampling; several MGs known to the principal investigator, but not to the interviewer, were invited to participate. Following eligibility screening, a consent form was sent.

Recruitment took place between September 2022 and March 2023. Interviews were conducted between October 2022 and March 2023. Participants were offered a $25 gift card for their time.

Data Collection

The study team designed a semi-structured interview guide that was informed by the current literature [15, 22-23]. (see Supplementary Material). Semi-structured interviews were conducted virtually using Microsoft Teams. The audio, but not the video, was recorded. All interviews were conducted by one member of the research team (AT).

Participants were asked to share their views on the ethics of HGE (both SGE and GGE), the types of conditions that should qualify for GGE (if any), how criteria for GGE could be determined, and lastly were presented with three scenarios to explore their views in an applied context. The following scenarios were presented:

1A) GGE on an embryo affected with spinal muscular atrophy type 0 (SMA) (a life-limiting and early-onset condition)

1B) GGE on an embryo that is a carrier for SMA type 0 (carriers are clinically unaffected)

2) GGE on an embryo associated with a significant genetic risk factor for unilateral cleft lip (a multifactorial condition)

3) SGE for an adult individual affected with hereditary deafness

A short demographic survey was administered prior to the interview. The interviewer took field notes during each interview. Following the first several interviews, emerging themes were identified, and the interview guide was updated accordingly. Interviews were conducted until thematic saturation (i.e., no new themes were found in the data) was reached [26]. The audio from the interviews was recorded and transcribed verbatim. Transcripts and findings were not returned to participants for feedback or review.

Data Analysis

Data analysis was performed concurrently with data collection. Thematic analysis, following interpretive description methodology, was used to analyze the transcripts and identify emerging themes [25]. Two members of the research team (AT, DH) developed an initial codebook after reviewing and memoing three transcripts. The same team members individually applied the initial codebook to one new transcript and met to review the robustness of the code scheme.

The codebook was updated accordingly. The updated codebook was then reviewed with the larger study team, who had extensive experience in qualitative research, to ensure rigour. Following this review, AT and DH further refined the codebook. The final code scheme was used by AT to code the remaining interviews using Dedoose software (Version 9.0.90). Following coding, three members of the research team (AT, MC, DH) met regularly to discuss emerging themes and share interpretations of the data. These themes were then discussed and refined at several committee meetings, with each research team member providing input. Flowcharts were used to visualize the data and to help identify themes.

Results

Demographics

Twelve participants (Table 1) took part in the interviews, which were approximately 30-50 minutes in length. Half of the participants (50%) were genetic counsellors, and half were medical geneticists (50%). Most participants identified as female (66.7%), and most reported their ethnicity as White (83.3%). Years of experience ranged from recent graduates to those practicing for over a decade. Most practiced in a general clinic (66.7%). Half (50%) of participants were from Ontario.

Table 1. Participant demographics

Characteristic		No. (%) of participants (*n*=12)
Gender		
	Female	8 (66.7%)
	Male	4 (33.3%)
Age		
	23-27	1 (8.3%)
	28-32	2 (16.7%)
	33-37	2 (16.7%)
	38-42	1 (8.3%)
	43-47	2 (16.7%)
	48-52	2 (16.7%)
	53-57	2 (16.7%)
Ethnicity		
	White	10 (83.3%)
	Asian	2 (16.7%)
Profession		
	Genetic counsellor	6 (50%)
	Medical geneticist	6 (50%)
Years of experience		
	0-2	3 (25%)
	3-5	2 (16.7%)
	6-8	1 (8.3%)
	9-11	1 (8.3%)
	12 or more	5 (41.7%)
Clinic type		
	Cardiac (adult)	1 (8.3%)
	Metabolics (pediatric)	1 (8.3%)
	General (adult/pediatric)	8 (66.7%)
	Ophthalmology (adult/pediatric)	1 (8.3%)
	Fertility	1 (8.3%)
Province		
	Ontario	6 (50%)
	Manitoba	2 (16.7%)
	Saskatchewan	1 (8.3%)
	Alberta	1 (8.3%
	British Columbia	2 (16.7%)

Qualitative Themes

Three themes were identified. GGE was reported to be morally concerning, as most participants cited safety and ethical concerns, such as off-target effects (i.e., unintended genomic changes), which could be damaging and irreversible. Many participants used the phrase "opening Pandora's box" to describe these concerns. Despite these concerns, many participants supported the use of GGE for severe conditions in order to alleviate suffering for both the future individual and their family. Regarding criteria for GGE (i.e., what constitutes a severe condition), participants expressed that we do not need to "reinvent the wheel".

Specifically, participants suggested that current guidelines for preimplantation genetic diagnosis (PGT-M) could be used as a reference. This would ensure justice, as participants expressed that the conditions couples could test their embryos for should be the same conditions couples can remove from their embryos. However, most participants were not aware that such PGT-M guidelines currently do not exist in Canada. In regards to SGE, participants expressed acceptance and support, voicing that it was not ethically distinct from current forms of treatment. These themes are discussed in detail below with illustrative quotes provided. Additional quotes can be found in Table 2.

Pandora's Box

Participants voiced multiple safety and ethical concerns regarding GGE. These concerns frequently centered on the broader societal implications of GGE, rather than the risk to the future individual alone. Participants used the term "Pandora's box" to describe this sentiment. For example, a common safety concern was the risk of off-target effects. If the process of GGE unintentionally introduced an off-target change with deleterious effects, this has the potential to impact not only the immediate individual but also subsequent generations, including their offspring. This generational effect would be difficult to contain. As one participant described:

> "I think the most – the biggest concern that I have is that this is a technology that is impacting the germline and can be passed down and if it's not perfect we could be introducing mutations into the genome that are going to then be propagated throughout the population. That could be really harmful in ways we don't really understand yet." (Participant 3).

Ethical concerns included the resurgence of eugenics, the misuse of the technology for non-therapeutic purposes (i.e., the notion of the "slippery slope" and "designer babies"), issues of access, and issues of human dignity (i.e., eradicating a condition undermines the value of those living with the condition). Participants expressed that GGE should be approached with caution, due to the historical context of eugenics and its adverse effect on society. As one participant described:

> "If we look back to times where people thought they were doing some really fantastic things, we now call it eugenics and we now criticize and are appalled at some of the well-meaning things that people have done. So I just think that we need to be really careful and conservative in a reasonable way." (Participant 6).

Participants voiced concern that if GGE was implemented in society, it would inevitably be used for non-therapeutic purposes, which they did not support. Participants used terms such as "slippery slope" and "designer babies" to describe this. As one participant stated:

> "And in terms of society, just the fact that we kind of never stop with one thing. I think it's inevitable that people will say well, what if I want my child to be an Olympian? It can be a slippery slope, sometimes, I guess." (Participant 12).

Some participants raised the issue of access, stating that GGE would only be accessible to those with financial means, which would exacerbate existing inequities. This assumption was based on the fact that GGE would not be publicly funded in Canada, as with PGT-M. As one participant described:

> "Just knowing the society that we live in, I just don't think I could ever fully be onboard. Because there is such social stratification already - we see it in IVF and fertility clinics, where only certain folks are able to access the service. I do have an inkling of a feeling that it would be very similar, where only the rich and the elite are able to access gene editing tools for future generations." (Participant 4).

Some participants voiced concern about the effect GGE could have both on the lives of those with disabilities, and the effect of the loss of disabilities on society. For example, some participants expressed that GGE could increase stigma and decrease available resources. As several participants described:

> "I also think that a risk could be the loss of people with disabilities…every person in our life is most likely going to develop a disability at some point, no matter how you want to define that word…individuals who have disabilities don't necessarily wish for them to be gone. And so, you know, the loss of that I think is a risk to society…" (Participant 1).

> "Anytime you introduce a technology that's new, and allows you to be selective, it does put some pressure on parents to use that technology and to make reproductive decisions based on that technology. And at the same time, it stigmatizes parents or patients who are affected. Their birth could have been prevented. So there's some stigma, and it might affect the decisions on funding and support. And the bottom line, if there are just less people born with a condition, they don't have a stronger voice." (Participant 10).

In general, many participants expressed unease when discussing GGE. Some expressed that it brought up unpleasant emotions. When probed, participants expressed that GGE made them feel uncomfortable because it crossed a line that could not be uncrossed and that it felt "unnatural". As one participant expressed:

> "It's hard to say, honestly. I think part of it is…we've evolved from single-cell organisms, humans, and we've been evolving based on our surroundings and based on exposures that we've had…and I just feel like humans are meant to just keep carrying on in the natural progression of things for the most part. And it feels like if we start

> meddling with that, who knows where – how far it will be taken and where the human race will go towards?" (Participant 3).

Despite these concerns, many participants supported the use of GGE for severe conditions. For example, if a condition was life-limiting and early onset, it could be considered for GGE in order to alleviate suffering for the future individual and their family. As one participant described:

> "I think the ones I'm thinking about are really life-limiting. Early childhood death - those ones are ones that people would think about clinically…because it's such an awful condition. You want to spare a family having to undergo that." (Participant 2).

Do Not Reinvent the Wheel

In order to determine criteria for GGE (i.e., what constitutes a severe condition), participants expressed that the decision-making framework already exists. Many participants used the phrase "do not reinvent the wheel". For example, participants stated that the conditions for which termination is allowed, for which there is newborn screening, and for which PGT-M is performed, should be the same conditions for which GGE is offered for. In particular, PGT-M was often cited as a reference point for GGE. As one participant described

> "I think it's the same question that PGT went through…it started with cystic fibrosis and sickle cell and Tay-Sachs and then it was like, maybe we do Huntington's, maybe do BRCA1 and 2. So I feel like the evolution of that question already exists in the sphere of PGT. And I don't know that we need to necessarily re-ask those questions from scratch…" (Participant 5).

Many participants were unaware that there are no guidelines in Canada that outline which conditions PGT-M can be performed for. Once this information was provided, participants expressed that such guidelines would be helpful, given that there is room for flexibility (i.e., the guidelines provide a framework rather than definitive instructions) and that patient populations should be involved in their development. As participants described:

> "I think that guidelines can be important in the context of building a framework, but it should not be a rigid framework. There should be some flexibility within it. For example, let's say we say no disabilities, but you have two blind parents who are saying, "We don't feel that the setup of our society has allowed us – would allow us - to parent a blind child. And here is what we went through in this ableist society. We as blind parents do not want a blind child." If we said, "no disabilities" we're not really taking in their lived experience…I think there needs to be wiggle room for people's experiences." (Participant 5).

> "I think in building those guidelines, we really need to take into account those communities. Communities of individuals who have cystic fibrosis, communities of deaf individuals, not just science and ethics and that kind of thing that we would normally have, but I think we need to survey the population and talk to someone who has hereditary hemochromatosis - what has your life been like, and what is that lived experience?" (Participant 7).

Participants also expressed that PGT-M guidelines could make current practices more consistent between centres, as the absence of such guidelines may lead to discrepancies between which conditions are tested for at which centres. As some participants described:

> "It would help to have some consistency in practice. I think where it's possible, guidelines are good, even if it's just based on expert opinion and consensus - that's still better than nothing." (Participant 10).

> "I can't think of anything that we have said no to, in terms of PGT-M. But we also have never had the question…what is the condition? We do genetic testing for hereditary hemochromatosis, which to me is not really a condition, but it's on a lot of expanded carrier screening panels. So other people are making the decision that it should be tested for. Who are we to then say, "Oh, well, this lab says it's a condition, but we're not going to test your embryos for that." So we test plenty of embryos for hereditary hemochromatosis, which I don't have an ethical problem with. I just think it's more of a concern for…we're charging people for that, when I think it's a non-condition. But that's my opinion and other people think it is a condition..." (Participant 7).

Some participants expressed that the creation of such guidelines could be challenging due to the inherent subjectivity of the perception of disease severity. As one participant described:

> "Even the individual experience of a condition is often very different, right? So even though you say cystic fibrosis, people may have a different idea of the severity based on their relative or their friend who has that condition. So it gets a bit challenging." (Participant 8).

Acceptance of Somatic Gene Editing

Most participants expressed support for SGE. It was often compared to current forms of treatment, with many participants expressing that as long as it was proven safe and effective, they did not see an ethical difference between current forms of treatment and SGE. Participants described that the decision to receive SGE should be up to the patient, as with all forms of treatment. As one participant described when responding to scenario 3 (SGE for hereditary deafness);

> "I think that that person, an adult making an informed decision about their health, should be allowed to at a somatic level. If they made the decision for a cochlear implant, I don't truly understand the difference between somatic editing that would give them the ability to hear, if we're willing to implant something to make them hear…We've already said – it's already medically indicated, if we are offering surgery." (Participant 5).

Many participants expressed that SGE was ethically distinct from GGE. Whereas GGE was stated to be controversial, SGE was stated to be a helpful form of treatment. As one participant described:

> "I think it's totally separate to be honest with you because I think one is proactive and one is reactive and those are two very different things. One is essentially a treatment for something and one is changing the genetic makeup of a person from the point of

conception…and I do think that those are two ethically very different things." (Participant 1).

Some participants voiced concern around issues of access for SGE. For example, participants were concerned that this technology would only be accessible to those with financial means and if so, this would exacerbate existing societal inequities. As one participant described:

> "Is this going to be a million dollars a treatment? And then are only rich families that are educated going to be able to access it? Because then…it's really terrible for the families that don't have access to that and now all of a sudden, this specific genetic condition only exists in low-income populations." (Participant 3).

One ethical concern participants expressed was the use of SGE for non-therapeutic purposes. Most participants did not support the use of any kind of gene editing for non-therapeutic purposes, such as cosmetic enhancement. As one participant described:

> "I just don't think that that is the purpose of healthcare. I don't think that's the purpose of genetic testing or gene therapies. In my mind, gene editing should be to help alleviate a very severe genetic condition that has no other options..." (Participant 4).

Table 2. Additional participant quotes

Pandora's box	"I do feel like it's opening a Pandora's box and that…for the family it would be life-changing to have that germline gene editing be available. But in terms of opening that box…once it starts, we don't have control over that. It leaves medicine and it becomes a potential global issue..." (Participant 3).
Do not reinvent the wheel	"Yeah, so I think that there's no need to reinvent the wheel when there is sort of existing guidelines that you can build upon." (Participant 8).
	"If we want to think about it ethically and morally we have already as a society agreed to what's acceptable to test for and what's not based off of what people are allowed to select for. I think that we kind of have a preconception of what we feel is appropriate or not. And I do think that…it's something that needs to be much further flushed out because currently there are a lot of discrepancies between individual laboratories…" (Participant 1).
Acceptance of somatic gene editing	"I think it'd be OK to offer it and then the person could make their own decision, just like we offer cochlear implants." (Participant 9).

Discussion

Gene editing technologies such as CRISPR-Cas9 offer unprecedented opportunities to treat genetic disorders [27]. As gene editing technologies advance, it will be crucial to understand the views of stakeholder groups regarding their application. To the best of our knowledge, our study is the first to investigate the perspective of genetics professionals on gene editing using a qualitative approach. The findings suggest that our participants have significant concerns around GGE, but do support its use for severe genetic conditions. Participants suggested that rather than develop criteria to classify severity to determine which conditions should be eligible for GGE, existing practices should be referenced. Specifically, participants suggested that current guidelines for PGT-M can be used as future guidelines for GGE. However, most participants were not aware that PGT-M guidelines do not currently exist in Canada. Lastly,

our participants showed strong support for SGE, which is consistent with previous literature [22]. Our study highlights a novel need for PGT-M guidelines in Canada, as well as adds to the growing literature on the acceptability and concomitant ethics of HGE.

In our study, participants expressed that GGE was ethically distinct from SGE. They voiced ethical and safety concerns around GGE and discomfort with its implementation in society. The concerns around GGE stemmed from its effect on society, rather than just on the future individual. Off-target effects were the most common safety concern, as they could persist throughout generations [29]. Ethical concerns included issues of access (i.e., only those with financial means would have access), the resurgence of eugenics, the misuse of the technology for non-therapeutic purposes (i.e., the notion of a "slippery slope" and "designer babies"), and issues of human dignity (i.e., undermining the value of those living with disabilities). There were concerns that if only those with financial means can access GGE, this would perpetuate existing inequities in society. As noted in our findings, participants drew comparisons between PGT-M and GGE, voicing that if GGE is available in the future, it is unlikely to be publicly funded, as is currently the case with PGT-M. This could lead to issues of justice, where only patients with financial means are able to access this healthcare resource. Such disparities could further entrench existing social inequities, leading to a society where certain genetic conditions are eradicated in affluent populations while persisting in those unable to afford the technology. Future policies should consider these ethical concerns when implementing new genetic technologies, such as GGE, and consider public funding models.

Many participants were concerned about the effect GGE could have on disability communities. Participants were also concerned that allowing the eradication of a condition from the germline may undermine the value of those living with the condition, increase stigma, and result in a decrease of available resources. Despite these concerns, many participants supported the use of GGE for severe conditions in order to alleviate suffering, both for the individual and their family.

Previous studies that have investigated the views of the medical community on GGE have found conflicting results and have mainly been quantitative. A study that surveyed members of genetics professional societies (with members from across the globe) found that the majority supported the use of GGE for therapeutic purposes. However, some participants voiced similar concerns as in our study, such as health-related uncertainties and the impact of GGE on society (e.g., adverse effect on disability communities) [22]. Waltz et al. surveyed research scientists who used gene editing in their work; the study found that the majority did not support the use of GGE to treat or prevent disease. However, the majority did support GGE to conduct preclinical research [23]. It is unclear if this population felt that GGE was unethical, or rather that it was too early to use GGE before more research is conducted. Our study shows both concern and support for GGE, suggesting it is a technology that may be used, but only under certain circumstances.

In regards to SGE, participants voiced support and enthusiasm for this technology. Many participants expressed a shared sentiment – SGE was not ethically distinct from current forms of treatment and should be offered if proven to be safe and effective. Participants embraced the ethical principle of autonomy, one of the four main pillars of medical ethics [28]. While the availability of SGE should not be restricted, participants stated that ultimately the use of SGE should be a decision made by the patient or guardian. Some participants voiced concern around

issues of access to SGE, stating that this is a treatment that should be accessible to all patients regardless of financial means, suggesting that SGE is not only ethical, but necessary. This suggests that SGE should be publicly funded. The only ethical concern participants expressed around SGE was the use of the technology for non-therapeutic purposes, such as cosmetic enhancement. No participants supported the use of either SGE or GGE for this purpose.

These findings are consistent with current literature on stakeholder views on SGE. Previous studies that have investigated the views of the medical community on HGE (e.g., clinicians, genetic counsellors, research scientists, educators) have shown that most participants were highly supportive of SGE for both research and clinical purposes [22-23]. Our qualitative study provides an understanding of the reason for this support - SGE is not ethically distinct from current forms of treatment.

Participants expressed that criteria for GGE (i.e., what constitutes a severe condition) can be built using existing guidelines. Participants described this as not having to "reinvent the wheel". In particular, PGT-M was often aligned with GGE. Many participants were not aware that Canada does not currently have guidelines for the types of conditions eligible for PGT-M; only non-medical sex selection is explicitly prohibited under the Assisted Human Reproduction Act. [11] Otherwise, decisions regarding PGT-M are made internally at each clinic [30]. Of note, one participant voiced concern regarding offering PGT-M for hereditary hemochromatosis, a condition from which most individuals do not experience any symptoms. These types of ethical concerns have resulted in multiple calls for PGT-M guidelines in Canada [30-31]. Our study elucidates a novel need for PGT-M guidelines from the perspective of a future GGE decision-making framework.

Most participants expressed that guidelines for PGT-M would be useful, given that they are flexible and constructed with input from diverse communities, such as patients as well as medical professionals. The participants who were aware that Canadian PGT-M guidelines do not exist (due to professional experience in the field) expressed that such guidelines would not only be useful as a reference for GGE, but would also improve current PGT-M practices, as inconsistencies exist across centres (i.e., differences exist as to which conditions PGT-M will be performed for).

The UK is one of the few countries where PGT-M is regulated by a statutory body, the Human Fertilisation and Embryology Authority (HFEA). The HFEA provides a list of pre-approved conditions for PGT-M [32]. When evaluating the eligibility of a condition, the HFEA considers features such as age of onset, symptoms of the disease, availability of treatment, quality of life, and clinical variability [33]. While Canada could adopt a similar system, it may be complicated by the fact that PGT-M is not publicly funded in Canada, as it is in the UK [30, 34]. Regulating private practice may be more challenging.

There are several limitations in this study. Although the study team aimed to recruit a diverse, pan-Canadian sample, half of participants were from Ontario and most identified as female and White. As such, the results may not represent a diverse set of perspectives. Further research is needed on the implementation and content of PGT-M guidelines in Canada.

Although several disease traits were put forward by our participants (e.g., life-limiting, early onset), participants struggled with providing a comprehensive list of traits to consider for GGE. Although the data was de-identified, it is possible that participants felt uncomfortable with incomplete anonymity, as the identity of the participants was known to the interviewer.

Throughout the interview process, several participants inquired about the de-identification process to ensure their responses could not be linked to their identities. A future project that collects information completely anonymously may provide further data.

Conclusion

This qualitative study has provided valuable insight into the views of genetics professionals in Canada on the ethics of HGE, as well as criteria for GGE. The findings indicate support and enthusiasm for SGE, as long as it is used for therapeutic purposes and is accessible to all patients, regardless of financial means. GGE was expressed to be controversial, with multiple safety and ethical concerns cited. Despite these concerns, the findings indicate support for GGE for severe conditions. In regards to GGE criteria, our study elucidates that current guidelines for PGT-M can be used as a reference, ensuring justice and consistency. Given that these guidelines do not currently exist, our study elucidates the need for PGT-M guidelines in Canada, both to improve current practices and to serve as a framework for GGE. As gene editing technology advances, it will be crucial to understand how to ethically implement it into society.

Declarations

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Disclosure Statement

No potential conflict of interest was reported by the authors.

Ethics Approval

Not applicable.

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