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RESEARCH ARTICLE

Attitudes of Members of Genetics Professional Societies Toward Human Gene Editing

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Abstract

Gene-editing technologies have improved in ease, efficiency, and precision. Although discussions are occurring around acceptable uses of human gene editing, limited data exist on the views of genetics-trained individuals. In 2017, we distributed an anonymous online survey to assess the attitudes of members of genetics professional societies toward gene editing ($N = 500$). Virtually all respondents were supportive of somatic editing in basic-science (99.2%) and clinical (87.4%) research on nonreproductive human cells. Only 57.2% were supportive of germline-editing basic-science research; 31.9% supported the transfer of viable embryos to humans for clinical research. While most favored future therapeutic uses of somatic (96.6%) and germline (77.8%) editing, there was little support for enhancement in somatic (13.0%) or germline (8.6%) cells. This study describes attitudes toward gene editing from genetics professionals worldwide and contributes to ongoing discourse and policy guidance in this domain.

Introduction

Gene-editing tools such as CRISPR-Cas9 have been successfully utilized to target, edit, modify, regulate, and mark genomic loci of a wide variety of cells and organisms.[1,2] However, important safety issues[3,4] and numerous ethical and social concerns remain about research and clinical applications of genome editing, its regulation, equity and access to the technology, and potential use for non-therapeutic (enhancement) purposes.[5–9]

General consensus exists among the scientific community that research applications of somatic editing should continue,[10] and somatic clinical trials have already begun.[11–13] There is significantly less agreement on the use of germline editing.[8,14,15] Some scientists advocate for a moratorium on germline editing until safety and efficacy issues are resolved and broad consensus is reached about appropriate applications.[3,10,16,17] A 2017 report by the National Academy of Sciences (NAS) and the National Academy of Medicine (NAM) stated that clinical trials for germline editing could be permitted in the future for serious conditions meeting stringent criteria.[18] Several international genetics professional organizations[3,5,6,18–21] have expressed support for basic-science research on germ cells and human embryos, with appropriate oversight, but all published statements agree clinical translation is premature. Countries vary in terms of whether germline-editing research is allowed (e.g. China[22] and the United Kingdom[23]) or restricted [e.g. the United States restricts funding of research on human embryos[24] and the Food and Drug Administration (FDA) prohibits trials that will alter the human germline[25]]. Most countries have existing regulatory frameworks for reviewing and evaluating somatic-editing research and clinical trials,[18] but laws around embryo research vary across countries, are often ambiguous, and may lack mechanisms for enforcement or monitoring.[26–28] International discourse on how—if at all—we as a society want to use these technologies is necessary and, indeed, already occurring.

Following the 2015 International Summit on Human Genome Editing, the NAS and NAM concluded that there should be an ongoing international forum to discuss acceptable uses of human gene editing and help inform policy decisions.[18] There is limited prior international comparative research in this domain. More than 20 years ago, a study by Macer *et al.*[29] described perceptions

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of gene therapy and bioethical reasoning in 10 countries. Several recent studies have examined public attitudes toward human gene editing in the United States, Canada, the United Kingdom, Japan, and China.[30–41] A meta-analysis of U.S. public opinion polls[30] found that most Americans favor somatic editing for clinical use in patients with serious diseases, with fewer supporting germline editing.

Data are especially limited on how genetics professionals—an important stakeholder group—view gene editing. Research scientists will develop and validate gene-editing techniques. Clinical genetics professionals will offer such technologies, and their patients will be affected by the clinical implementation of gene editing. Both groups play important roles in educating the public, and their perspectives are important to inform policy and practice in this field. To understand the views of genetics professionals better and to facilitate further discussion, we distributed an online survey to assess attitudes toward gene editing around the world, with the aim of capturing a wide range of global and cultural perspectives.

Methods

We designed an anonymous online questionnaire to characterize the attitudes of members of genetics professional societies across the globe toward research and clinical applications of somatic versus germline human gene editing. The Stanford University Institutional Review Board reviewed the study protocol and determined it to be exempt from continuing review due to participant anonymity.

Measure

The questionnaire, administered through Qualtrics,[42] consisted of 85 items, primarily using a five-point Likert-type scale, divided into six sections: (1) demographics, (2) research applications of human gene editing, (3) clinical uses of human somatic gene editing, (4) clinical uses of human germline gene editing, (5) views toward human embryo research, and (6) general views toward human gene editing. For questions about research applications (section 2), we asked respondents to indicate support for applications taking place at the present time. For questions about clinical applications (sections 3 and 4), we asked respondents to indicate support for potential future applications if and when such gene editing becomes safely available. Each section included space for comments. Survey questions were designed by an international group of genetics professionals with backgrounds in genetic counseling, bioethics, and health-services research. The survey was pilot tested for clarity, organization, and length, and then revised based on feedback.

Subjects

Our target population was genetics professionals practicing across the globe. Individuals were eligible to participate if they were trained in a genetics-related field as a clinician (physician, genetic nurse, or genetic counselor), laboratory scientist, Ethical, Legal and Social Implications (ELSI) researcher, or educator. This study used a convenience sample of individuals who were members of human genetics professional societies known to the authors. Between November 28, 2016, and February 15, 2017, e-mail invitations were sent to members of 10 different genetics professional organizations across the globe (Supplementary Table S1); the questionnaire was accessible until March 23, 2017. No compensation was provided. Given our desire to obtain a broad international sample, and in recognition that we were unable to obtain direct mailing by all genetics societies worldwide, the recruitment e-mail (sent once to each organization's electronic mailing list) encouraged individuals to forward the questionnaire to genetics colleagues. Based on membership data provided by the organizations, we estimated that the questionnaire was distributed to at least 13,000 professionals, assuming some overlap in membership across the societies. We were unable to determine an exact response rate, but conservatively estimated a rate of 4.6% ($n = 631/13{,}718$).

Analysis

Response data were analyzed with IBM SPSS Statistics for Windows v24.0 (IBM Corp., Armonk, NY). Surveys were included if at least two-thirds of the questions were completed. Since respondents were permitted to skip items, the sample size varied by item. Descriptive statistics summarized responses to each item. The responses to five-point Likert-type items were collapsed into ''supportive'' and ''against'' categories (Supplementary Methods). Neutral responses were tabulated.

Respondents were asked to indicate their level of support for numerous types of future clinical uses of somatic and germline editing. Given high correlations among these variables, new scales for ''therapeutic'' and ''enhancement'' were created for statistical analyses (Supplementary Methods). Paired-sample t-tests were used to compare support for somatic versus germline editing. To correct for type 1 error, given the number of statistical tests conducted, we used a Bonferroni adjustment and set the level of significance at $p < 0.002$ ($p = 0.05/24$).

Repeated measures analyses of variance (ANOVAs) were conducted to compare support for future clinical uses of gene editing across varying clinical features of the condition for which treatment might occur (e.g., high vs. low penetrance). Follow-up pairwise comparisons were run with Bonferroni adjustments.

The Supplementary Methods and Supplementary Tables S1, S2, and S3 address trends associated with demographic factors and the methods used for these analyses.

Comments were left by 39% (196/500) of respondents who elaborated on their views. Formal coding of participant comments was not performed, but illustrative quotations are included to provide additional context and supplement the quantitative data.

Results

Demographics

Of the 631 survey responses, 131 either did not meet eligibility criteria ($n=4$) or had completed less than two-thirds of the survey ($n=127$), resulting in 500 valid completed surveys. Respondents who indicated their profession as ''other'' ($n=27$) were re-categorized into the most suitable category based on their described profession. ELSI professional subtypes (bioethics, law, policy, and health services) were merged into a single profession category: ''ELSI researcher.''

Table 1 describes the sample. We achieved representation from 48 countries, although the majority of respondents originated from (63.5%) and/or resided in (74.9%) North America. Most of our respondents were clinicians (57.5%). The majority had been practicing for <10 years (60.5%) and were 25–39 years of age (52.4%).

Overarching views toward human gene editing

Figure 1 describes the overall views toward human gene editing, including how somatic and germline editing fit into respondents' current personal values and belief systems. Most respondents (87.5%) felt that somatic editing is morally acceptable and does not conflict with their cultural (89.2%) or religious (86.8%) beliefs. Somatic editing was particularly acceptable if no alternative treatment is available (91.9%). Overall, while most (76.7%) felt that individuals should have the right to decide for themselves whether to undergo gene editing, many (41.4%) also felt that parents should have the right to edit their children's genes after birth.

Table 1. Demographics

Participant characteristics	n *(%)*	*Participant characteristics*	n *(%)*
Age, years ($N=499$)		Profession ($N=499$)	
20–24	26 (5.2)	Physician	67 (13.4)
25–29	117 (23.4)	Genetic nurse/counselor	212 (42.5)
30–34	91 (18.2)	Clinician—other	8 (1.6)
35–39	54 (10.8)	Clinical laboratory scientist	36 (7.2)
40–44	44 (8.8)	Research scientist	148 (29.7)
45–49	23 (4.6)	ELSI researcher	17 (3.4)
50–54	37 (7.4)	Educator	11 (2.2)
55–59	37 (7.4)		
60–64	35 (4.0)	Family status ($N=473$)	
65–69	13 (2.6)	Biological children	220 (46.5)
70–74	10 (2.0)		
75+	12 (2.4)		
Continent of origin ($N=496$)		Continent of residence ($N=498$)	
Africa	14 (2.8)	Africa	12 (2.4)
Asia	55 (11.1)	Asia	28 (5.6)
Europe	69 (13.9)	Europe	41 (8.2)
North America	315 (63.5)	North America	373 (74.9)
Oceania	38 (7.7)	Oceania	41 (8.2)
South America	5 (1.0)	South America	3 (0.6)
Years in area of practice ($N=499$)		Self-reported religiosity ($N=473$)	
0–4	222 (44.5)	Not at all religious	209 (44.2)
5–9	80 (16.0)	Slightly religious	128 (27.1)
10–14	52 (10.4)	Moderately religious	86 (18.2)
15–19	34 (6.8)	Strongly religious	50 (10.6)
20–24	32 (6.4)		
25+	79 (15.8)		
History of a Mendelian genetic illness[a]		History of a complex genetic Illness (self-defined)[a]	
Personal	37	Personal	80
Partner	16	Partner	40
Close family member[c]	53	Close family member[b]	146

Sample size (N) varies between variables because respondents were allowed to skip questions.
[a]Percentages are not reported because respondents were allowed to select multiple responses. [b]Parents, siblings, or children.
ELSI, Ethical, Legal and Social Implications.

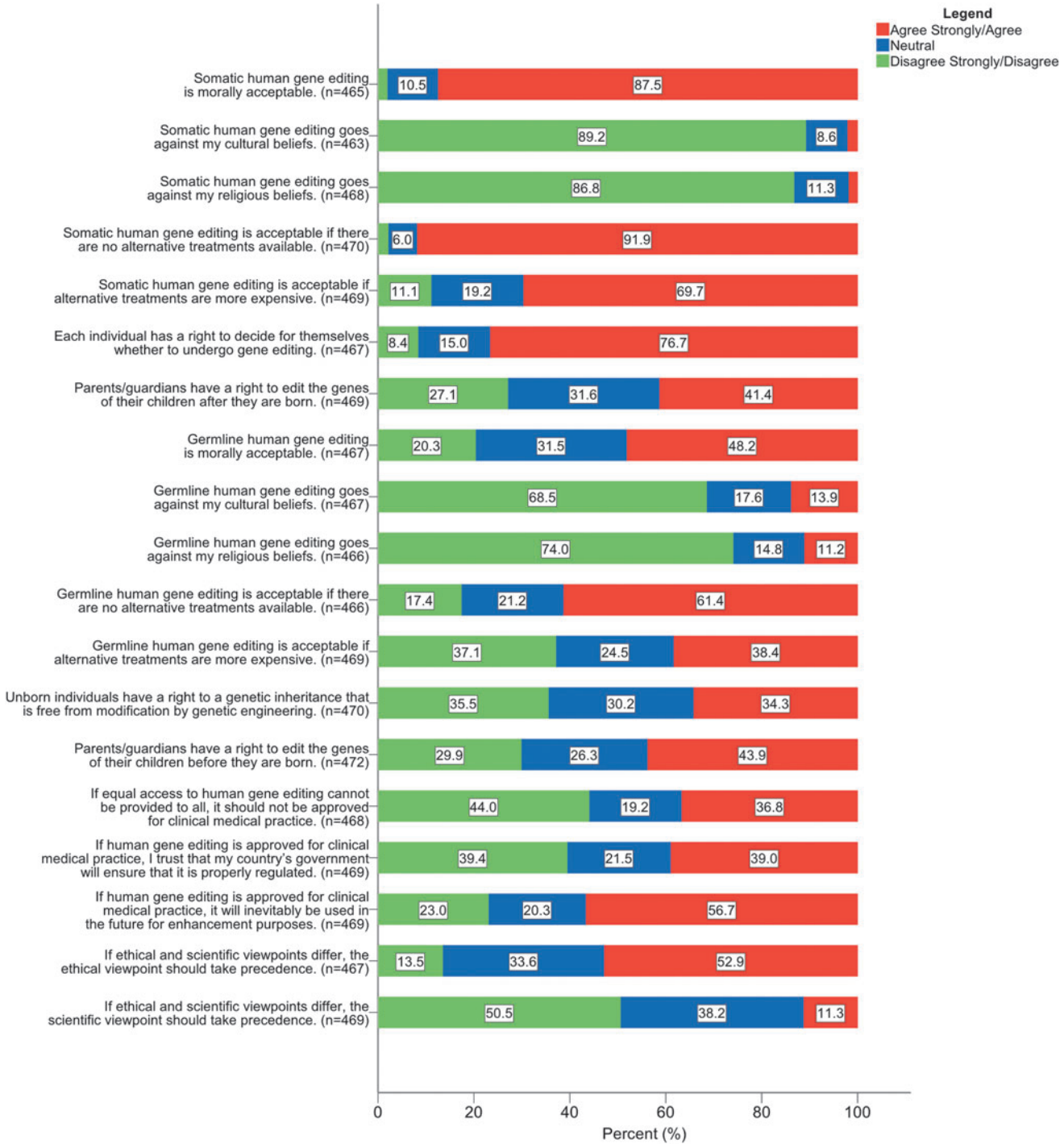

FIG. 1. General attitudes toward human gene editing.

Respondents were more divided about germline editing (Fig. 1). Fewer felt that germline editing is morally acceptable compared to somatic editing (48.2%; $t = 17.36$, $p < 0.001$), with almost a third indicating they were ''neutral.'' Compared to somatic editing, fewer felt that germline editing does not conflict with their cultural (68.5%; $t = 11.44$, $p < 0.001$) or religious (74.1%; $t = 8.41$, $p < 0.001$) beliefs. A slight majority (61.4%, statistically fewer than with somatic editing; $t = 14.32$, $p < 0.001$) felt that germline editing would be acceptable if no alternative treatment is available, but respondents were split on whether it is acceptable if an alternative is available but

more expensive. Respondents were mixed in their beliefs about whether unborn individuals have a right to a genetic inheritance free from modification by genetic engineering, and many (43.9%) felt that parents should have the right to edit their children's genes before birth (Fig. 1).

Genetics professionals were divided in their views toward future clinical implementation of human gene editing. Respondents were split on whether gene editing should be approved without guaranteed equal access for everyone and whether they trust their country's government to regulate gene editing properly. A slight majority (56.7%) felt that if approved for clinical practice, it will inevitably be used in the future for enhancement purposes. Some respondents expressed particular concern about the regulation of germline editing:

> Modifying genes to cure disease is one thing. Interfering with the fabric of humanity is another. Ethical issues [need to be addressed] and control over human genome editing is not strict enough, and without these, the room for dangerous science is great.
>
> Much more research is needed before germline editing should be allowed. It may eventually be possible and actually very useful medically to treat genetic disease, but it also has the highest potential for abuse … Well-thought-out policies and ways to implement these policies should be in place before it is allowed to be carried out.

Attitudes toward somatic gene-editing applications

Support was high for basic-science (99.2%) and clinical (87.4%) research on nonreproductive cells (Table 2) and for future clinical approaches to somatic editing for therapeutic purposes (96.6%; Table 3 and Fig. 2A). There was significantly less support for somatic editing for diseases with lower penetrance, later age of onset, less significant impact on life-span, and lesser degree of disability due to the condition (repeated measures ANOVAs, $p < 0.001$).

There was little support (13.0%) for somatic editing for enhancement purposes (Fig. 2A). One respondent remarked:

> I'm definitely in favor of helping those with disabilities, but not for aesthetic purposes nor improvement of human function.

Table 2. Support toward research uses of gene editing

	% Supportive
Basic-science research on *human somatic cells* (nonreproductive cells; $N = 498$)	99.2
Clinical research on *animals* (nonreproductive cells) for the development of human *somatic* (nonheritable) gene-editing applications ($N = 496$)	88.3
Clinical research on *humans* (nonreproductive cells) for the development of human *somatic* (nonheritable) gene-editing applications ($N = 498$)	87.4
Basic-science research on already existing *nonviable human embryos* (e.g., aneuploid, triploid; $N = 497$)	88.5
Basic-science research on already existing *viable human embryos* ($N = 497$)	57.2
Clinical research on *viable human embryos* with the goal of conceiving pregnancy, but not live birth, for the development of human *germline* (heritable) gene-editing applications ($N = 498$)	31.9

Table 3. Support toward future clinical uses of gene editing

	% Supportive	
	Somatic	Germline
Type of application		
Therapeutic[a]	96.6	77.8
Correction of a mutated allele in a carrier of a genetic condition	—	47.8
Enhancement[b]	13.0	8.6
Penetrance of condition		
High (e.g., Mendelian disorders; >80%)	95.8	76.1
Moderate (e.g., complex disorders; 20–80%)	74.6	59.4
Low (<20%)	44.5	38.9
Prevalence of condition		
High (>1 in 10,000)	84.8	65.3
Moderate (1 in 10,000–1 in 100,000)	84.6	65.5
Rare (<1 in 100,000)	84.0	65.7
Age (in years) of onset of condition		
Childhood to adolescence (0–20)	91.6	73.5
Adulthood (21–60)	88.5	66.3
Later in life (61+)	74.0	49.5
Impact of condition on life-span		
Fatality in childhood	96.2	78.2
Shortened life-span or risk of sudden death	94.6	75.1
No significant effect on life-span	63.6	41.5
Degree of disability due to condition		
Severe impact (i.e., unable to perform basic activities of daily life)	96.8	79.0
Moderate impact (i.e., additional time and/or effort needed to perform basic activities of daily life)	89.2	67.8
Mild impact	54.3	37.7

Sample size (N) for responses varies between 493 and 500 and is not individually noted.

[a]Treatment for a genetic condition causing physical or intellectual disability.

[b]Improvement of appearance (e.g., hair/eye color, height), physical abilities (e.g., athleticism), or cognitive abilities (e.g., memory, IQ).

Attitudes toward germline gene-editing applications

Respondents were less supportive of germline-editing research, with 57.2% supporting the use of existing viable embryos for basic-science research, 41.5% supporting the creation of embryos for this purpose, and 31.9% supporting the transfer of viable embryos to humans for clinical research (Table 2). Some respondents commented that germline-editing research should not be considered at present in order to foster trust in somatic-editing research first:

> …the research community should agree to a moratorium on germline genome editing applications in order to

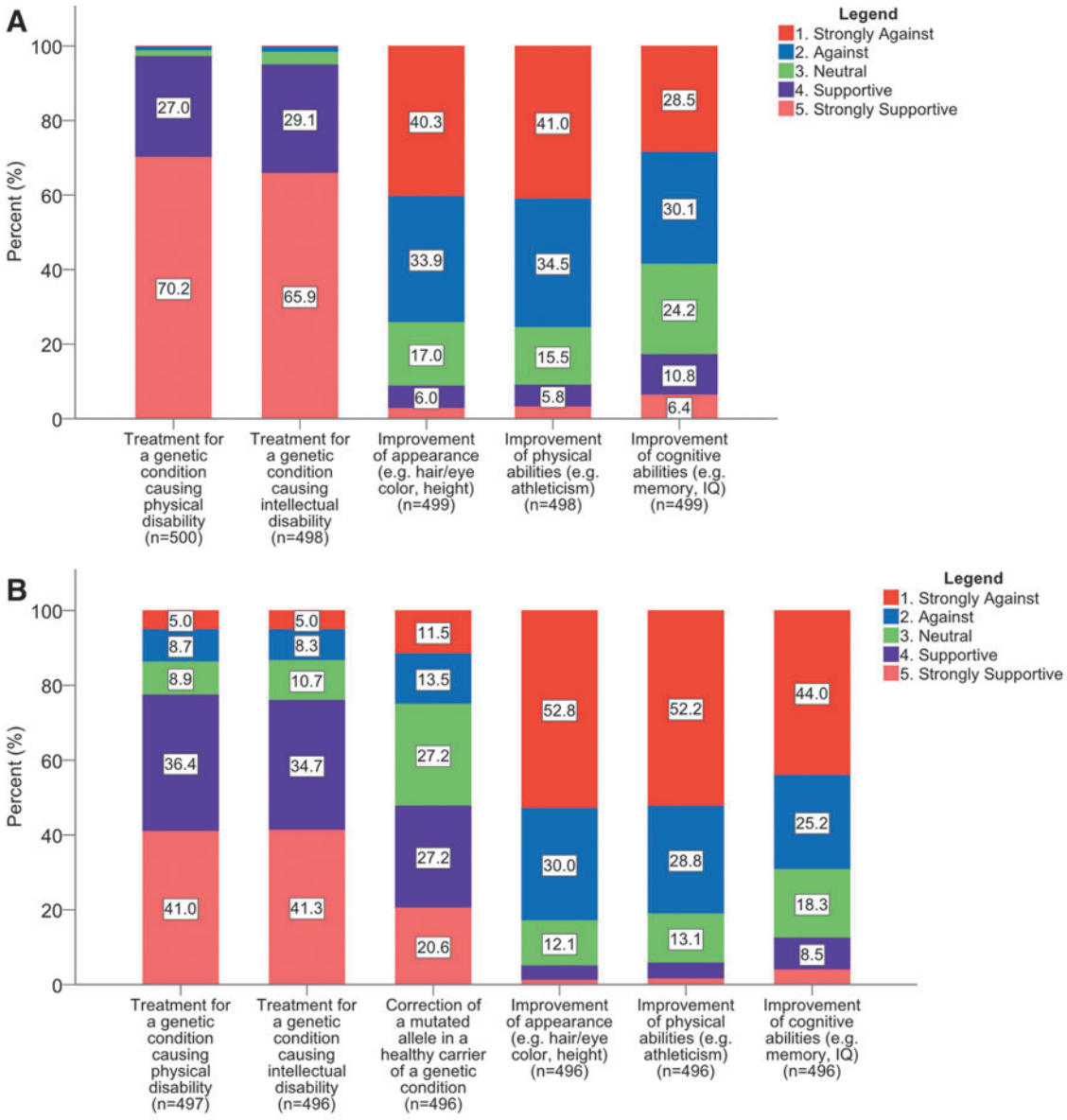

FIG. 2. **(A)** Support toward future clinical uses of somatic gene editing. **(B)** Support toward future clinical uses of germline gene editing.

> promote public trust and support for … somatic genome editing.
>
> I believe that we should first get to a point where we can cure as many diseases as possible through somatic editing, even if it occurs early on in life such as post-birth, but we should *not* go into the arena of germline editing until the field of somatic editing has matured significantly. We have a lot to learn, and we are not ready for this.

There was relatively high support (77.8%) for future clinical uses of germline editing for therapeutic purposes (statistically fewer than with somatic editing; $t = 13.31$, $p < 0.001$; Table 3 and Fig. 2B). As in somatic editing, there was significantly less support for germline editing for diseases with lower penetrance, later age of onset, less significant impact on life-span, and lesser degree of disability due to the condition (repeated measures ANOVAs, $p < 0.001$; Table 3). Compared to somatic editing, fewer respondents ($t = 10.24$, $p < 0.001$) believed that future enhancement applications of germline editing are acceptable (8.6%; Fig. 2B). Some felt germline-editing applications should not be pursued without a medical necessity:

> I believe that germline gene editing research would be beneficial to address genetic defects causing death or

> disability; I do not think parents should be able to have germline gene editing to change traits that do not have a harmful impact on the health or physical/mental abilities of their offspring (especially in cases where the offspring could later choose to have somatic editing of traits they wished to change).
>
> There are alternative options available (IVF with [preimplantation genetic diagnosis]) for known germline carriers—this seems like using technology for the sake of using technology rather than a practical use.

Although the majority of respondents were supportive of therapeutic applications of germline editing, comments expressed concerns about the future impact of clinical applications, including medical unknowns and the impact on society:

> Prevalence, penetrance, severity, etc. don't bother me so much as us playing God and deciding what's desirable. Who's to say there won't be a selective advantage from some of these conditions/traits in a thousand years and we messed it up by eradicating it?
>
> I have real issues with germline gene editing. There is a societal perspective that testing/medicine can guarantee a healthy baby. Accidents can still happen. A world which sees physical and intellectual disability as a ''problem'' that should be ''corrected'' and prevented in future generations through gene editing will be an unwelcome place for those who acquire disability. Also, what about people who choose not to use gene editing? Will they be judged and denied access to services? We've all heard anecdotal stories of parents of children with Down syndrome being asked, ''Didn't you find out in time?''—the inference being ''in time to terminate,'' as if that's the only choice. I don't want this attitude to become any more entrenched.

Discussion

With increasing calls to understand the attitudes of various stakeholders toward gene editing,[5,6,18] our study adds data on professionals' views that could inform gene-editing policies. In line with recent recommendations to continue efforts to develop somatic-editing treatment,[10] our respondents are highly supportive of somatic-editing applications. While there is significantly less support for germline editing compared to somatic editing and views are more divided, the majority of genetics professionals in this study feel that there may be acceptable uses in the future, and nearly one third supported clinical germline-editing research studies when our data were collected in 2017, despite it not being recommended by multiple position statements.[5,6,10] Finally, our findings suggest a much higher level of acceptance among respondents for future therapeutic applications compared to enhancement-related approaches, and variation in support based on the clinical features of the condition for which treatment might occur. We interpret this to indicate that respondents are not wholly supportive of all applications of gene editing, but rather feel that approval should only be given when appropriate criteria are met: for health-related purposes where there is a clear indication and proven benefit. These findings are consistent with public opinion polls.[30,32–41] Moving forward, there will be a need to define more precisely what conditions constitute a ''therapeutic application''; this is an important area of future study.

Earlier this year, scientists and ethicists from seven countries called again for a moratorium on clinical applications of germline editing and emphasized the need for an international governance framework.[17] While each country ultimately has the authority to regulate its own activities according to its own values, conflicting regulatory approaches regarding human gene editing could have serious consequences for the common heritage of humanity.[43] In our globalized world, individuals can cross borders to access technologies that are not available in their home country. Given the significant and widespread ramifications, global debate and continued deliberation are occurring now, with the challenging goal of reaching a consensus on acceptable uses of this powerful technology and its regulatory norms.

Study limitations

This study is a convenience sample drawn from the e-mail lists of professional genetics organizations, with an estimated response rate of 4.6%. Studies involving health-care providers are generally characterized by low response rates, especially those that are online, without incentives, and without follow-up reminders.[44] Additionally, electronic surveys have inherent biases such that those with strong feelings may be more likely to complete the survey. This may have overestimated the strength of attitudes in our results. Our survey was only available in English and targeted members of genetics professional organizations, who may already have an interest in the topic. Importantly, this survey occurred prior to the 2018 births of the babies who underwent germline gene editing[45] and may not reflect current attitudes toward gene editing among professionals. Finally, our participant numbers outside of North America were not large enough to perform a rigorous international comparison. Given the legitimate biases and size of our population, a more thorough assessment is needed to characterize the relationships between demographic variables and attitudes. While our results may not be generalizable to

all genetics professionals globally, they represent a range of perspectives and can serve as a foundation for future research.

Conclusion

Our exploratory study has demonstrated a high level of support for human gene editing among genetics professionals, particularly the pursuit of future therapeutic applications of somatic editing and openness to deliberations on germline uses. Nonetheless, professionals also expressed concerns about the future regulation of clinical gene editing, indicating a need for an ongoing conversation before translation into clinical practice. Our study adds to the emerging data, documenting similarities and differences in attitudes between some stakeholder groups. As clinical trials for somatic gene editing move forward, and deliberations about germline gene editing continue, a wide range of perspectives is still needed to understand societal views better on incorporating human gene editing—particularly germline—into clinical settings on a global scale.

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Author Disclosure Statement

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