

A Dichotomy of Information-Seeking and Information-Trusting: Stem Cell Interventions and Children with Neurodevelopmental Disorders

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Abstract Parents and primary caregivers of children with Cerebral Palsy (CP) and Autism Spectrum Disorder (ASD) are faced with difficult treatment choices and management options for their children. The potential of stem cell technologies as an interventional strategy for CP and ASD has gained attention in the last decade. Information about these interventions varies in quality, resulting in a complex landscape for parent decision making for a child's care. Further complicating this landscape are clinics that advertise these interventions as a legitimate treatment for a fee. In this study, we surveyed individuals who considered taking their child with ASD or CP abroad for stem cell interventions on their use of different sources of stem cell related health information and their level of trust in these sources. Participants reported that while the Internet was their most frequent source of information, it was not well-trusted. Rather, information sources trusted most were researchers and the science journals in which they publish, other parents of children with CP and ASD, and healthcare providers. These findings highlight a dichotomy between information-seeking preferences and information-trusted sources. We discuss the challenges of health science communication and present innovative opportunities to increase communication with trusted and

reliable sources as part of an integrated multi-pronged approach.

Keywords Stem cells · Cerebral palsy · Autism spectrum disorder · Stem cell interventions · Trust · Ethics

Introduction

Parents of children with Cerebral Palsy (CP) and Autism Spectrum Disorder (ASD) are faced with difficult treatment choices and management options for their children. CP and ASD are both common neurodevelopmental disorders affecting children in early childhood and persisting throughout the lifespan. CP, a chronic non-progressive disorder that compromises motor control, speech and, in some cases, cognitive functioning, affects approximately 1–2 of every 1000 live births [1]. ASD similarly affects approximately 2 in every 1000 children and children with ASD experience impaired social and behavioral skills [2]. The potential of stem cell technologies as an interventional strategy to mediate the suffering of children affected by CP and ASD has gained considerable attention in the last decade [3] and is currently the focus of several ongoing clinical trials [4, 5]. While research continues, stem cell clinics offer and widely advertise services categorized as therapy or treatment for a fee [6–8]. Stem cell tourism, where individuals and their families travel outside their country of residence to receive stem cell interventions, has become an increasingly popular form of medical tourism [9]. Previous research has demonstrated interest in stem cell tourism for children with CP and ASD, with some parents chronicling their stories in the print media

We use parents, caregivers and parents and caregivers interchangeably in this paper.

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[10, 11]. The vulnerability of children in stem cell tourism makes this a particularly salient concern [12].

The portals for information about stem cell interventions abroad have been well-documented and are varied: the Internet, direct-to-consumer advertising, social media, news media and patient advocacy groups [10, 11, 13–15]. Direct-to-consumer advertising, through stem cell clinic websites and social media, is one of the primary avenues of information and regularly provides optimistic evaluations of the promise of these interventions [7, 16]. Individuals considering travelling abroad also seek out the experiences of patients returning from these clinics through testimonials on stem cell websites, accounts on personal blogs and word of mouth [17–19]. News media can influence its readers through agenda setting and framing. The degree of attention placed on issues in the media can highlight certain points of view and marginalize others [12]. News coverage of stem cell interventions abroad tends to be largely positive, often providing an uncritical account of the benefits and risks of stem cell interventions abroad. Media engagement with researchers results in the most balanced perspective [10, 11]. Other information sources, such as patient advocacy groups and scientific organizations, provide passive online educational information. However recent research on parent vaccination attitudes, for example, suggests that such educational materials may have a limited impact on parent behaviours [20].

These portals of information routinely, although not always, generate hype [21], contravene published and professionally accepted standards of care and ethics practice [13], and may compromise trust in research and in the patient-physician relationship [22, 23]. Physicians are obligated to provide information and advice about any risks in medical interventions abroad while respecting patients' autonomy in healthcare decision-making [23, 24]. There has been recognition that trustworthy bidirectional discourse that respects patient and caregiver autonomy can encourage informed hope and well-grounded decision making [25]. Trust is pivotal for parents who must decide on which sources of information to rely. It is built and strengthened through iterative social processes over time and is predicated on the underlying assumption that those we trust are competent and motivated to act in our best interests [26, 27]. Where there is uncertainty, or where the potential for risks are high as in the case with stem cell interventions abroad, trust requires a leap of faith leaving decision-makers particularly vulnerable [28].

In the present study, we explore the use of and trust in sources of information for stem cell interventions offered abroad for children with CP or ASD.

Methods

Survey Instrument

The survey instrument was adapted from prior research on preferred sources of health information for individuals with neurodegenerative disorders [29, 30] and customized to fit the current research context of children with major neurodevelopmental conditions. Results from a content analysis of print media coverage of stem cell therapies for CP and ASD [10] were used to further refine the survey. Members of the research team iterated and refined the research instrument to ensure its content validity. The final survey consisted of 15 closed-ended questions and 1 open-ended question. The closed-ended portion of the survey included questions regarding demographics (age, gender, income, country of residence, child with CP or ASD, age of child and self-reported symptom severity), and about interest in stem cells and stem cell tourism (Table 1). This section of the survey consisted of Yes/No and multiple choice questions. Respondents could skip questions not applicable to their interest or knowledge base. The open-ended question allowed respondents to elaborate on their answers to the discrete question regarding most trusted source of information. The study was approved by the University of British Columbia Behavioural Research Board under protocol number H14-01043.

Data Collection

Data were collected from February 13 to March 13, 2015 using the FluidSurvey online platform which is compliant with Canadian privacy (all data reside on Canadian servers) and accessibility standards (W3C). The target population consisted of individuals 18 years or older with a child with CP or ASD. We focused on these groups because: (1) CP and ASD are two of the most common neurodevelopmental disorders affecting children, (2) stem cell clinical trials are underway for each, and (3) both CP and ASD have been a focus in stem cell clinic advertising [8, 10, 11, 18].

Email invitations to participate in the voluntary, anonymous survey were disseminated by NeuroDevNet, Inc., a Canadian Network of Centers of Excellence focused on neurodevelopmental disorders, to key stakeholders including physicians with links to patient populations, patient advocacy groups, non-profit support service agencies and individuals living with CP and ASD with popular social media channels. Through snowball methods, these stakeholders distributed the survey invitation further to their communities. The study was also advertised via social media channels of the Stem Cell Network, another Canadian Network of Centers of Excellence, and the National Core for Neuroethics, a Canadian national research resource in neuroethics.

Table 1 Quantitative survey questions and available responses

Questions	Available responses
“Have you heard about stem cells before this survey?”	Yes / No
“Have you considered seeking stem cell therapy for your child outside your country?”	Yes / No
“What was the outcome when you considered seeking stem cell therapy for your child outside of your country?”	I travelled outside my country for stem cell therapy for my child I plan to travel outside of my country for stem cell therapy for my child in the future I seriously considered it but have decided against it I briefly considered it before deciding against it I am still thinking about it but haven’t made a decision
“What countries did you or are you currently considering?” [choose all that apply]	China Mexico Germany India Panama Costa Rica United States Other, please specify... No specific country
“What country did you travel to for stem cell therapy?” [if respondent indicated they had already gone abroad] [choose all that apply]	China Mexico Germany India Panama Costa Rica United States Other, please specify... No specific country
“What sources of information did you use to learn about stem cell therapies offered by facilities abroad?” [choose all that apply]	Doctor or allied health professional such as a nurse or physician assistant Health professional who practices alternative forms of medicine, such as a chiropractor or homeopath Patient advocacy groups Parents of children or adolescents with similar health concerns Family, friends, co-workers Science journals or researcher Television or radio Print media such as newspapers and magazines Internet Other, please specify...
“What Internet resources did you use to learn about possible stem cell therapies?” [if respondent indicated they used the internet as a source of information] [choose all that apply]	Health information websites such as WebMD Government websites such as Health Canada Patient advocacy group websites NeuroDevNet website Stem cell clinic websites Social media (i.e. Facebook, Twitter) Blogs written by medical professionals Blogs written by people with similar health concerns Internet message boards frequented by people with similar health concerns Other, please specify...
“Of these sources, please tell us which you trust most for learning about stem cell therapy abroad.”	Doctor or allied health professional such as a nurse or physician assistant Health professional who practices alternative forms of medicine, such as a chiropractor or homeopath Patient advocacy groups Parents of children or adolescents with similar health concerns Family, friends, co-workers Science journals or researcher Television or radio Print media such as newspapers and magazines Internet

Respondents self-selected to participate and therefore constitute a voluntary web-based referral and convenience sample.

Settings in the FluidSurvey Platform prevented multiple submissions from the same computer. The online survey

contained detailed consent information on the first page and participants had the right to withdraw from the study at any time.

Analysis

Participant demographics and other quantitative data were summarized with descriptive statistics using Microsoft Excel software. Qualitative data were analyzed using an iterative thematic approach [31]. Two trained researchers developed the coding frame by hand-coding answers to the open-ended question independently and comparing and revising the codes until there was consensus. To ensure reliability, both coders applied the finalized codes to all the data from the open-ended question [32]. Any remaining discrepancies between coders were solved through discussion and mutual agreement and codes were adjusted accordingly. The quotes provided in the results section below were chosen to illustrate major themes.

Results

A total of 62 individuals participated in the study. All participants completed both the closed-ended and open-ended questions. We report here only on the data from individuals who expressed interest in stem cell tourism (55 %, $n = 34/62$) given the focus of the study on the lived experience of parents considering travelling abroad and their use of and trust in varying sources of information. Since the majority of responders were parents of children with CP (76 %, $n = 26$; ASD: 24 %, $n = 8$), we pooled the data into a single set for analysis.

Demographic characteristics for respondents are presented in Table 2. The majority of respondents self-reported as female (71 %, $n = 24$) and resided in Canada (71 %, $n = 24$) and the United States (23 %, $n = 8$). The age of respondents' children ranged from 2 years to over 21 years; over half (67 %, $n = 23$) the children were under the age of 12 (Table 3). Seventy-nine percent of respondents ($n = 27$) reported the severity of their child's disorder as moderate to severe.

Seventy-one percent of participants ($n = 24$) were still contemplating going abroad at the time of the survey. Fifteen percent of responders ($n = 5$) reported that they had considered seeking stem cell interventions in another country but ultimately decided against it. Twelve percent ($n = 4$) had already taken their children to another country for stem cell interventions: USA (6 %, $n = 2$), Panama (3 %, $n = 1$) and China (3 %, $n = 1$).

Sources of Information

Participants who considered taking their children to another country accessed multiple sources of information to

Table 2 Demographic characteristics of study participants ($n = 34$)

Characteristic	n (%)
Age, years	
25–34	8 (24)
35–44	12 (35)
45–54	9 (26)
55–64	4 (12)
65+	1 (3)
Gender	
Female	24 (71)
Male	10 (29)
Country of residence	
Canada	24 (71)
USA	8 (23)
UK	1 (3)
Greece	1 (3)
Annual income	
Less than \$20,000	3 (9)
\$20,000–50,000	7 (21)
\$51,000–100,000	16 (47)
More than \$100,000	8 (23)

learn about stem cell interventions. The Internet was the most commonly cited source for information - seeking (88 %, $n = 30$). Participants used several online resources including, most frequently, stem cell clinic websites (71 %, $n = 24$), as well as social media (56 %, $n = 19$). Participants also accessed the Internet to connect with other parents of children with similar health concerns through online message boards (41 %, $n = 14$) and blogs (47 %, $n = 16$). In addition, participants turned to child advocacy groups (24 %, $n = 8$), science journals and researchers (18 %, $n = 6$), and physicians and

Table 3 Characteristics of respondents' children ($n = 34$)

Characteristic	n (%)
Child with CP or ASD	
CP	26 (76)
ASD	8 (24)
Age of child, years	
2–5	13 (38)
6–11	10 (29)
12–18	8 (24)
19+	3 (9)
Self-reported severity of child's disorder (scale 1–5)	
1 - Mild	1 (3)
2	6 (18)
3 - Moderate	9 (26)
4	12 (35)
5 - Severe	6 (18)

other allied health professionals (21 %, $n = 7$) for information on stem cell interventions.

Trust in Sources of Information

While the Internet was used most frequently for information among those who had considered stem cell interventions abroad, a higher proportion of respondents identified science journals and researchers, other parents of children with similar health concerns, and physicians or allied health professional as the most trusted sources of information (Fig. 1). Only 10 % ($n = 3/30$) of individuals who reported using the Internet in information-seeking identified it as their most trusted source of information. In contrast, 91 % ($n = 10/11$) of individuals who cited other parents of children with similar health concern as a source information also identified them as their most trusted source.

Qualitative analysis revealed several major themes underlying perceptions of trust for information sources – bias, personal lived experience, expertise, and bidirectional communication. These themes were largely delineated by the source of information. Each quote below is from a unique source.

Themes Related to Perceptions of Trust

Bias

Science journals and researchers emerged as one of the most trusted sources of information because they were seen as the least biased. This was in part because information from this source is considered to be evidence-based. For instance:

“Journals/researchers probably have the most unbiased opinions and the least propensity toward reliance on anecdotal evidence alone.”

“Obviously, nothing trumps the hard facts the come from testing through the proper scientific method.”

Participants emphasized that science journals and researchers had the least financial motivation, which stood in contrast to the concern of several participants that physicians were financially influenced by pharmaceutical companies:

“Most interested in findings for other reasons than profit.”

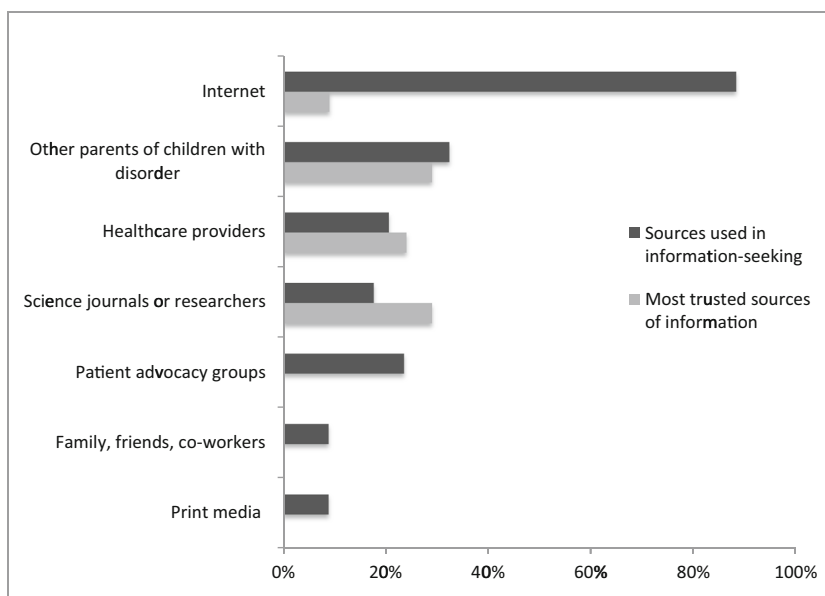
“...why would I trust sources that have monetary interests at the forefront and/or don’t really know what it is all about. Too many therapies are not therapy and offer false information. They become fads and money makers for people - off the backs of people who are looking for hope.”

Scientific articles and researchers were also viewed as less emotionally biased than parents of children with similar health concerns. Here, some participants worried that other parents were emotionally invested in new treatments for their children. For instance:

“I think there is the least amount of bias here. Instead I feel that conclusions/information are presented based on evidence. I value the first-hand experience of parents but there is so much emotion attached that it can be biased.”

Moreover, some participants viewed stem cell research as cutting edge and sophisticated, and preferred to learn about

Fig. 1 The dichotomy of information-seeking and information-trusting: Sources of information used by parents of children with CP and ASD considering treatment abroad ($n = 34$)



new developments from those closest to the research rather than through other channels such as the media:

“Because stem cell therapy is a cutting edge development in science and I wouldn’t trust the vulgarized explanation one would get in the mainstream media. It would be over-simplified. I would want the more precise and scientific explanation of it.”

Lived experience

Despite caution regarding bias, the lived experiences of other parents who sought out stem cell interventions for their children were valued. Participants felt that other parents were a unique source of support as they face similar challenges in managing care and learning about new treatments:

“People I have connected with and who have similar challenges understand the value of finding answers and help. And they know the power of sharing and supporting.”

Some participants also explained that other parents were trustworthy because they had nothing to gain by providing false information about stem cell therapies:

“You trust the people that have been or are dealing with the things you have, they have nothing to gain by telling you false info.”

Moreover, there was the sense that other parents with children who had undergone stem cell treatments abroad were in the best position to relay their personal experiences with these treatments, including their efficacy:

“People that have experienced it would have the best advice.”
 “Parents of children with similar health concerns speak from a place of personal experience. I realize my child probably won’t have the same outcome but it gives hope knowing the possibilities.”

Expertise

Participants reported trusting physicians or other healthcare professionals due to their credentialing, knowledge and experience. Physicians and other health workers were viewed as ‘experts’ due to their training and participants thought this

gave them the best qualifications to recommend treatments. One parent explained:

“Because doctors go to school for many years to be experts in their field and I trust my son’s doctors a great deal. With things like this I feel most comfortable with the experts.”

Participants also valued the experience of physicians in treating these disorders and this experience led them to feel that physicians had the ‘*right information*’:

“Because of their medical experience and they can look at your specific case and help you decide what is right for you.”

Conversely, a perceived lack of experience or knowledge led some participants to be wary about their physician’s or health professional’s advice, especially if the individual was not a specialist in the area:

“It depends on the doctor: is it a general practitioner, or someone who actively and successfully treats children with autism and has studied the area of stem cell therapies?”

Doctor-patient relationships

An important component of trust in doctor-patient relationships is communication. When communication was open, straightforward and bi-directional, participants trusted physicians because they felt they had their child’s best interests at heart, whereas poor communication led to frustration. For example:

“I expect my family physician, who knows my son and has treated him for years, to be honest and straightforward about what he knows and what he does not know. My son’s neurologist, who has so far refused to encourage me in regard to stem-cell neurological therapy, would be willing to recommend treatment if he thought that efficacious and ethical treatment were available. These doctors have proven reliable (and conservative in treatment recommendations) in the past, and I have no reason to suspect that they would deliberately mislead me.”

“And doctors/other health professionals can be a mixed-bag. I value and respect and trust most, but sometimes I find they have their own personal biases that fuel their recommendations, or probably more so, that they are too cautious to provide any kind of recommendation and

just nod along when I present what I know and don't really commit to anything, which is really frustrating.”

One woman, while discussing why she placed her trust in other parents, explained:

“The other issue is that there tends to be this ego thing across many physicians. They are the experts and know everything. They tend to be offended when their patients want to cross borders to get treatment. What they fail to realize it is not about them. It is what is best for the child.”

Multi-level information seeking

Finally, just as participants accessed several sources of information for learning about stem cell interventions, a number of participants also expressly discussed how they trusted multiple sources together in decision-making:

“So many answers, I would want to hear it from a professional of stem cell research, data is good, but true stories are great as well.”

In one instance, a participant preferred science journals or researchers as the trusted source of information but trusted medical blogs by professionals to help elucidate unclear information:

“I prefer to read the information and numbers from studies' findings as there is no personal opinion, just outcomes. If at that point, direction seems unclear I look to medical professionals' blogging to get an idea of their views.”

Discussion

In this study we examined the use of and trust in different sources of information for parents who considered taking a child with ASD or CP abroad for stem cell interventions. Our findings suggest a distinct dichotomy between the most frequent source parents use to access information and the information that they trust.

Similar to results from other studies examining health-related information-seeking [17, 18], respondents in the present survey primarily sought related health information from the Internet. Information gleaned from the Internet is often brought to physicians for clarification [33] or is used as a stimulus to open a dialogue about potential treatment options

[34]. Both of these strategies may be useful in assisting parents to navigate the increasingly complex landscape of stem cell intervention information found online [13]. Ryan et al. [9] has reported, however, that information regarding stem cell interventions found on the Internet can also influence parent decision-making directly and can be used to override physician advice.

In contrast to their online information seeking practices, participants reported that they trusted researchers, the science journals in which they publish, healthcare providers, and the advice of other parents most. Despite prior research by Master and Sipp [15] that the stem cell tourism industry challenges trust in researchers with claims of conflict of interest, in this study researchers and science journals were trusted sources of information. Like results reported in Critchley et al. [35], respondents cited openness, honesty and freedom from hidden financial or emotional conflict as features defining trustworthiness in researchers. Perceived freedom from financial gain was also a defining feature for the trustworthiness of science journals. Nonetheless, only a fifth of participants reported seeking information from researchers and science journals directly. This highlights a gap in the relationship between knowledge holders and knowledge seekers. Several issues may account for this gap. The first is that individuals may lack access to the science journals in which stem cell science is published whereas information online is readily accessible. The second is that the general population has low levels of science and health literacy, which is likely to make navigating and understanding the scientific literature onerous [36–38]. Critiques of this science deficit model, which assumes public attitudes about science are negatively affected by low levels of science literacy, find that scientific illiteracy does not threaten attitudes towards science [39]. That is, despite low levels scientific literacy the public still trusts science and researcher expertise.

As in other research on children with neurodevelopmental disabilities [40], participants in this study valued the understanding and shared experiences of other parents who had children with similar disabilities. In research on stem cell tourism in general, individuals seeking therapies abroad have been found to rely on other patients when making decisions about treatment [9, 18, 41, 42].

Reliance on the Internet for information and the high level of trust in other parents make it all the more important for physicians and other healthcare providers to maintain a trusting relationship in order to contextualize the information parents are receiving from these sources. Respondents stressed the importance of healthcare provider communication, openness and honesty and were hesitant about approaching their child's physician about stem cell interventions when these qualities were lacking. Barriers to communication have been identified in previous research including the concern that dissuading patients or their families from seeking medical services abroad may harm the physician-patient

relationship [43–46]. Furthermore, physicians often lack adequate information about interventions in a field that is continuously changing [43, 45] and may prefer that patients take the lead in their medical care [23, 44, 47]. These factors can contribute to a reluctance to discuss stem cell interventions that might result in the perception of physician indifference [18, 45], or in the case of one of our respondents, as arrogance, potentially damaging trust in the patient-physician relationship. As Rachul and others have reported, damaged relationships with physicians at home may indeed elevate the experience of individuals abroad [17–19].

The majority of respondents were still contemplating taking their children abroad for stem cell intervention or had decided against it, suggesting that opportunities exist to engage in dialogue with parents of children with CP or ASD as they consider treatment options. However, it is not likely that increased education and communication will deter all those considering taking their child abroad. Reports from other research indicate that individuals do considerable research prior to travelling abroad and are often prepared to accept potential risks [18, 19, 42]. In addition, the power of hope and the belief that these interventions are the only option should not be underestimated [18]. We found that trusted sources of information with the potential to communicate reliable information, such as researchers, scientific journals, and healthcare providers, are not the most highly utilized. Petersen et al. [18] note that individuals are compelled to be active agents in healthcare decisions, therefore parents are likely to be motivated to seek out their own information. The Internet represents an accessible information source that offers the opportunity for individuals to receive rapid updates on health information and engage with multiple viewpoints.

We suggest several opportunities to increase communication with trusted and reliable sources. First, information-sharing must continue to reach beyond traditional communication channels and the Internet should be utilized as a portal for proactive engagement. Examples of this kind of engagement are provided by both professional societies such as the International Society for Stem Cell Research (ISSCR) website (<http://www.closerlookatstemcells.org/>) and “Patient Handbook on Stem Cell Therapies”, The National Stem Cell Foundation of Australia and Stem Cells Australia “The Australian Stem Cell Handbook” and by individual investigator groups (e.g., (http://www.amc.edu/academic/bioethics/documents/SCPatientBookletFeb_2014.pdf)).

Our second suggestion is for the increased involvement of patient advocacy groups that have the organizational resources and networks to reach a large number of individuals with their messaging [15, 48]. While the findings did not indicate high levels of trust in patient advocacy groups for information on stem cell interventions abroad, this may reflect the lack of available information from these groups rather than distrust.

Third, social media channels, such as Twitter and Facebook, also present the opportunity for healthcare providers, researchers and patient advocacy groups to provide parents with high quality and understandable information [49]. Twitter in particular has gained recognition for its potential in public engagement and knowledge translation [50, 51]. For instance, one study looking at stem cell conversations related to spinal cord injury and Parkinson’s disease on Twitter found that the most shared frequently tweets related to these conditions were those reporting research findings [14]. Other research has suggested that blogs can play a role in rapidly disseminating reliable and transparent information on emerging health research to the public [52]. Both social media and blogs allow for an engaged discussion between experts, advocates and patients and their families.

Finally, given the difficulties physicians can face in staying up to date on the latest developments in stem cells [43, 45] and their concerns about damaging the doctor-patient relationship, another avenue of proactive engagement with parents lies in Scott’s [53] call for stem cell counsellors. These counsellors, akin to genetic counsellors with psychosocial training and a focus on non-directive communication, could work alongside physicians to connect with parents seeking treatment for their child abroad in person or over the Internet and provide guidance about the potential risks of unproven therapies to facilitate informed decision-making. This kind of communication could play a vital role in contextualizing current research findings in a meaningful and sensitive way that conveys realistic expectations, in recognition that disillusionment and lost hope in traditional treatment in an individual’s home country is associated with interest in emerging technologies abroad such as stem cell interventions [18, 54].

This study complements other efforts to characterize information-seeking practices and perspectives of parents who are interested in accessing stem cell interventions for the treatment of common neurodevelopmental conditions. A limitation is the sampling strategy and small sample size. Parents with an interest in stem cells may also have been more likely to respond to the survey and leading to volunteer bias in the data. We also hoped to explore differences between families with children with ASD and CP independently and by condition severity but the limited number of responses overall prohibited this. We do note anecdotally that the dichotomy of information-seeking vs. information-trusting appears to stand for both groups separately. We also note that the biggest difference between the two is that no ASD parents reported seeking information from science journals or researchers compared to 23 % ($n = 6$) of CP parents. The sample also had a high proportion of women and individuals under 45. Younger women have been noted in previous research to be the most trusting of physicians [33], and younger groups more trusting of science overall [55]. Finally, our survey was administered online; further research is needed to more deeply elucidate the

perspectives and priorities of the broader community of stakeholders affected by CP and ASD, including the affected children themselves.

The finding that parents engage most with a source of information they trust least, and less with sources of information they trust most highlights the gap between knowledge holders, such as researchers and physicians, and knowledge users. The results, however, also signal that in addition to conventional physician consultations, innovative opportunities exist for knowledge holders to engage with patient communities through multiple social media and online platforms and through a potential new class of healthcare providers, stem cell counsellors, as part of an integrated, multi-pronged approach to increasing communication with trusted and reliable sources.

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Compliance with Ethical Standards

Conflict of Interest The authors declare they have no conflicts of interest.

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