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Parents' perspectives on conversations about prognosis and an assessment of prognostic information available online: A mixed-methods study

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ABSTRACT

Background: Conversations about prognosis for genetic neurodevelopmental conditions are becoming more frequent; however, there is a lack of evidence and guidance on how to approach these conversations and frame the information being provided.
Objective: (1) To understand how parents perceive prognostic conversations with healthcare professionals and their preferences for these conversations, (2) To investigate the framing of prognostic information found online.
Methods: This was a mixed-methods study, comprising of (1) a thematic analysis of interviews with parents and (2) a quantification of prognostic information available on the internet that portrayed a negative message. The strategy to classify the framing of prognostic information was defined iteratively, informed by the information found online.
Results: We interviewed 32 parents from across Australia. Parents had a child with a genetic neurodevelopmental condition, such as Fragile X syndrome (28 %), 22q11.2 deletion syndrome (16 %) or Angelman syndrome (16 %). Parents reported their preference to discuss their child's potential strengths as well as challenges regarding prognosis. They reported that conversations about prognosis often focused on the child's possible deficits and that online information they encountered was similarly framed negatively. Our analysis of online information confirmed parents accounts: 95.3 % was coded as negative, while only 4.7 % was positive/neutral.
Conclusions: Our data provide evidence of an over-emphasis of deficit-framed prognostic information about genetic neurodevelopmental conditions. The initial exposure to negative information may adversely affect parents' psychological well-being and expectations, which future research could address. Health professionals could consider strengths-based framing of prognostic information gained from current and emerging technologies when returning results to families. Findings from this study can help to inform health communication practices as well as online content development.

1. Introduction

Neurodevelopmental conditions are childhood-onset conditions associated with cognitive, neurological, or psychiatric impacts.[1] The aetiology of neurodevelopmental conditions is heterogenous and multiple genetic and environmental factors influence the phenotypic outcome.[2] These conditions are collectively the most prevalent chronic conditions in paediatric medicine.[3]

There are many paediatric conditions with a known genetic cause that manifest a neurodevelopmental phenotype.[3] These conditions have different genetic causes but are similar in that they present with neurodevelopmental features like attention deficit hyperactivity disorder, autism spectrum disorder, anxiety, intellectual disability, and behavioural manifestations.[4]

The diagnostic pathway for neurodevelopmental conditions often involves multiple interactions with the healthcare system and the journey towards a diagnosis can be protracted.[5] Establishing the genetic basis for a child's neurodevelopmental phenotype can provide additional information about their prognosis and facilitate medical management and access to support services.[3]

For some conditions, such as Fragile X syndrome, scientists have made advancements in developing new tests that may be able to provide

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more accurate long term prognostic information.[6,7] These advancements in genetic testing are in turn driving an increasing focus on how prognostic information produced from these tests is communicated to parents.[8]

Recent research on prognostication in genetic neurodevelopmental conditions highlight a need for personalised approaches to prognostic conversations.[9] Parents view prognostic information to be important as it helps to guide expectations on the progress their child is expected to make and the challenges they might face.[10,11] Parental views and experiences of receiving a diagnosis for their child can evolve with time. Parents often hope that a diagnosis would offer certainty concerning the child's behaviours, though after a diagnosis and with time, it often leads to parents feeling increasingly worried about their child's vulnerability.[12] Parents of children with cancer express a preference to receive prognostic information that gives them hope for the best outcome whilst also being aware of the worst outcome for their child.[13,14] Similarly for neurodevelopmental conditions, prognostic information should provide a balanced picture about the condition through discussing both the potential challenges and strengths.[15–17] The framing of prognostic information through use of deficit based- and strengths based-language can influence whether the information conveys a positive or negative image.[18–20]

The internet is often relied on as a source of information, particularly for rare genetic conditions where there can be a considerable amount of uncertainty surrounding the prognostic outlook.[21] Information found online can vary greatly in accuracy and the stochastic nature of the internet makes it difficult to ensure that information is updated, and correct information is reported.[22]

A growing field of research seeks to critically appraise health information available to individuals and families.[18,19,23,24] These studies aim to assess the extent to which the information provides a comprehensive picture of the condition and how the use of linguistic framing influences the portrayal of the condition. It is unknown whether prognostic information found online provides a balanced outlook of childhood genetic neurodevelopmental conditions.

We set out to explore parents' experiences of receiving prognostic information about their child's genetic neurodevelopmental condition and to assess the framing of prognostic information that is available online.

2. Methods

We used a mixed-methods, sequential, exploratory design[25] in that our first, qualitative stage consisting of interviews with parents, informed our second, quantitative stage which was an environmental scan and content analysis.

2.1. Qualitative stage (semi-structured interviews)

The qualitative stage of this study is as described in Turbitt et al.[26] We briefly explain the methodology below. The data generated were analysed by MB and ET to answer the research question being addressed in this study.

2.1.1. Participants and recruitment

We used purposive sampling to recruit parents of children with genetic neurodevelopmental conditions. Advertisements and posts about the study were distributed in newsletters and on the Facebook pages of support organisations such as Fragile X Association of Australia, Angelman Syndrome Association Australia and Rare Voices Australia. Interested parents were provided a link to a REDCap survey to register their interest or could register their interest via email.

We used the information power model to determine the number of participants required to answer the research question.[27] Using this model, we took into consideration the study aims, sample specificity, use of theory, quality of dialogue and analysis strategy. Although the research aims were narrow, as we included parents of children with a range of conditions and of varying age, we required more participants than initially anticipated to satisfy information power. We evaluated information power throughout the study and increased the number of participants as the quality of dialogue was varied. A sample size of 32 was sufficient to reach information power. We offered participants a $50 gift voucher to acknowledge their time.

Our inclusion criteria included that parents were 18 years or older, able to understand and speak (or write) English and had a child with a diagnosed genetic neurodevelopmental condition. The child could be any age to increase the pool of possible participants given the rarity of conditions. Furthermore, for most conditions parents remain life-long carers and some children are not diagnosed until adolescence or adulthood. We excluded parents from participating if their child did not have a genetic diagnosis or if the child's other parent had already participated in the study.

2.1.2. Data collection

ET conducted interviews between July and September 2021. ET is a social scientist and senior lecturer and had no previous relationships to participants. We interviewed parents by Zoom (with or without video), telephone or by email. The range of modalities by which parents could participate enabled them to participate in a way they felt most comfortable (for example, if they did not want to speak with us or did not have the time to do so they could still participate via email). We developed the interview schedule for a wider study[26] and questions were developed with input from advocacy group leaders, health professionals and researchers. We piloted the interview schedule with two families of children with Fragile X syndrome and their feedback was incorporated.

The interview schedule covered questions around gaining information about the child's condition and diagnosis, their experiences with genetic testing (including receiving diagnostic and any prognostic information), their thoughts on prognostic information being informed by genetic testing, clinical experiences, and their decision-making processes (Supplementary Table 1). We focused on analysing aspects of the interviews that explored participants' lived experience of receiving and learning diagnostic and prognostic information about their children's neurodevelopmental condition.

2.1.3. Data analysis

The interviews conducted by Zoom or telephone were transcribed verbatim using Rev automated transcription services,[28] checked for accuracy and anonymised. We anonymised the email interviews. We used codebook thematic analysis.[29] Development of the coding tree started with focusing our analysis to answer the research question for this study, and then inductively coding based on participant responses to create a codebook. MB and ET independently coded the transcripts using NVivo.[30] We grouped the codes and developed common concepts. These concepts were further developed to themes through regular discussions held with the study team. DA and AM were involved in the regular discussions and contributed knowledge and advice from their clinical experience.

We obtained ethics approval from the Royal Children's Hospital Human Research Ethics Committee (HREC 69604) and the project was ratified by the University of Sydney Human Research Ethics Committee (ETH21-5714).

2.2. Quantitative stage (environmental scan and content analysis of online information)

We conducted a scoping review of grey literature, also referred to as an environmental scan,[31–33] whereby we reviewed web pages containing prognostic information. The scan was conducted for the eight neurodevelopmental conditions included in the qualitative stage of the study: 16p11.2 Deletion syndrome, 22q11.2 Deletion syndrome, Angelman syndrome, Dup15q syndrome, Fragile X syndrome, Mosaic

Down syndrome, Phelan-McDermid syndrome and Sotos syndrome. Environmental scans provide a way to learn about health information available online in a passive and unobtrusive manner.[31–33] We developed a classification strategy to analyse how prognostic information is framed and to determine whether the information provides a balanced and comprehensive picture of the condition. The classification strategy is based on a form of content analysis methodology that requires manual annotation of text.[20]

2.2.1. Search strategy

The environmental scan was conducted by AG in November 2022 using the search engine Google Australia. We conducted the search using search terms developed based on our interview data from the qualitative stage and previous findings about the type of prognostic information most sought out by parents.[34] Our search terms were: prognosis OR prediction; symptoms OR signs OR characteristics OR indication; future OR prospect OR expectation OR forecast OR outlook; abilities OR potential OR skill OR strength OR progress; challenges OR problems OR difficulties. We cleared the web browser cache before each search to minimise Google search optimisation. We exported the first three pages of results using the SEOQuake plugin for Mozilla Firefox.[35] Studies have shown most users do not look beyond the first three pages of web pages and the majority of users only look at the first page of hits.[31] Furthermore, search results after the first 50 sites are unlikely to meet criteria.[32] We excluded all sponsored web pages.

For each genetic condition, we concatenated search results and removed duplicate web pages. This resulted in a list of sites for each condition, with the sites being ranked by their position in the search result.

2.2.2. Selection of eligible web pages

To assess the web pages for eligibility, we developed and applied the following selection criteria to the contents of the webpage, not including other information contained within the web page. We applied the following criteria to include web pages, (a) containing information relating to one or more of the eight genetic neurodevelopmental conditions included in the qualitative study, (b) containing prognostic information (e.g., including information in dot point format, single sentences, and paragraphs of text), (c) targeting health professionals OR targeting parents and carers of children with conditions included in the qualitative study (d) moderated by the publisher OR medical resources OR online encyclopaedia AND, (e) written in any language. We excluded web pages that (a) were not moderated (b) were not freely available or (c) contained information in the format of a research article. We reviewed web pages in the order found on the search results page (descending order). AG and ET independently screened the web pages against the inclusion/exclusion criteria and compared decisions. We discussed any disagreements and revised the criteria until substantial agreement (kappa score >0.7) was reached.[36] Once the agreement threshold was achieved, AG continued with the remaining sites. We reviewed until 10 eligible web pages were identified for each condition.

2.2.3. Content analysis

We manually extracted web page characteristics using a predetermined data extraction form and saved the data in NVivo (Supplementary Table 3).[30] To develop the coding strategy, the study team reviewed the literature to inform our understanding of negative, neutral and positive framing of health information.[20] We identified all information present on the web page about prognosis. AG and ET undertook a trial phase of coding to further inform our negative, neutral and positive classifications based on the range of prognostic information found online. We discussed discrepancies in coding with the study team and finalised a classification strategy. AG and ET continued to code the data until substantial agreement (kappa score >0.7) was reached. We classified each instance of prognostic information as either negative or positive. Neutral statements were classified as positive. This allowed us to determine whether both negative and positive prognostic outlooks were included on the web page and to what extent this information provided a balanced picture of the condition. We identified prognostic information as taking the form of either words (e.g., list of symptoms), phrases, sentences or paragraphs.

We identified prognostic information as negative when parents were likely to find the information worrisome. Negative information focused on challenges that their child might face and was written using deficit-based language. We identified prognostic information as positive when a neutral and/or positive outlook was portrayed and when strengths-based language was used. Examples of prognostic information classified as either negative or positive can be found in Table 1.

We used NVivo to extract the percentage of content classified as either negative or positive.[30] For each web page, we used the formula below to calculate an overall percentage of prognostic information classified as negative.

$$\textit{Prognostic information classified as negative} = \frac{\textit{negative}\ (\%)}{\textit{negative}\ (\%) + \textit{positive}\ (\%)}$$

3. Results

3.1. Qualitative stage

Fifty-five parents expressed interest in the study. Of these, five parents were not invited to participate as they contacted us after the recruitment target was reached. Of the remaining 50 parents that had expressed interest, 14 did not respond to emails inviting them into the study, and four were unable to schedule a time for an interview. There were no parents excluded based on the eligibility criteria, leaving a total of 32 parents that participated in the study. The interviews took place by Zoom, phone or by email. Of the 32 parents, 16 participated via telephone, 12 via Zoom (with video), and four via e-mail. Interviews ranged from 17 to 56 min (average length 34 min).

The participants had children with Fragile X syndrome (28.1 %), 22q11.2 deletion syndrome (15.6 %), Angelman syndrome (15.6 %) and a range of other conditions (see Table 2). There were three families with more than one child with Fragile X syndrome. The majority of participants indicated their child was diagnosed postnatally (91.4 %), with only 5.7 % indicating that their child was diagnosed prenatally. Over half (59.4 %) of the participants reported completing university or tertiary education, a further 18.8 % completed high school and 15.6 % completed technical education or another further education. Most of the participants (75 %) identified as Australian or New Zealand European

Table 1
Examples of prognostic information classified as negative, neutral/balanced or positive.

Instances of Negative Prognostic Information	Instances of Neutral/Balanced Prognostic Information	Instances of Positive Prognostic Information
DiGeorge syndrome is a condition present from birth that can cause a range of lifelong problems, including heart defects and learning difficulties.	Importantly, the syndrome can be quite variable from one person to the next, and not everyone with the deletion will have the same abilities or challenges.	People with PMS enrich the world. They attend school, develop outside areas of interest, have friends, participate in the community and family events, even move away from their family home.
Common difficulties often (but not always) experienced by the child with Fragile X Syndrome: Poor non-verbal communication	Individuals with Angelman syndrome will require lifelong care, but can live long, happy lives.	With ongoing treatment and support, adults diagnosed with DiGeorge syndrome live active and fulfilling lives with limited interruption from their condition.

Table 2
Interview participants characteristics.

Characteristic	Number	Proportion (%)
Child's condition		
Fragile X syndrome	9	28.1
22q11.2 deletion syndrome	5	15.6
Angelman Syndrome	5	15.6
Other rare del/dup	5	15.6
Phelan-McDermid syndrome	3	9.4
Dup15q	2	6.3
Mosaic Down Syndrome	1	3.1
16p deletion	1	3.1
Sotos syndrome	1	3.1
Age of child(ren) at time of qualitative data collection		
>2 years	2	5.7
2–5 years	13	37.1
6–10 years	8	22.9
11–17 years	8	22.8
18+ years	3	8.6
Unknown	1	2.9
Age of child(ren) at time of diagnosis		
Prenatally	2	5.7
>2 years	19	54.2
2–5 years	10	28.6
6–10 years	3	8.6
Unknown	1	2.9
Location		
Metro	22	68.8
Rural	5	15.6
Unknown	5	15.6
Location (state)		
New South Wales	12	37.5
Victoria	10	31.3
Queensland	4	12.5
Western Australia	2	6.3
Tasmania	1	3.1
Unknown	1	3.1
Based overseas	2	6.2
Highest level of education		
University of tertiary institution	19	59.4
Secondary school (range year 7–12)	6	18.8
Technical or further education institution	5	15.6
Unknown	2	6.2
Self-reported race/ethnicity		
Australian/New Zealand European	24	75
Indian	2	6.3
Coptic Egyptian	1	3.1
European	1	3.1
Italian/South American	1	3.1
Maltese	1	3.1
Unknown	2	6.3

ethnicity. The other participants were Indian (n = 2, 6.3 %), Coptic Egyptian (n = 1, 3.1 %), European (n = 1, 3.1 %), Italian/South American (n = 1, 3.1 %), and Maltese (n = 1, 3.1 %).

3.1.1. Theme 1: prognostic information framing by health professionals

Parents discussed that the information they received from their health professional about their child's diagnosis and expected development was often negatively framed. Parents reported that health professionals focused on providing information about what their child wouldn't be able to do and what developmental and life milestones they wouldn't achieve. Parents often described finding little utility in this deficit-framed prognostic information.

> *"And he kind of said, 'don't expect a lot. He won't achieve anything. He won't be a normal child, you'll have to do a lot for him. You'll have to support him an awful lot. Don't expect him to walk or talk or anything like that because you're expecting way too much.'"* - Participant 29: parent of an 11-year-old with a rare deletion/duplication syndrome

> *"We didn't enjoy that experience [receiving the diagnosis] at all. And because it really was like 'he won't walk, he won't talk, he won't you know, make friends, he won't get married, he won't drive a car, he won't have a job.' It was like, he won't do anything basically. So, we found our experience with the geneticist really disheartening and really negative."* - Participant 25: parent of 12-year-old and 8-year-old children both with Fragile X syndrome

Parents reported a preference for more balanced conversations regarding prognosis, discussing both strengths and challenges for their child's future.

> *"I just feel like there needs to be a more positive approach to, 'okay, like these are the results we've found out. This is sort of like the doom and gloom almost of the diagnosis, but here's a little bit of information to look forward to about your child.'"* - Participant 18: parent of a 5-year-old with Angelman syndrome

3.1.2. Theme 2: Health professionals' limited knowledge about rare genetic conditions led parents to access online information, which was often deficit-based

Parents discussed performing their own research of their child's condition as they felt they needed more information than what was provided by health professionals. Some parents reported that they turned to the internet for this self-directed research as they had a significant waiting time for their appointment with a genetics service or other doctor.

> *"I was having to research everything myself. I basically had to educate everyone that came into contact with him. No one had heard of it. No one knew anything about it. [I had] constant arguments with professionals in trying to get him the correct treatment and therapies and stuff."* - Participant 28: parent of two children (20 and 10 years old) with Fragile X syndrome

> *"I suppose the most disappointing thing for us is the paediatrician that we were seeing at the time clearly wasn't trained in [the condition], so really had no answers. The paediatrician literally Googled it and […] I don't think that that particular paediatrician was very good at giving bad news […] Then he literally printed off the information from the dup15q foundation, about the possible presentations. And […] that was basically it, So, he wasn't very helpful at all."* - Participant 7: parent of a 6-year-old with dup15q syndrome

When performing this self-directed research, parents often described using Google as the first source of information.

> *"And so, as with all parents, [following the diagnosis] we all get on Dr. Google, have a look, see what that all means. And we sort of went, "oh, well, yeah, that's sorta fits him.""* - Participant 11: parent of an 11-year-old with 16p deletion

> *"[…] immediately, as soon as we opened the [results] letter, we first tried to interpret it because it just said the deletion, we didn't even understand what a deletion meant. And that's when we jumped onto Google. And as we all know, Google just presents the worst of one picture."* - Participant 16: parent of a 2-year-old with Angelman Syndrome.

Parents described being faced with mostly negative or deficit-framed information through their own online research, with some parents avoiding the internet altogether as they had heard that their child's condition was negatively portrayed online.

> "*I've pretty much stayed off Google since I've had her diagnosis because I was told not to, because when [there are] varying degrees of the condition, if you Google it, some scary things can come up. That's what my sister said, because she did [look up the condition on Google].*" - Participant 21: parent of a 7-year-old child with Phelan-McDermid syndrome

> Researcher: "*At the time that the paediatrician told you that diagnosis, what other sort of information did they give? Was there anything around how they think [child's name] is likely to develop as he gets older?"*

Parent: *"No, she said, "don't Google it." I could see tears in her eyes so I'm like "oh my god" cause I didn't know what it was. So other than not Googling it, she gave me some information sheets on what [the condition] was to read through. So I didn't Google it and I joined these Facebook groups thinking I'd talk to other people who are in similar circumstances and that's how I'm learning about it a little bit. Just hearing what other people have to say without Googling it and finding out the worst-case scenario cause I'm trying to stay as positive as possible for him."* - Participant 24: parent of a 2-year-old child with Fragile X syndrome

"We'd gone home and we'd researched both disorders and, you know, felt pretty shocked by what we saw. We were really hoping it wasn't Angelman syndrome because that seemed the more severe [condition]. Also the fact that it would mean he would be non-verbal for life. That for me was very upsetting." - Participant 23: parent of a 3-year-old child with Angelman syndrome

Parents descriptions of the combination of doing their own research and receiving deficit framed information led us to the second part of our study. Information is readily available online for parents to access. As parents described finding little utility in deficit-framed information, we sought to systematically and objectively review how information is framed online.

3.2. Quantitative stage

Our online search using Google Australia identified 1279 web pages across the eight genetic neurodevelopmental conditions. The kappa score for the trial eligibility screen where two reviewers, AG and ET, independently assessed the web pages against the eligibility criteria was 0.53. As this was below our pre-determined cut-off value of 0.7, AG and ET refined the criteria and conducted a second round of independent screening for 20 web pages for Angelman syndrome and 20 web pages for Fragile X syndrome (in order of rank). The kappa score for the second trial screen was 0.94, which was deemed suitable for a single reviewer AG to continue screening the remaining web pages.

For the web pages screened as eligible ($n = 80$), we extracted web page characteristics including the type of publisher. Eighteen web pages (23 %) were managed by an academic research centre. Fourteen web pages (18 %) were published by medical centres or hospitals. Twelve web pages (15 %) were from non-profit organisations and nine web pages (11 %) were from support groups. The remaining were published by medical news web pages (9 %), government (9 %), Wikipedia (8 %), a commercial publisher (5 %) and three were research databases (4 %). (Table 3; Supplementary Table 4).

3.2.1. Framing of prognostic information found online

We first identified all prognostic information present on the web page and assigned each instance as either negative or neutral/positive. Out of the 80 web pages assessed, 23 (28.8 %) web pages contained information classified as both negative and neutral/positive. The remaining sites (71.3 %) contained information with only a negative classification (Fig. 1 and Supplementary Table 2). The proportion of prognostic information classified as negative per web page ranged from 45.4 % to 100.0 %, with an average of 95.3 % across all web pages (Fig. 1 and Supplementary Table 2).

The finding of an overemphasis of negatively framed prognostic information confirmed parents reports of encountering negative information about their child's condition when searching online.

Table 3
Web page characteristics from web pages identified through the environmental scan.

Type of site	Number of sites
Academic - research centre	18
Academic - research database	3
Commercial	4
Government resource	7
Medical Centres and Hospitals	14
Medical news website	7
Nonprofit organisation	12
Support group	9
Wikipedia	6

4. Discussion

Our findings provide evidence of an over-emphasis of deficit-framed prognostic information about genetic neurodevelopmental conditions both communicated from health professionals and available online. Parents perceived a clear lack of balance in the discussion of prognostic outcomes, and that clinicians' framing contained little to no positive discussion of strengths and expected abilities. The framing of prognostic information found online was highly skewed towards deficits or impairment. Our data, supported by existing literature in other contexts, suggests that parents see value in balanced discussion of prognostic outcomes and want to learn about both challenges and expected abilities.[17]

Prognostic discussions and information found online can impact parents' psychological well-being, the quality of decision making, and overall expectations for what life is like for people with neurodevelopmental conditions.[11] Exposure to negative information, particularly in the initial stages of diagnosis, could harm parents' mental well-being and expectations.[37–39]

Uncertainty is a common feature of prognosis, particularly in the context of genetic neurodevelopmental conditions.[17] Many parents search for a diagnosis for their child's condition to explain the cause and understand more about the future.[10] However, receipt of a genetic diagnosis raises more uncertainties for parents due to the wide variability within conditions.[34] Such prognostic uncertainty can result in both short and long-term distress.[17]

Given that it is generally not possible to alleviate prognostic uncertainty, the ways in which prognosis and uncertainty are communicated to parents requires particular attention. Strategies to manage uncertainty as it is experienced across the medical care continuum are well established. Best practices emphasise the need for transparency and open disclosure of uncertainty. This is imperative for the delivery of patient-centred care.[40,41]

The findings of our study challenge the traditional deficit-based approach in medicine.[42] Historically, clinical medicine focuses on deficits. By contrast, a strengths-based approach recognises and builds on a person's strengths.[43] Such an approach can be particularly relevant to chronic conditions such as genetic neurodevelopmental conditions which are life-long. A strengths-based approach aims to provide a balanced view of both potential challenges and abilities, avoiding overly-optimistic portrayals, though retaining hope for families.[44] It is important to highlight that strengths-based framing does not ignore challenges that families may encounter or provide an unrealistically optimistic outlook; rather a strengths-based approach balances both potential strengths as well as challenges.

While there are no published guidelines for prognostic discussions in genetic neurodevelopmental conditions, recommendations from other contexts may be useful to consider.[41,45] Such guidelines focus on the importance of fostering hope while providing realistic information to families about their child's prognosis. For example, the ALIGN framework developed with parents of critically ill infants with neurological conditions includes five stages for communicating neurologic prognosis.[46] Similar to our findings, the "inform" stage of ALIGN involves providing honest, thorough, and balanced (i.e. both challenges and strengths) information.[46] For the development of websites containing prognostic information, published guidelines serve as a credible guide to ensure information is respectful, neutral and objective.[47]

The language used when discussing prognosis should also be carefully considered as our research showed. Previous work recommends

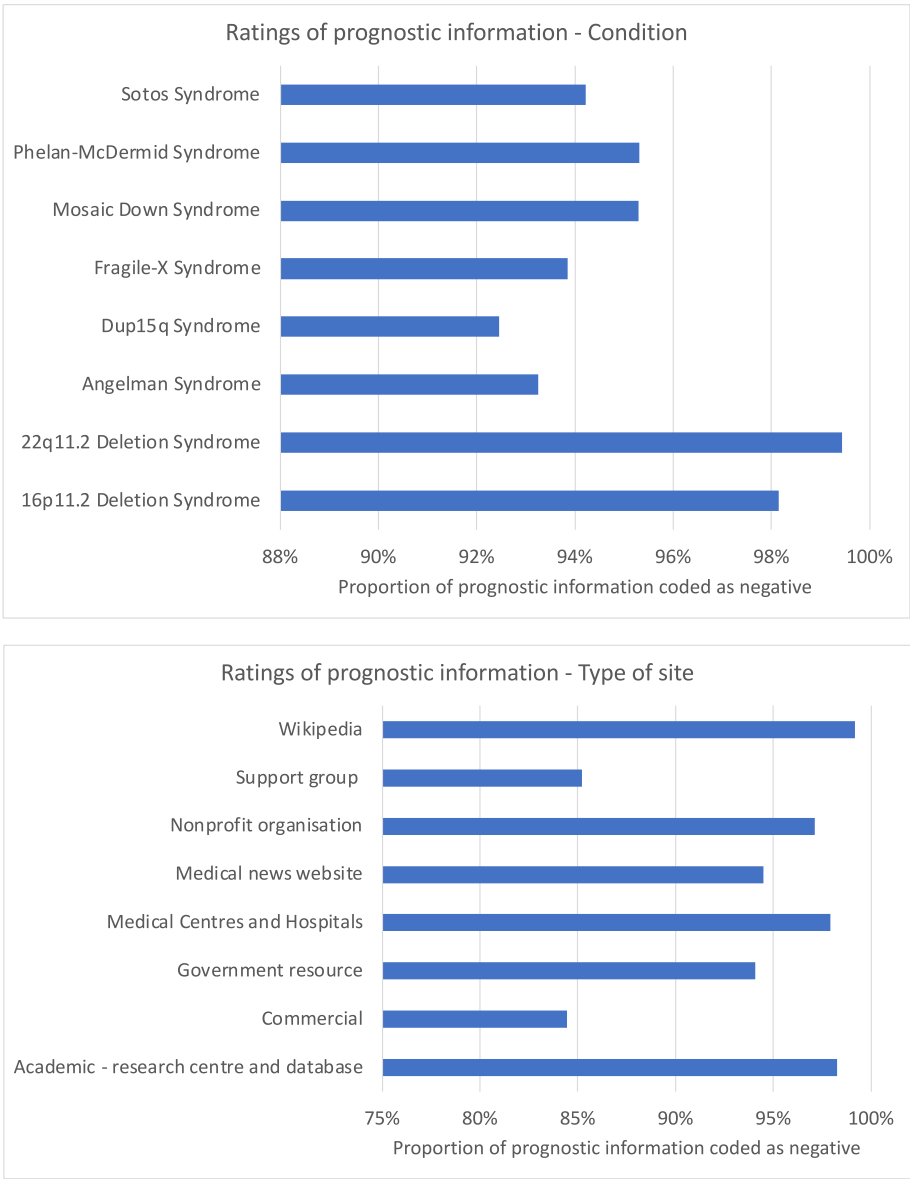

Fig. 1. Ratings of prognostic information found online categorised by genetic condition and type of site.

moving away from alarmist and negative terms such as "poor prognosis", and "grim" when discussing prognosis with families and instead clearly articulating the range of possible outcomes.[48,49] Such negative language may reflect health professionals' personal biases about disability, which can impact how prognostic conversations are framed.[50] Reflecting on the potential biases health professionals have when discussing prognostic information may be a useful strategy for those tasked with discussing prognoses with families.[51–53] For those creating online content about the prognoses of genetic neurodevelopmental conditions, engaging with parents to co-design information could be an effective strategy.

Our work had some limitations that are important to acknowledge. In our qualitative research, parents were asked to recall their experiences. Time and emotion can have an impact on memory such that people often remember negative encounters, more so than positive.[54] Future research could audio record prognostic conversations or use simulated clients to analyse how health professionals deliver prognostic information. Furthermore, our sample was limited in ethnic and geographical diversity with a majority being Australian or New Zealand European and residing in New South Wales or Victoria.

Regarding our quantitative research, the internet is dynamic and constantly changing which means that our findings would only be relevant for the content that was analysed at the time of our review. The algorithms used to generate search results would likely change with time making it difficult to replicate the search results. The environmental scan was conducted using Google Australia, however, there are other search engines that consumers might use when searching for information about a genetic neurodevelopmental condition.

5. Conclusion

Our results indicate a focus on deficit-based prognostic information about genetic neurodevelopmental conditions, conveyed by both healthcare professionals and online. This is in contrast to parent preferences for more balanced information that encompasses anticipated strengths. Our research has implications for practice in that health professionals could consider strengths-based framing of prognostic information gained from current and emerging technologies when returning results to families. Those producing online information about genetic neurodevelopmental conditions should consider providing

balanced information highlighting both strengths and challenges for individuals living with these conditions and their families.

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CRediT authorship contribution statement

Akira Gokoolparsadh: Writing – review & editing, Writing – original draft, Visualization, Methodology, Investigation, Formal analysis, Data curation. **Meg Bourne:** Writing – review & editing, Writing – original draft, Visualization, Methodology, Investigation, Formal analysis, Data curation. **Alison McEwen:** Writing – review & editing, Supervision, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **David J. Amor:** Writing – review & editing, Supervision, Conceptualization. **Erin Turbitt:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

Abbreviations

None.

Declaration of competing interest

The authors have no conflicts of interest to disclose.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.dhjo.2024.101718.

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