Current Developmental Disorders Reports (2024) 11:21–31
https://doi.org/10.1007/s40474-024-00291-1

Fostering Hope and Acknowledging Uncertainty: Meeting Parents' Needs and Preferences When Communicating Prognosis in Genetic Neurodevelopmental Conditions

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Accepted: 19 January 2024 / Published online: 31 January 2024

Abstract

Purpose of Review We sought to summarise recent research on prognostication in genetic neurodevelopmental conditions, focusing on parent preferences for prognostic conversations. We further aimed to explore recommendations about communicating children's prognoses with parents at the time of diagnosis and beyond.

Recent Findings Our review revealed growing research on prognostic conversations in oncology settings and for conditions that are life-limiting; however, there remains little research in the context of genetic neurodevelopmental conditions. The literature indicates a shift from censoring prognosis towards open discussions emphasising predicted challenges and abilities. The little research that has been done shows that parents seek prognosis discussions tailored to their preferences, relating to the timing, depth, and mode of delivery of information. Divergent perspectives between parents and healthcare professionals complicate prognostic communication and may relate to the stance of the healthcare professional (such as preconceived views and biases), and gaps in their training or within evidence-based interventions.

Summary There is a need for personalised, sensitive approaches to prognostic conversations with parents and to address societal biases that influence the stance and behaviours of healthcare professionals in those conversations. Future research should prioritise understanding that parental needs are diverse, improving communication strategies, and expanding information modalities. Focus should also be on reflexively identifying healthcare professional and societal stereotypical views on disability, mitigating biases for effective prognostic discussions with parents regarding genetic neurodevelopmental conditions.

Keywords Prognosis · Genetic neurodevelopmental condition · Uncertainty · Communication · Paediatrics · Parents

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Introduction

When a child is diagnosed with a genetic neurodevelopmental condition, many parents turn to healthcare professionals for answers to questions such as "what does this mean for my child's future?" These conversations are vital in shaping parents' perceptions, decision-making, and well-being as they begin to understand and integrate new information about their child's genetic makeup. The primary driver of this review was to gain a deeper understanding of the findings from current research about prognostic conversations relating to genetic neurodevelopmental conditions with a particular focus on what can be learnt from parents with personal experience.

Neurodevelopmental conditions impact the developing brain and manifest in childhood [1]. These conditions overlap clinically; many children with neurodevelopmental conditions exhibit cognitive, behavioural, social, and

emotional impacts [2]. Examples of the more common neurodevelopmental conditions include autism spectrum disorder, attention-deficit/hyperactivity disorder, cerebral palsy, and intellectual disability. These conditions have a combined prevalence of ~17% among 3- to 17-year-old children in the USA [3]. Neurodevelopmental conditions are often associated with a diverse range of functional impacts in communication, mobility, adaptive behaviour, and self-care [1].

While neurodevelopmental conditions may arise due to external factors including infection, birth complications, prenatal alcohol exposure, or severe malnutrition, in most instances, genetics significantly contributes to the underlying cause [4]. As such, genetic testing is recommended to assist in the diagnosis of children with intellectual disability, autism, and global developmental delay [5]. Where a genetic diagnosis is determined, these conditions are referred to as genetic neurodevelopmental conditions and include conditions such as Down syndrome, Fragile X syndrome, Angelman syndrome, and Rett syndrome.

Genetic neurodevelopmental conditions are lifelong, and very few have specific drug treatments targeting the underlying molecular mechanism [6]. There remain advantages, beyond treatment, to identifying genetic diagnoses. Diagnosis can explain a child's condition and position families to tailor care, communication, and learning support based on the likely course of the condition and their child's predicted developmental trajectory [2]. A genetic diagnosis should also allow for preventative healthcare through targeted health screening and support access to appropriate therapies and services [7]. Further benefits include the potential for families to build supportive connections with other families with a child diagnosed with the same condition [8]. Genetic information can be used to inform the parents' future family planning [8].

Genotype-phenotype correlations are available for some genetic neurodevelopmental conditions and can offer some personalised prognoses [9], although frequently a broad range of trajectories are possible [5]. Currently, most discussions that healthcare professionals have with families about prognosis rely on scientific data at the group level or the healthcare professional's own clinical experience, rather than individualised information tailored to the parent and child.

Recent advances in genetic technology have improved prognostication and the ability to predict the degree of cognitive and behavioural impact in some genetic neurodevelopmental conditions. For example, new prognostic genetic tests are being developed that aim to provide more precise and personalised prognostic information to predict the extent of a child's disability [10, 11]. This type of prognostication in neurodevelopmental conditions is relatively new, as is the application of personalised prognostic information to discussions between healthcare professionals and parents about their child's prognosis. Therefore, our review aims to summarise contemporary research on prognostication in genetic neurodevelopmental conditions and explore recommendations about communicating children's prognoses with parents.

Genetics of Neurodevelopmental Conditions

Current Genetic Testing

First-line genetic tests aim to determine an underlying diagnosis for children with intellectual disability, autism, and global developmental delay [12]. This genetic testing often occurs at around 2 years of age or older, triggered by recognition at this age of a lack of development of the milestones of mobility, play, communication, and learning [13]. More families are receiving a genetic diagnosis as these tests become more widely available. Internationally, genetic testing for these indications is typically ordered by paediatricians and funded either through the public health system or private insurance [14, 15].

The availability of public funding for genetic testing has also shifted the diagnostic pathway in recent years. Previously, these tests were exclusively overseen by those with specialised expertise in genetics including clinical geneticists and genetic counsellors who handled ordering and interpretation. Broadening access to funding has allowed healthcare professionals without specialised genetics training to order these tests and receive results [16]. Consequently, paediatricians and other specialists such as neurologists are more frequently having conversations with families about genetic testing, genetic diagnoses, and prognoses based on genetic information.

Future Genetic Testing—Expanding Availability in Other Contexts

While most genetic testing for neurodevelopmental conditions occurs in the early childhood period, after onset of signs or symptoms, there are instances where a genetic diagnosis will be made earlier, including the newborn period or prenatally. However, genetic neurodevelopmental conditions are not screened for routinely in the newborn period. Currently, these conditions may still be detected prior to symptom onset, for example through genetic testing in the neonatal intensive care unit (NICU) [17] or if there is a known family history of the condition and families opt to test (for example, in Fragile X syndrome) [18]. However, the addition of genetic testing for neurodevelopmental conditions on the newborn screening panel or routine testing for all babies in the NICU is gaining momentum, with many pilot programs underway [19, 20, 21].

Access to genetic testing for expectant parents to learn the genetic makeup of their unborn child is higher than ever before [22]. This includes prenatal screening, which is routinely offered to pregnant parents [23]. With the development of non-invasive prenatal testing (NIPT), additional genetic neurodevelopmental conditions are being identified during pregnancy [23]. In addition, genetic carrier screening, ideally undertaken pre-conception to inform parents of the chance of having a child with a genetic condition, is often undertaken prenatally [24]. In November 2023 in Australia, genetic carrier screening was added to the Medicare Benefits Schedule [22]. The test covers cystic fibrosis, spinal muscular atrophy and the most common cause of inherited intellectual disability, Fragile X syndrome. In the prenatal context, where an increased chance result or a diagnosis is received, expectant parents rely on prognostic information as they make decisions about the future of their pregnancy [25]. Differences between the prognostic information provided in prenatal and postnatal contexts have been described [26••]; however, a prenatal focus is outside the scope of our current review which focuses on the postnatal stage, following symptom onset.

Prognostication in Genetic Neurodevelopmental Conditions

Prognostic Information and Testing

Emerging prognostic genetic tests, such as those based on an individual's epigenetic profile, are in development for some genetic neurodevelopmental conditions [10, 11]. These prognostic tests could provide more personalised prognostic information, including the ability to anticipate the functional impact expected for the child. One example is in the condition Fragile X syndrome, for which a test has been developed based on evidence that links increased methylation levels (an epigenetic marker) to lower intellectual functioning and increased behavioural challenges [10]. Such a test could provide families with more precise prognostic information and, notably, can be conducted on bloodspot samples, potentially enabling its use in newborn screening [10].

While such prognostic genetic tests may offer more precise and personalised information about a child's future, there are limitations. As with many medical tests, there is potential for inaccurate test results and subsequent prognostic predictions that do not eventuate. For example, in the Fragile X syndrome epigenetic test, prognostic predictions are more accurate for males than females [10]. Furthermore, the extent to which environmental factors such as early intervention and therapy, and the family and social context can impact outcomes is unknown. Finally, families vary in their preferences for receiving prognostic information. While some families desire more information about their child's future, others report fears around the loss of hope and other psychological implications of receiving a challenging prognosis [27].

The focus in genetic medicine has traditionally been on the diagnostic yield and clinical utility of genetic tests, particularly for presentations where treatment options are limited [28]. However, little attention is given to how healthcare professionals and families communicate prognostic information in genetic neurodevelopmental conditions [29].

Review Methods and Database Outputs

The diverse multidisciplinary authorship for this review included two parents of children with a neurodevelopmental condition along with clinical and research experts in genetic neurodevelopmental conditions. We developed our search strategy using the population, concept, context (PCC) framework [30], where the population consisted of parent or child, the concept included terms such as goal, communicate, or discuss, and the context was prognosis. The initial inclusion of neurodevelopmental condition and relevant synonyms as context in a scoping search significantly narrowed the number of results. We then omitted neurodevelopmental conditions, which allowed a broader search to other contexts that may inform prognostic communication in relation to neurodevelopmental conditions.

An example search string in ProQuest Central was: noft(parent* OR caregiver* OR carer* OR child* OR minor* OR infant*) AND noft(prognos*) AND noft(goal* OR decision* OR share* OR partner*) AND noft(discuss* OR communicat* OR "message framing" OR "breaking bad news" OR disclos*). In this database "noft" searches the title, abstract, and any other article sections excluding the full text. We limited the search to the past 5 years (2019–2023) to focus on new and current evidence. Only peer-reviewed articles in English were included.

We searched ProQuest Central (on 26/09/23), ordered results by relevance, and screened the titles and abstracts of the first 400 of 802 results. Ordering by relevance meant that there were 33 relevant articles in the first 100 which reduced to only two relevant articles in those listed 300–400. We next searched Google Scholar (on 26/09/23) which produced 17,300 results. We screened the title and abstracts of the first 100 of these results, producing 39 after removing duplicates with ProQuest. Finally, we searched Medline (26/09/23—969 results), Web of Science (on 27/09/23—887 results), and PsychInfo (on 27/09/23—145 results). There was a total of 1416 articles across the five databases once duplicates were removed. We screened the title and abstracts of these 1416 articles, resulting in 178 articles for full-text screening. We supplemented this with an additional 11 articles that

were not included in the search, though were identified based on our expertise and familiarity of the field. Of these 189 articles, 48 were retained after full text screening.

Three authors (ET, EC, and PS) extracted and summarised relevant information from the full text of included articles, to a shared Excel spreadsheet. Extracted information included the title, first author, publication year, and context (health condition or specialty, and paediatric or adult focus). Key points of the article were then extracted, discussed by all authors, and thematically synthesised to answer our review question.

Communicating Prognostic Information

Summary of the Articles Included in This Review

Included articles were predominantly in the context of oncology, the NICU or paediatric intensive care unit (PICU), or neurological conditions and injury and to a lesser extent genetic neurodevelopmental conditions. While most articles were focused on children, we included some of adult context which were relevant to the review question. Characteristics of the included studies are presented in Table 1.

Table 1 Characteristics of included studies

Characteristic	Number of studies, *n* (%)
Year published*	
2013	1 (2%)
2016	1 (2%)
2018	5 (10%)
2019	8 (17%)
2020	5 (10%)
2021	8 (17%)
2022	10 (21%)
2023	10 (21%)
Adult or paediatric setting	
Paediatric	38 (80%)
Adult	5 (10%)
Both	5 (10%)
Medical context or specialty	
Oncology	10 (21%)
Neurological conditions and injury	10 (21%)
NICU or PICU (condition not specified)	9 (19%)
Neurodevelopmental condition (no genetic diagnosis)	6 (13%)
Other (cystic fibrosis, spinal muscular atrophy, neuromuscular disease, or heart failure)	4 (8%)
Genetic neurodevelopmental condition	3 (6%)
Disability (condition not specified)	3 (6%)
Palliative care (condition not specified)	3 (6%)
Study design or type of article	
Primary research	
Qualitative	16 (33%)
Mixed methods	4 (8%)
Quantitative, survey	3 (6%)
Quantitative, experimental	1 (2%)
Secondary research	
Systematic or scoping review	8 (17%)
Other	
Commentary or expert review	15 (31%)
Study protocol	1 (2%)

NICU neonatal intensive care unit, PICU paediatric intensive care unit

**Articles outside 5-year date range of the search were from supplemental articles added by authors*

What Parents Want in Prognostic Conversations About Their Child

As would be expected, parents have varied thoughts and preferences about prognostication conversations about their child. Some parents reported the need for definitive prognostic information they can apply to their own situation [31], whereas others acknowledge and are comfortable with uncertainty as an inherent part of prognostic information [32]. The literature generally supports a "yes, but" answer to the question, "do parents want to know their child's prognosis?" While parents value honest and comprehensive prognostic information [33••], they also want the opportunity to guide the amount of information received, when and where it is delivered, and how it is relayed based on their communication preferences [34]. For example, in the oncology or end-of-life context, some parents wanted smaller chunks of prognostic information provided across several conversations [34, 35], though for some this may not be feasible depending on their individual situation such as in the case where a child's condition suddenly worsens [34].

Research into patient and parent lived experiences, primarily in the context of life-threatening illness and end-of-life (see e.g., [35, 36, 37]), has informed a shift away from paternalistic censorship of prognosis, towards more open and honest conversations [36]. Typically, prognostic conversations following a genetic neurodevelopmental diagnosis differ from other areas of practice as, rather than a focus on the potential for survival, they are often concerned with the potential for life with neurologic impairment [33••]. Mueller's work on prognostic imagination for those diagnosed with a genetic condition recognises the complex ways that people envision their lives based on varied sources of prognostic messages and the impact on hopes, dreams, fears, and life plans [26••].

While parents clearly value clinical prognostication (i.e., based on the clinical experiences of healthcare

professionals), they also seek acknowledgment of the limits of that clinical knowledge [32]. Their views reflected in research [32] remind healthcare professionals to recognise the multidimensional factors influencing a child's current and future health and development. While parents view that genetic information is important, so too are a plethora of environmental factors such as attuned care, therapeutic intervention, and inclusion across the lifespan. As one parent whose child had an increased chance of cerebral palsy stated "give predictions but leave room for hope that work and therapy can change this." ([38] p804)

One study in paediatric neurology discussed that parents do not expect prognostic certainty and encourage uncertainty acknowledgement by healthcare professionals [33••]. Uncertainty is an inherent part of prognostication for those providing care to infants with neurologic conditions who often lack adequate data to estimate prognosis with the same level of certainty as is possible in other contexts such as in acute injury or illness [33••].

Studies report that parents of children in the NICU or with neurological conditions appreciate a careful and humble attitude from healthcare professionals [32, 39, 40]. Such a humble attitude may be at odds with the identity of a healthcare professional to present to parents as the expert [32]. A father interviewed as part of a recent study about communicating prognosis for infants critically ill with neurological conditions reflected that: "I think what they could have done better, is they could not be afraid to be honest and say, 'We don't really know.'" ([33••] e804)

Parents reportedly prefer to receive balanced, strengths-based prognostic information that includes information about skills and abilities along with challenges [27]. Provision of such strengths-based information requires healthcare professionals to consider challenges as well as the possibility of living well with disability [32]. Similarly, Byrne *et al.* report that parents of children with cerebral palsy did not appreciate a deficit focus and also felt frustrated when prognostic conversations were too general [38].

The studies reviewed reveal that there can be divergent views between parents and healthcare professionals about disability and life with a neurodevelopmental condition [41••]. Prognostic conversations occur in the context of a society where there are negative stereotypes, resulting in bias and stigma against people with disability [42]. Indeed, discriminatory and negative attitudes towards children with disability have been found when measuring attitudes of healthcare professionals across a range of settings including neurodevelopmental conditions such as cerebral palsy and those caused by an additional chromosome (trisomies 13 and 18) [32].

Challenges and Opportunities for Improvement in Prognostic Communication

Balancing Honesty and Hope

Healthcare professionals have expressed difficulty in balancing honesty and hope during prognostic conversations in the end-of-life context [34]. A further challenge noted is that health professionals across a range of paediatric disability contexts may inadvertently frame prognostic discussions to align with their own preferences or biases towards a particular outcome [39]. There are contradictory findings related to the benefits and challenges of optimistic and pessimistic framing in such discussions [43••, 44]. The belief held by healthcare professionals that less optimism could support realistic assessments of the future for children in the NICU [43••] contrasts with parents' perceptions that prognostic conversations about cerebral palsy or cancer are overly pessimistic [38, 45]. Yet, some parents also experience overly optimistic conversations as disconcerting and hinder the therapeutic relationship [44, 46, 47]. While the balance of honesty and hope can be challenging, parents have expressed that honesty (whether optimistic or pessimistic) promotes hope [44, 47].

The notion of conflict in balancing honesty and hope may surface implicit views held by both healthcare professionals and parents about disability and quality of life (QoL) [32, 48]. Health professionals' assumptions about genetic conditions or intellectual disability may bias clinical care and decision-making [49] and have potential to influence how parents think about their child [26••]. QoL is a subjective and complex concept that is difficult to measure and depends on the standpoint of the viewer: some individuals with health conditions or disability perceive their QoL as similar or better than others without conditions or disability, while some parents and healthcare professionals may report the individual's QoL as worse [39, 48].

Within prognostic discussions, a focus on the child's current and expected clinical presentation may overlook both the complexity of QoL and the human capacity for adaptation, an important factor in child and family outcomes [39, 50]. Such outcomes for children and families rest upon factors wider than condition related symptoms, and include access to services [51], societal inclusion [51] and norms [50], technology advances, values, and spirituality [32]. These outcomes can all be influenced by prognostic information [26••]. Hope is critical and can always be maintained [46, 52]. While hope can conjure thoughts of miracles [53], hope can also be found in adjusted goals, belief in child and family's potential, connection with others, and feeling supported [46, 54].

In a commentary about use of the term "poor prognosis" in paediatrics, Bogetz and colleagues discuss that a

healthcare professional's assumption of a poor prognosis conceals prognostic uncertainty, limitations, and inherent judgement within prognostication [55•], while also either marginalising or overshadowing parents' interpretations of QoL, meaning, and hope [33••, 39, 48, 50, 55•]. Furthermore, ambiguous linguistic "shortcuts", including terms such as grim or lethal or use of the modifier poor, to convey a prognosis may prompt different interpretations between parents and healthcare professionals [37, 56] or include value-based terms and slurs even if unintended [57•].

Discordance Between Healthcare Professionals' and Parents' Concerns in Prognostic Communication

A further challenge in communicating prognosis is that parents and healthcare professionals may have discordant concerns or interests in the conversation [53]. Healthcare professionals may prioritise medical aspects of prognosis or social services for supports, when parents wish to explore daily living scenarios including challenges that arise [51] or seek information about specific supports and the coordination of supports [38].

Healthcare professionals who communicated prognosis after a diagnosis of a high-risk brain tumour were found to present prognosis in terms of population-based statistics and dichotomous descriptive formulations; such as "possible but unlikely" and "possible and most likely", or, "hoped for" and "unfortunate" ([31] p4). In response to this information, parents often sought to individualise and personalise the prognosis to their child [31]. Generalisations (i.e., in relation to populations or groups) caused frustration for parents of children with cerebral palsy or 16p11.2 deletion syndrome [38, 58], and this discordance between what healthcare professionals can provide and what parents want to hear reflects just one of the challenges of communicating prognostic information which continues to carry uncertainty.

Uncertainty in Prognosis and Interpretation

Prognostication entails significant uncertainty [32, 57•, 58, 59]. Some healthcare professionals omit discussions of prognosis due to uncertainty [60] or fail to include the meaning of a prognosis, thereby increasing the potential for uncertainty [61]. Uncertainty was also invoked by some healthcare professionals in response to parents who sought clear and concrete predications [31, 62]. Therefore, uncertainty can be both a challenge when it is a property of prognostic information, though can also be used by health professionals as a tool for managing parents' expectations. Further uncertainty arises through the interpretation of the communicated prognosis [62], evident through differences in the way two parents can interpret the same discussion [31]. The timing for prognostic discussions is uncertain, as some individuals may not wish to discuss the future [26••, 63, 64] while others have experienced a long genetic diagnostic journey and are seeking detailed prognostic information [13]. Individual parents can respond differently to uncertainty, with some interpreting uncertainty as a threat and others perceiving it as an opportunity [39]. In a study of surrogate decision makers of adults with traumatic brain injury, the presence of too much or too little uncertainty was found to influence surrogates' experiences of prognostic conversations [62].

Parental Distress

Parents may experience anxiety while preparing for their consultation, and there is potential for psychological distress during prognostic discussions [51, 65], particularly when parents are unprepared for such conversations [66]. Parents' psychological states may impact their ability to absorb information or consider questions [64, 65], which underscores suggestions for written information [65], pacing and staging information [34], revisiting information [37], and follow-up appointments [65].

Discomfort and Gaps in Knowledge

Studies focused on the PICU and life-threatening conditions identified that some healthcare professionals feel uncomfortable or challenged when discussing prognosis in this context [32, 36, 60, 67], in part due to training limitations [36] and lack of time and resources [68]. Multiple consultations may be required to understand parent needs, values, and perceptions for individualised communication [57•], and allow space for evolving needs and understanding [26••, 50]. There is also a gap in evidence of interventions to improve conversations about prognosis related to genetic neurodevelopmental conditions. Discussion of existing interventions for prognostic communication with patients with cancer suggested that interventions may increase the frequency of communication but not reduce discordance among healthcare professionals and patients [63].

Impacts of Prognostication

The process of communicating prognosis impacts both parents and healthcare professionals. Prognostic communication can be stressful for healthcare professionals who feel uneasy or under prepared for making predictions about the future [32]. Parents may be vulnerable to inaccurate information or harmful and costly interventions through a fear of not doing enough to improve their child's outcomes [69]. Parental knowledge of prognosis can enable partnership with healthcare professionals to make informed choices about services and supports [51, 64]. While prognostication can empower parental decisions, such discussions can also

lead to hopelessness and worries about the future [26••, 64, 68, 70]. Prognostic knowledge may influence the life plans and identity of the family and child [26••]. Of note, young people with cystic fibrosis report that learning about prognosis does not affect their own personal goals or life plans, despite healthcare professionals suggesting it is not uncommon for shifts in goals and life plans [70], again surfacing discordance and highlighting the limitations of knowledge to date. Parents may need to adapt to a prognosis that requires them to accommodate changes to their expected future [31]. However, prognostic discussions centred on population-level statistics may not support this process of adaptation [31].

Finally, assumptions about the prognosis may bias clinical care and decision-making [49]. One study highlighted the influence of neonatologists' assumptions about prognosis on clinical care in the NICU [49]. This work studied the impact of a neonate's diagnosis of a genetic neurodevelopmental condition (Williams syndrome, associated with intellectual disability, though does not affect acute survival) on neonatologists' care decisions. Neonatologists were more likely to favour palliative care over invasive interventions for a neonate with Williams syndrome, compared to a neonate without Williams syndrome [49]. The authors state that assumptions about the quality of life for individuals with intellectual disability may have influenced care recommendations.

Recommendations for Communicating Prognosis

Prognostic Communication Tools and Models

Across the studies in this review, several provided recommendations for improving prognostic conversations. Overall, there were seven distinct communication tools and models that could be used to facilitate more effective prognostic discussions about neurodevelopmental conditions. The central focus across these models is the importance of fostering hope while providing realistic information aligning closely with parent preferences. The models recommend healthcare professionals aim to strike a balance between acknowledging the seriousness of the child's condition and instilling hopefulness in parents regarding their child's future development, care, and support.

The models of COMPLETE intervention [71], OuR-HOPE [32, 40], Serious Illness Conversation Guide [72], EMPATIA guide [57•], and ALIGN [33••] were all described in the studies captured in the review. These models emphasise the significance of maintaining realistic hope without crossing into unrealistic optimism. The models encourage tailoring information to prevent families being overwhelmed, and framing the prognosis in a way that acknowledges uncertainties while highlighting positive aspects and expectations. These models stress the value of empathy, partnership, and open communication. Recommendations to achieve these aims include healthcare professionals engaging with parents in a respectful, empathetic manner that fosters a partnership rather than a one-sided delivery of information. Strategies are discussed such as reflective practice (OuR-HOPE [32, 40]), asking open-ended questions about families' sources of strength (Serious Illness Conversation Guide [72]), and providing emotional support (ALIGN [33••]). SPIKES [73] highlights the importance of understanding the family's perspective and providing support beyond just medical information. Additionally, the emphasis on acknowledging uncertainty in ALIGN [33••] and NEO-SPEAK [74] demonstrates a shared recognition that prognostic information can often involve uncertainty, and that it is crucial to communicate this uncertainty openly and honestly.

Planning for and Holding Prognostic Conversations

The research reviewed mirrored the models and frameworks, with a focus on healthcare professionals holding honest and balanced prognostic conversations (i.e., discussing both challenges and positive aspects of abilities) [35, 38, 41••, 44, 45, 52, 66]. While a common recommendation, this balance was also identified as a challenge which highlights the need for further research into interventions which support healthcare professionals' understanding of parent hopes, perspectives, and readiness for prognostic conversations.

The importance of language used in prognostication also featured across four of the included articles [51, 55•, 56, 73]. In particular, the language used can at times reflect the negative stance of healthcare professionals towards individuals with disability and their lives. Bogetz *et al.* recommend moving away from the term "poor prognosis", towards more specific information such as the need for life-long support [55•]. Similarly, Cortezzo *et al.* suggest that using alarmist and negative terms such as grim to describe the prognosis of various diagnoses should be replaced with a clear articulation of the range of possible outcomes [56]. These authors further recommend against the use of developmental delay without further specific details as families may misinterpret such language as meaning the child will most likely catch up in the future. Cadwagan *et al.* recommend explaining to parents that it is the wider environment and society surrounding the child that creates disability, not the child's impairment itself [51].

Further recommendations offered include individualising the timing of discussions [70], and pacing or "chunking" prognostic information if required [34, 35, 37, 57•]. Finally, the limited research to date supports providing guidance to healthcare professionals that they should be proactive and bring up the concept of prognosis with

Box 1 Summary of five key recommendations to support healthcare professionals to plan for prognostic conversations with parents

1. Reflect on your values and life experience
- *Consider your experience and understanding of life with disability*
- *Acknowledge both potential challenges and positive aspects of the child's predicted developmental trajectory*

2. Partner with the family
- *Recognise the process of communicating prognosis impacts both parents and healthcare professionals*
- *Aim to understand individual perspectives and priorities*
- *Provide support beyond medical information (refer as appropriate)*
- *Acknowledge the limits of clinical knowledge*

3. Be aware of language
- *Keep in mind how framing and language choice may be impacted by personal assumptions and biases*
- *Avoid alarmist and negative terms such as poor prognosis or grim*
- *Clearly articulate the spectrum of possible outcomes*

4. Acknowledge uncertainty and foster hope
- *Develop a shared recognition with parents that prognostic information can involve uncertainty*
- *Maintain realistic hope and recognise capacity for adaption*
- *Support the family to connect with others who have lived experience of the diagnosed condition*

5. Consider the timing
- *Be proactive in initiating conversations about prognosis while being attuned to parental readiness*
- *Use techniques such as pacing and staging information according to parents' preferences, with the option for follow-up appointments*

parents, rather than waiting for parents to raise this topic [66, 70]. Box 1 summarises the recommendations for health professionals to plan prognostic conversations with parents.

Limitations

While we did not aim to systematically review the literature, our search and screening strategy may have missed relevant, recent research. Overall, the review is also limited by the small number of studies that consider prognosis in genetic neurodevelopmental conditions, or in fact in chronic conditions. In the literature, there is an over-representation of life-limiting conditions with prognosis used synonymously with likelihood of survival. Through reviewing this literature, we now question whether the term prognosis (defined as the likely course of a medical condition) was in fact accurate to capture the topics that parents wanted to discuss when conceptualising their child's future in the context of neurodevelopmental conditions. Prognosis assumes a focus on clinical manifestations and discounts wider considerations for the child as a whole person, the family unit, and what life will be like.

We chose to focus on prognostic discussions between parents and healthcare professionals, though note the importance of including children in these discussions, which was outside the scope of this review. A future review could focus specifically on communicating prognoses to those living with genetic neurodevelopmental conditions, including children.

Conclusions

The key findings of this review were that parents hold diverse preferences regarding prognostic conversations for their children, appreciating honesty balanced with uncertainty, and have particular preferences, wanting control over the timing, depth, and delivery of information. Recent shifts in clinical practice across all the specialties included in this review emphasise transparency in prognostic communication, even while uncertainty remains a significant component. In genetic neurodevelopmental conditions, predictions should focus on life with neurological impact and available supports, rather than survival. Parents value a humble approach from healthcare professionals that acknowledges uncertainty and encourages balanced, strengths-based information, considering both challenges and the potential for a fulfilling life with disability. Divergent perspectives between parents and healthcare professionals highlight negative stereotypes held by healthcare professionals and societal biases against disability, complicating prognostic communication and potentially impacting outcomes.

We echo the suggestion that more research that is inclusive of both parents and a wider range of healthcare professionals in this area is urgently needed to guide prognostic conversations [29]. This is important, particularly as families are gaining greater access to genetic information about their children and these conversations are to be held by healthcare professionals without specialised genetics training. Research must focus on enabling

healthcare professionals to convey prognostic information about genetic neurodevelopmental conditions that meets the needs of parents and supports the best outcomes for children and their families.

Author contributions E.T., E.C., P.S., A.M., and D.J.A. contributed to conceptualisation, manuscript revisions and approve the final manuscript. E.T. ran the search and screened the titles and abstracts. E.T., E.C., and P.S. screened the full texts, extracted and analysed the data. E.T. wrote the initial first draft.

Funding Open Access funding enabled and organized by CAUL and its Member Institutions

Compliance with Ethical Standards

Conflict of Interest The authors declare no competing interests.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- • Of importance
- •• Of major importance

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