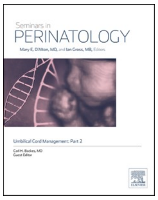
ARTICLE IN PRESS

SEMIN PERINATOL xxx (xxxx) xxx

Contents lists available at ScienceDirect

Seminars in Perinatology

journal homepage: www.elsevier.com/locate/semperi



Looking beyond diagnoses to functioning: using the F words and personalizing care in neonatology

Emilie Thivierge [a], Thuy Mai Luu [a,b], Peter Rosenbaum [c], Paige Terrien Church [d], Rebecca Pearce [e], Annie Janvier [a,b,f,g,h,*]

[a] CHU Sainte-Justine Research Center, Montréal, Canada
[b] Department of Pediatrics, Université de Montréal, Montréal, Canada
[c] Department of Pediatrics, and CanChild Centre, McMaster University and McMaster Children's Hospital, Canada
[d] Department of Pediatrics, Harvard Medical School, Beth Israel Deaconess Medical Center, Boston, MA, USA
[e] Parent representative; involved in Canadian Premature Babies Foundation, Canada
[f] Division of Neonatology, Hôpital Sainte-Justine, Montréal, Canada
[g] Bureau de l'éthique Clinique, Université de Montréal, Canada
[h] Unité d'éthique clinique et organisationnelle, Hôpital Sainte-Justine, Montréal, Canada

ARTICLE INFO

Keywords:
F-words
Prematurity
NICU, Neonatology
Patient important outcome
Neonatal follow-up
Developmental pediatrics
Neonatal outcomes
Prenatal consultations
Communication
Palliative care
Disability
Disability paradox
Clinical ethics
Family-centeted care

ABSTRACT

Extreme prematurity is associated with significant risk of mortality and morbidities. Neonatal follow-up assesses health outcomes of babies as they grow older to improve care and contribute to research and quality improvement initiatives. Recent investigations demonstrate that parents and clinicians/researchers disagree about what is defined as a "severe outcome". Families report they need balanced information about functioning rather than medical diagnoses. Many functional domains other than the presence/absence of impairment are not evaluated during neonatal follow-up. This article recommends how to shift communication with parents of preterm infants throughout the NICU hospitalization – from discussions that are medicalized and deficit-based to those that reflect the processes of growth and development. This includes understanding family-important outcomes and how to communicate with parents using the 'F-words' for child development based on the World Health Organization's integrated biopsychosocial framework for health: Functioning, Family, Fitness, Fun, Friends, and Future.

Introduction

Extreme prematurity carries significant risks of mortality and morbidity. Possible alterations in typical brain development have led to a long tradition of evaluating neurodevelopmental outcomes of these babies as they get older. In this context, neonatal follow-up programs exist for two main purposes: (1) to identify early signs of developmental delay so the child can be referred in a timely manner to intervention services to optimize functioning, and (2) to document long-term neurodevelopmental outcomes of health as well as impairment. The latter facilitates (i) prognostication based on perinatal characteristics that can inform decision-making prenatally or in the neonatal intensive care unit (NICU); (ii) monitoring neonatal practices through benchmarking, supporting quality improvement initiatives in various units; and (iii) assessment of the impact of interventions within research protocols.

The origins of what is measured during neonatal follow-up assessments date back to a paper published in 1968 that examined the neurodevelopmental outcomes of babies who developed respiratory distress syndrome. With evolving technologies to support survival of these babies, neonatologists wanted to know about their long-term outcomes and whether survival was acceptable. Investigators examined whether children developed cerebral palsy and/or developmental delays.[1]

Nowadays, most researchers reporting on outcomes of prematurity will describe children as having no, 'mild', 'moderate' or 'severe'

---

[*] Corresponding author at. Department of Pediatrics and Clinical Ethics, University of Montreal, Neonatologist, Clinical Ethics unit, Sainte-Justine Hospital, Address: 3175 Chemin Côte-Sainte-Catherine, Montreal (QC), H3T 1C5.

E-mail address: anniejanvier@hotmail.com (A. Janvier).

https://doi.org/10.1016/j.semperi.2025.152102
Received 15 April 2025; Received in revised form 30 May 2025; Accepted 3 June 2025

neurodevelopmental impairment. This classification is usually done using a combination of items such as the presence or not of cerebral palsy, developmental delay based on a standardized assessment, hearing impairment, or visual impairment. This classification does not consider that children exist on a continuum. Most importantly, individuals born extremely preterm and their parents were never asked about these categorizations and the values (e.g., 'severe') assigned to them. In fact, recent data indicate that parents do not agree with how clinicians and scientists categorize their child, and that their definition of what constitute a 'severe' outcome is not in agreement with that of neonatologists.[2,3]

CASE

To illustrate our point, consider Mia's story, published in the American Journal of Bioethics in 2022.[4] "Helen came to the hospital with her husband Peter, presenting symptoms of threatened preterm labor at gestational age (GA) 23 weeks +4 days. She had become pregnant while on contraceptives, and had three children, aged 3, 5 and 9 years. Three hours later, Mia was born. Due to a rapid delivery, there was no possibility for proper prenatal counselling. Mia appeared vital at birth and was stabilized on non-invasive ventilation, and surfactant administration through a tracheal catheter. Her skin appeared immature, and she had transitory electrolyte disturbances during the first days of life. After 2 days, she was intubated due to apneas, and bilateral grade 2 intraventricular hemorrhages (IVH) were found, which progressed to grade 3 on one side. The parents stayed in the Neonatal Intensive Care Unit (NICU) around the clock and participated in Mia's care."

In most NICUs, Helen and Peter would be met daily, and they would hear about serious "A's and B's" (apneas and bradycardias) requiring Mia to be intubated. During rounds, daily desaturations, hyponatremia and weight loss would have been mentioned, as well as how those could be dealt with. Potential outcomes for Mia based on her brain bleed would be discussed (as described in the *American Journal of Bioethics* article from which Mia's story is extracted[4]): survival with and without NDI, potential of severe disability and diagnoses such as cerebral palsy and deafness. All the problems Mia might have or may develop related to her prematurity would be also described to her parents, sometimes using medical jargon represented by three letter acronyms: BPD, ROP, NEC, PDA, etc. As time went by, her parents would even start to use some of those three-letter shortforms to describe the trajectory of their child and her future.

The goal of this current paper is not to review outcomes after intracranial hemorrhages of different degrees, nor when palliative care is acceptable. Based on Mia's story, we have discussed this case and published such a review.[5] Rather, the aim of this article is to examine how to shift communication with parents of preterm infants throughout the NICU hospitalization from discussions that are medicalized, deficit-based, and binary to those that reflect the fluid processes of growth and development that are occurring in the environment of the NICU. This includes reviewing important parent/family-identified outcomes, and how to communicate with parents in the NICU using the 'F-words' for child development[6] based on the World Health Organization's integrated biopsychosocial framework for health.[7]

Summary of current research: the parents' voice project

The Parents' Voice Project is a large multicenter Canadian initiative that comprises several studies seeking to investigate parental perspectives and family-important outcomes after extremely preterm birth.[8] In one study, over 1000 consecutive parents of children born at <29 weeks attending a neonatal follow-up clinic in Canada for their 18–24-month visit were asked to rate their child's neurodevelopment as follows: no neurodevelopmental impairment, or mild, moderate or severe neurodevelopmental impairment. Their child then underwent standardized neurodevelopmental assessment. Parents' classifications were compared against the Canadian Neonatal Follow-Up Network (CNFUN) classification of NDI. Agreement between the two was poor ($\kappa = 0.30$; 95 % CI: 0.26–0.35): parents usually described their child's development as normal or less impaired than classifications based on CNFUN guidelines, and only 12 % of parents of children classified as having a 'severe' NDI according to the CNFUN definition agreed.[9]

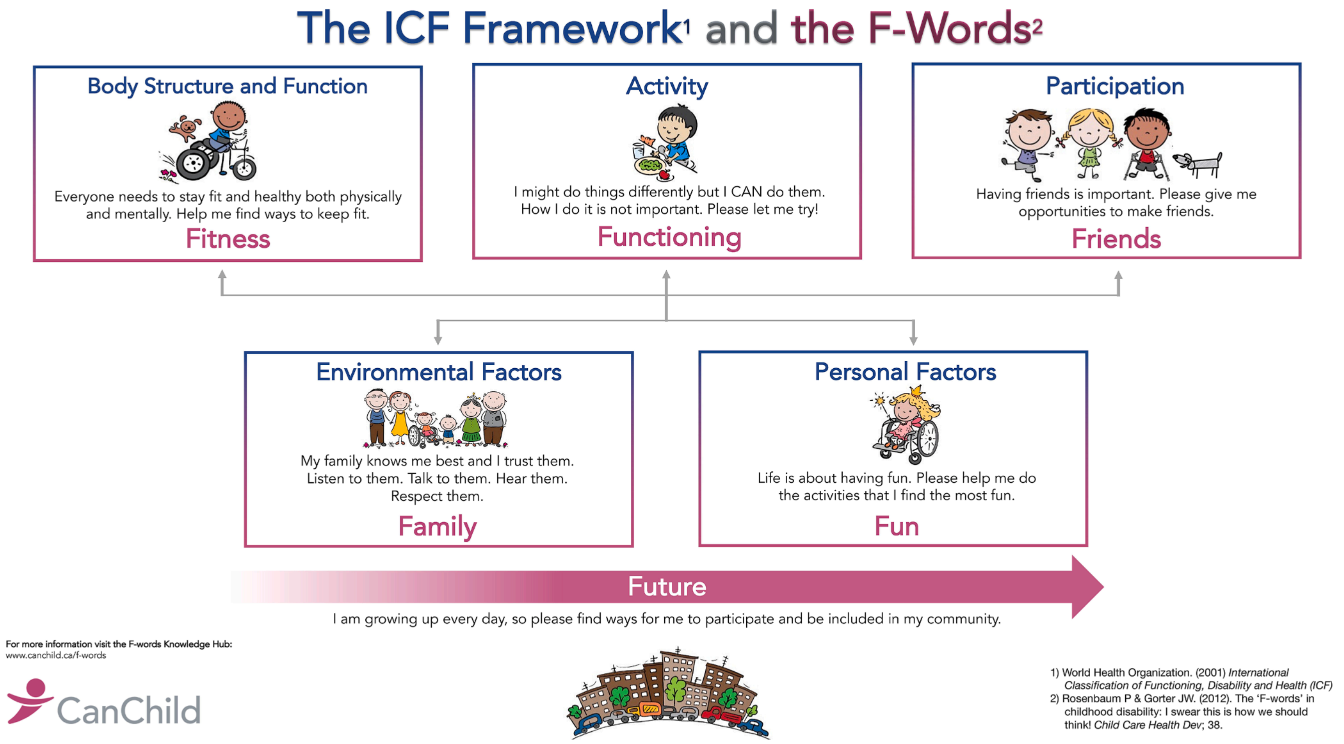
In another study, ten clinical vignettes described 18-month-old children with different components of 'severe' neurodevelopmental impairment (as per neonatology classification) and one scenario of a typically developing child (control) .[10] The 827 parents and stakeholders (including individuals who were born preterm) were asked whether the cases described represented a 'severe' condition. The proportion of respondents rating a scenario as 'severe' ranged from 5 % for 'severe' cognitive delay to 55 % for having both cerebral palsy and 'severe' language delay. In other words, what is considered 'severe' in the scientific literature was not often rated as such by preterm birth stakeholders including parents, individuals born preterm, healthcare professionals, researchers, trainees, and educators,[10] which is consistent with previous work from Saigal et al. in 199,9.[11]

In other studies, 248 parents of extremely preterm children were asked to help identify relevant outcomes that should be communicated to parents in the NICU, including the impact of the preterm birth on their lives, the health of their child, and their information needs. Parents reported on outcomes not only related to neurodevelopment (ability to walk, communicate, learn), but also to respiratory health, feeding, sleeping or behavior. The majority identified positive and negative impacts after preterm birth.[12] Parents wanted a more balanced perspective, more optimism from doctors (what is going well, not only what is wrong), and more practical, actionable advice.[13] As part of the Parents' Voice Project, all results from the different studies were reviewed for interpretation with a group of parent advisors, clinicians, and researchers. The main messages were that: (1) it is possible to integrate family perspectives in neonatal research, (2) functioning should be preferred over diagnoses.[14] Seven domains were identified as being important to report in research data collection: their child's well-being, quality of life/functioning, socio-emotional/behavioural outcomes, respiratory health, feeding, sleeping, and caregiver mental health.[15] In order to start measuring these accurately, a consensus of experts and parents identified and agreed upon the use of brief, inexpensive, and family-friendly validated questionnaires using literature reviews.[16]

We asked ourselves how a more balanced perspective, more optimism from doctors, as well as more developmentally relevant advice could be integrated in the NICU. Some specialities, such as developmental medicine, increasingly use a strengths-based framework when communicating with families. Further, childhood development is referenced as a process, an unfolding, rather than a binary state of 'normal' or 'abnormal'. Unfortunately, neonatology, developmental pediatrics, and rehabilitation medicine are not often seated at the same tables. The remainder of this article will examine the integration of the F-words approach in the NICU to develop a common language to describe growth and development, functioning, disability and health.

The integrated biopsychosocial framework for health and the F-words for child development

The World Health Organisation (WHO) proposed an integrated biopsychosocial framework for health (the ICF – International Classification of Functioning, Disability and Health), to recognize clearly that we are more than our body structure and organ function.[7] The ICF framework can help clinicians and families recognize and create a broader and more complete picture of the health and life situation for a patient. The framework is universal, holistic and applicable for any health condition. It recognizes the person as inter-connected to their community. Indeed, it is essential to consider the environment and the context of a child's life when evaluating a child's health state and functioning. Most importantly, it is strengths-based, uses neutral language, with the focus being



Everyone needs to stay fit and healthy both physically and mentally. Help me find ways to keep fit.

I might do things differently but I CAN do them. How I do it is not important. Please let me try!

Having friends is important. Please give me opportunities to make friends.

My family knows me best and I trust them. Listen to them. Talk to them. Hear them. Respect them.

Life is about having fun. Please help me do the activities that I find the most fun.

I am growing up every day, so please find ways for me to participate and be included in my community.

For more information visit the F-words Knowledge Hub:
www.canchild.ca/f-words

1) World Health Organization. (2001) *International Classification of Functioning, Disability and Health (ICF)*
2) Rosenbaum P & Gorter JW. (2012). The ‘F-words’ in childhood disability: I swear this is how we should think! *Child Care Health Dev*; 38.

Fig. 1. The integrated biopsychosocial framework for health and the F-words for child development. Reprinted with permission.[17]

on the level of health and functioning, not disability.

In 2012, Drs. Rosenbaum and Gorter published a paper called “The F words in childhood disability: I swear this is how we should think!” This article describes six F-words, grafted onto the ICF framework for health, that should be the focus in child development and hence of childhood disability: Functioning, Family, Fitness, Fun, Friends, and Future (Fig. 1).[6] The F-words approach to health, built directly onto the ICF, brings forward individual attributes in a way that is meant to be engaging and easy to remember. Having a neurodevelopmental diagnosis such as cerebral palsy, autism, intellectual disability or ADHD does not, and should not, define the child, nor does it speak specifically about functioning.

The F-words have led to an important shift in speaking about disability with families, with a dedicated training program, tools and comprehensive videos for clinicians, families and patients (See https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability for access to a rich resource of free materials and tools.) .[17] This strengths-based way of thinking also builds on and addresses the ‘disability paradox’.[18] Clinicians often have an ableist view of the world and may not understand how, for example, one can be a wheelchair user and be happy.[19] It has been demonstrated that people with disabilities adapt, with the universal focus of their individual F-words being more important than their diagnosis. Thus, the F-words approach de-emphasizes the concept of ‘fixing’ a child, and rather promotes an emphasis on development, child and family strengths and achievements. Having a disability does not mean that a person cannot have a good quality of life. Our goal is that neonatology can also approach development using this recommended strengths-based lens that focuses on functioning and participation and think beyond diagnoses.

Returning to Mia: Mia’s parents have heard about the impacts of her bleeds in her brain and have been told she may never walk and has increased risks of developmental disorders and “severe disability”. They remember that day very well and have decided to give Mia a chance. In the original article, in the ethics journal from which the case is taken, because of the “severe” disabilities associated with the brain bleed the parents are offered to reorient care, namely, to remove the respirator and hold Mia while she dies. But (unlike in the Journal of Bioethics reference where she dies to prevent a “severe outcome”[4]), they have decided to give her a chance and see how things will develop in the NICU. They hope the rest of her course could be more optimal. In the first weeks of life, Mia’s parents are met daily during rounds. They still hear about A’s and B’s, her chronic lung disease (CLD) that may become a BPD, her electrolytes and which are too high and too low, her weight gain in grams, how they are changing her nutrition in her veins, etc. They consider their child very sick, with all the changes that need to be done every day to keep her alive. After a month, they are told by clinicians she will probably develop BPD, that NEC and sepsis are less of a concern, and that soon she will have eye exams to evaluate ROP. The road in front of them seems very long. (It should be noted that Mia has a unilateral grade 3 intraventricular hemorrhage, that is very different from some more significant bleeds in very sick unstable patients) .[20]

How can clinicians speak with each other, and particularly with Mia’s parents, about Mia’s developing body structure and function, potential activity, participation? Environmental factors and personal factors are interrelated and will equally influence her health and functioning. An F-words-based approach encourages us to focus on factors that are important to families and to all children’s development – their participation, activities, and environment. How can clinicians communicate with Mia’s parents in a constructive and honest fashion, using the F-words as opposed to a list of diagnoses and a deficit-based approach (what some call the ‘catalogue of doom’)? In other fields, when children have serious conditions, clinicians speak about diagnoses and what they can do to help. Here as elsewhere, there are many things that can be done to reframe discussions about Mia and, without minimizing the seriousness of her current health issues, to reflect that she is a growing baby, in an unnatural environment, and to consider ways to help Mia if she later lives with cerebral palsy or a hearing impairment. If we examine Mia’s situation, the F-words can be used as a lens through which to consider and speak about the predictions of long-term outcomes after a unilateral IVH grade 3. What is important are not only the challenges Mia may have, but also what can be done to help promote her functioning and development.

Unique communication challenges in neonatology

Parenting in the NICU is an intense journey. Many parents are mourning a normal pregnancy, delivery, and breastfeeding experiences. Parents struggle to build intimacy with their child amid technology and medical uncertainties.[21] For parents of sick, older children, "good parent beliefs" have been shown to foster positive growth. This concept, first introduced by Dr Chris Feudtner, explains that parents endorse a broad range of beliefs that represent what they perceive they should do to be a good parent for their sick, hospitalized child.[22] Engaging parents individually regarding what they perceive to be the core duties they must fulfill to be a good parent enables more personalized support. This concept is also essential for parents of babies in the NICU, although their path is complex. It is difficult for parents who have an infant in the NICU to figure out what it means to be a "good parent". Parenthood is different in the NICU. Some parents may feel like bad parents because they may believe that they caused the preterm birth, although this is almost never the case. This internal sense of guilt is magnified and reinforced unintentionally by medical labels such as "incompetent cervix" or "placental insufficiency" or "failure to progress".[23] Some parents may feel conflicted about whether to invest emotionally in an infant who could die, who could have future health problems, or who simply looks too fragile or not yet like a real human.[21] Medical technology that also alters a child's appearance is not optimal for parent-child bonding. Many parents are preterm themselves and as such, need to be supported in a new way of being a parent. To get there, their previously held parenthood beliefs, expectations, and hopes often undergo transformations; several recommendations from clinicians can be helpful, such as managing their conflicted emotions, creating flexible care models, choosing words wisely, and empowering them through their journey.[21] In summary, parents in the NICU need to hear and internalize three essential messages that overlap but are each important: (i) you are a parent, (ii) you are not a bad parent, and (iii) you are a good parent.[21]

Prenatal consultations

Neonatal clinicians often meet prospective parents before the birth of their child. Unfortunately, parents do not generally learn about parenting in the NICU during the prenatal consultation. In the prenatal setting, professional recommendations state neonatologists should discuss with parents possible conditions that their child may develop.[24] The antenatal consultation is usually deficit focused. Indeed, policy statements recommend a standardized approach to providing parents with information about mortality and morbidities.[25,26] Checklists have been developed to ensure all the adverse diagnoses are mentioned. On the other hand, parents want a personalized consultation: to know what diagnoses mean for a child's functioning and to understand how they can be parents – for example, what they can do, and how they are part of the team in the NICU[27,28] In this context, personalized prenatal consultation should be the norm. Checklists have been developed to help speak about those important items, while also integrating life and death discussions.[29,30] Prenatal workshops and support groups that are family-centered, for parents expecting their baby to be hospitalized in the NICU at birth, also help.[31]

About life and death

This paper is not focused on communication with parents about withholding and withdrawing life-sustaining interventions, as several articles about this topic exist, such as the mnemonic SOBPIE.[32] Unfortunately, in the NICU, some babies are so sick they die despite life-sustaining interventions. For example, Mia may have a catastrophic NEC or pulmonary hemorrhage and die despite interventions. In other cases, parents and clinicians may have to make the decision to continue or stop life-sustaining interventions. It is important that when parents are asked to make those decisions, they make them with information that is relevant to their specific situation rather than simply based on statistics and diagnostic labels. Stating that Mia is at high risk of "severe disability" without describing functioning and what that means to the family, should be avoided, especially when parents of children living with that condition do not describe their status as 'severe'.[19]

During the NICU stay

Prematurity is very different from other conditions. It is not a disease that can be fixed or cured, like a broken bone, an infection, or cancer. Some clinicians may feel they are creating disabled children, as opposed to saving a sick child.[33] Too often, everything that is outside the norm is seen as, or becomes, 'abnormal' – a disease or a problem to fix. Rarely, however, in the process of growth and development do such binary concepts exist. Rather, the NICU is an environment in which humans grow and develop outside of the uterus. The aim of neonatologists is to promote growth and development while avoiding iatrogenic complications. But what is a disease and what is to be anticipated as the expected development outside of the womb? Some pathologies are life-threatening problems that need immediate attention and to be fixed (e.g. pneumothorax). On the other hand, others are expected as the normal clinical/developmental trajectory of a preterm infant, and yet, defining these as clinical diagnoses is misleading. Developmentally and physiologically, very small babies require ventilatory support at birth. Yet, clinicians (and medical recommendations alike) often use the word "resuscitation", both in academic papers and when speaking to parents, to describe expected respiratory support.[25,26] It is developmentally appropriate for Mia to need a ventilator to support lung growth; it is also expected that she needs a feeding tube until she can mature enough to learn to feed by mouth. A ventilator and tube feedings support Mia's growth and development. Other common conditions further describe the adaptive changes to development that occur because of the NICU environment as a list of diagnoses such as "rule out retinopathy of prematurity (ROP)'' or a diagnosis of "ROP stage 0" (or 1), describing expected retinal development or early mild aberrancies in retinal development that will often have little or minimal impact on functioning later on.

Parents often report that clinicians are pessimistic and give them the 'catalogue of doom' about their child, while they expect them to cope and bond. It is possible for clinicians to avoid medicalizing fragile growing babies and help parents throughout the hospitalization. As mentioned earlier, clinicians are often taught to think about many results that are "not normal" as problems that needs to be fixed. As outlined above, it is possible to explain to parents what a typical clinical trajectory looks like for a baby like Mia – e.g., what is expected for her gestational age, such as needing a ventilator and a feeding tube for weeks. During rounds, we could describe what is expected 'developmentally' with attention to the specific gestation and individual patterns, and what is outside of that range. Individually, some babies are better at digesting their milk, others have more apneas. Some parents ask, "*Is it normal for a baby at that age to be like this?",* and we can aim to answer that question for all preterm infants: 'What is developmentally appropriate and what isn't'. If we come back to Mia, it is expected, and therefore appropriate for her gestation, for her to have transitory electrolytes anomalies due to her immature kidneys and it is not surprising that she needs to be intubated or that she cannot yet feed by mouth.

This reframing moves away from the lists of neonatal diagnoses (the three letter words) that are disease-focused, fixed in time and space. This also reminds us of the importance of actively removing worries and diagnoses when communicating with parents. In the NICU, time is an essential variable of both the development of new abilities and progression and potential resolution of health impairments. Indeed, we often need to update and reconsider function as the baby grows. Fixed predictions are unwise as we do not have the full story of the rapidly developing infant and their family. Coming back to Mia's brain bleeds, the team should acknowledge that her brain will be monitored closely, and that these bleeds may impact her future development but that as of

Table 1
Sentences with F-words that can be used to speak about Mia's long-term outcomes.

FUNCTIONING	*"Babies like Mia can have significant challenges with how they move around, how they communicate and how they learn, as they grow up. Even if this happens, our goal is to help Mia do whatever she wants to do to be a happy kid. This may require some support and help, but what is important is that she is able to function. Mia could develop cerebral palsy. For babies born early like Mia, this means she may have problems moving her legs like other children. But there are many ways to help children move around, such as special shoes, braces and other tools, and generally, they are able to walk. "*
FAMILY	*"Parents are essential to babies' health and development. We know that parents of babies like Mia describe additional challenges, such as stress, days missed at work, and a loss of the family equilibrium. On the other hand, they also describe positive impacts of their experience such as gratitude, a gain in perspective, what is important and what is not, and stronger family bonds. Parents can optimize the development of their children a great deal and there are many things parents can learn as a family." Research also shows how families can be supported to develop a sense of empowerment, confidence, and competence in their parenting roles.*[37]
FITNESS	*"Babies like Mia can have health issues such as breathing problems or problems walking, but their health can be optimized so they are fit physically and mentally. Sports may need to be accommodated to allow participation but increasingly, adaptive sports are available and can be very competitive."*
FUN	*"Mia will be able to engage in activities she enjoys". It is up to others to ask what Mia finds fun, and build her environment, and her 'therapies' (as needed) around her values."*
FRIENDS	*"Mia will be able to have relationships and friendships with other children."*
FUTURE	*"As Mia grows, we will want to reassess these F-words and help her establish future goals. Mia may not have a disability as she grows up, but if she does, she will be able to participate in setting goals for herself: what does she like, what does she want to do, with whom. We will be able to work together to optimize her environment and give her tools to reach her goals and live a full life on her terms. Parents are important in supporting children as they develop."*

right now the prognostic uncertainty of a bilateral grade 3 intraventricular hemorrhage is a challenging reality for parents and for clinicians. F-words can be used (Table 1) to speak about brain bleeds, even while recognizing potentially uncertainty and challenges. Since diagnoses cannot be equated to functioning, we suggest that clinicians integrate the F-words in discussions around potential impairments that arise while in the NICU.

Using the F-words in neonatology

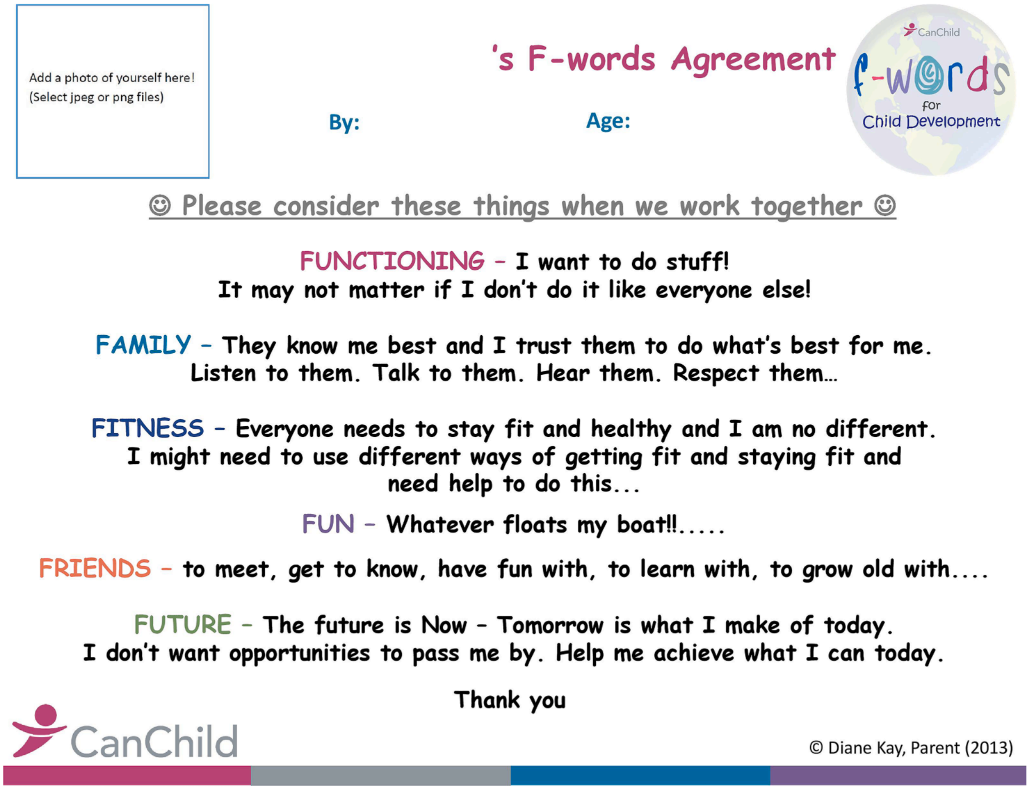
F-words could be introduced to parents in neonatology at the antenatal consult, to help them to frame their expectations in the immediate moments after birth, as well as after a baby is admitted in the NICU (Fig. 2)[17] Ideally, F-words should be integrated into daily care and rediscussed at key turning points in the hospitalisation to make sure that individual family- and child-specific priorities are being set to address the needs of families and children.

Circling back to Mia, she has now been in the NICU for one month, has been extubated, and is on bilevel positive airway pressure (BiPAP), reflecting her growth and development. She still has apneas and bradycardias mostly at the end of her nasogastric feeds. Her unilateral grade 3 IVH has not progressed, although PVL may develop. Fig. 3 shows what her current F words could look like.[34]

After an event that may signal impairment

As previously discussed in another article with our collaborators,[19] here are our suggestions to optimize discussions after an event regarding the possibility of disability:

1. Initiate professional group (team) reflections before important discussions with families with the goal of delivering balanced, individualized care that is free of bias as much as possible.



Add a photo of yourself here!
(Select jpeg or png files)

's F-words Agreement

By: Age:

☺ Please consider these things when we work together ☺

FUNCTIONING – I want to do stuff!
It may not matter if I don't do it like everyone else!

FAMILY – They know me best and I trust them to do what's best for me.
Listen to them. Talk to them. Hear them. Respect them…

FITNESS – Everyone needs to stay fit and healthy and I am no different.
I might need to use different ways of getting fit and staying fit and need help to do this...

FUN – Whatever floats my boat!!.....

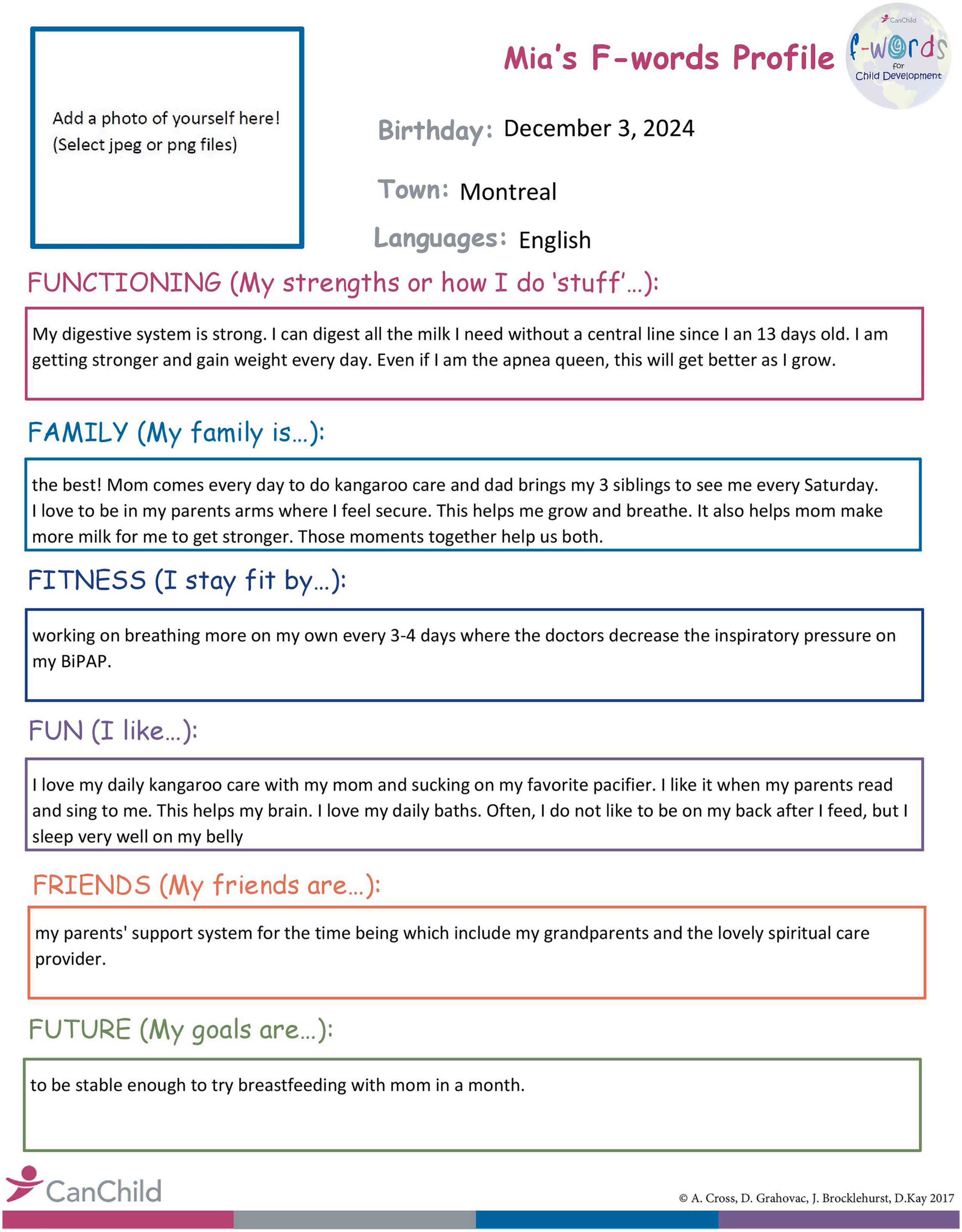
FRIENDS – to meet, get to know, have fun with, to learn with, to grow old with....

FUTURE – The future is Now – Tomorrow is what I make of today.
I don't want opportunities to pass me by. Help me achieve what I can today.

Thank you

© Diane Kay, Parent (2013)

Fig. 2. Example of F words tool. Reprinted with permission.[34]



Add a photo of yourself here!
(Select jpeg or png files)

Mia's F-words Profile

Birthday: December 3, 2024

Town: Montreal

Languages: English

FUNCTIONING (My strengths or how I do 'stuff'…):

My digestive system is strong. I can digest all the milk I need without a central line since I an 13 days old. I am getting stronger and gain weight every day. Even if I am the apnea queen, this will get better as I grow.

FAMILY (My family is…):

the best! Mom comes every day to do kangaroo care and dad brings my 3 siblings to see me every Saturday. I love to be in my parents arms where I feel secure. This helps me grow and breathe. It also helps mom make more milk for me to get stronger. Those moments together help us both.

FITNESS (I stay fit by…):

working on breathing more on my own every 3-4 days where the doctors decrease the inspiratory pressure on my BiPAP.

FUN (I like…):

I love my daily kangaroo care with my mom and sucking on my favorite pacifier. I like it when my parents read and sing to me. This helps my brain. I love my daily baths. Often, I do not like to be on my back after I feed, but I sleep very well on my belly

FRIENDS (My friends are…):

my parents' support system for the time being which include my grandparents and the lovely spiritual care provider.

FUTURE (My goals are…):

to be stable enough to try breastfeeding with mom in a month.

Fig. 3. Sentences with F-words that can be used to speak about Mia's current F words. Reprinted with permission.[34]

2. Avoid words such as 'normal' and 'abnormal'. Focus on functionality and the impact that neurodevelopmental diagnoses may have on the day-to-day life of children and their families.
3. Describe outcomes as they relate to families, focusing on functioning rather than medical diagnoses. Focusing on the F-words as important guides to outcome allows a family to truly comprehend the future possibilities for their baby (Fig. 2). Get help from specialized clinicians if you do not know about the functioning related to a condition.
4. Use objective, value-neutral language to describe neurodevelopmental outcomes. This allows for families to derive their own meaning and to make decisions based on their values, rather than taking on medical biases.

Near discharge

In the Parents' Voice Project, parents do not ask for more information about diagnoses! Rather, they want to know about what these diagnoses mean for their child and their family and what they should do about it practically, as well as what to anticipate. For example, a father of a baby born 23 weeks GA reported that being told about his child's diagnosis of BPD was not useful. Rather, after 5 months in the NICU, he wondered why he was only informed, the week of discharge, that home oxygen and tube feedings meant that his son should avoid daycare and crowds for at least a year and that there were significant risks of rehospitalisation and many appointments that required significant family reorganization.[35] Our results resemble recommendations parents make to one another on social media about what they should know. One example is the "Hand to Hold" website created by parents of premature babies. Such social media sites often include themes such as "Take care of yourself", "What you can do as a parent", "Prepare for home", etc.[36]

After discharge

Development is inherent to all children, taking place over months and years. This is an important reframing from the mindset of the minute-by-minute evolution of a baby's health in the NICU, or the assumption of the inevitability of a sad life based on a diagnosed neurodisability. As far as neuroplasticity and outcomes are concerned, there is a profound difference between a 70-year-old with a significant brain bleed compared to a baby born at 23 weeks GA. Yet we don't incorporate this notion enough in our discussions with parents. Babies and their parents grow and develop. In the neonatal follow-up clinic, we've noticed a lot of parents who have been painted a very bleak picture of what their child's future will look like. Hence, we suggest asking parents: *What have you been told about your child? Have you ever been told your child won't be able to do certain things?* This way, misconceptions and fears are laid out in the open, allowing for a personalized discussion of what is important to individual families. It also often allows us to remove well-intentioned but perhaps overly pessimistic prognostications that are based on the infant or child's earlier challenges in functioning that are now quite evidently wrong. As mentioned, development is not a binary model of normal or abnormal but rather a fluid process with tremendous variability. For premature babies, it's not about 'rehabilitation' or a return to baseline.[37] Rather, we are *nurturing development* for the child and family to *become* and to *belong*.

Conclusion

Based upon considerable evidence from parents of infants who have been in the NICU, it is clear that clinicians in the NICU need to seize opportunities to rethink and reframe how we communicate with families in the NICU. While remaining honest about the clinical status of infants, it is essential that we recognize the power of our words, and the considerable inclination to frame issues in terms of problems and diagnoses in neonatology, while prognosticating based on statistical probabilities. The F-words for child development, now widely used in other fields, provide tools and ideas that can be helpful to all of us.

Disclosures

The authors report no proprietary or commercial interest in any product mentioned or concept discussed in this article.

All authors have had a substantial contribution in:

a) conception and design, acquisition of data, or analysis and interpretation of data; AND
b) Drafting the article or revising it critically for important intellectual content; AND
c) Final approval of the version to be published; AND
d) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved

CRediT authorship contribution statement

Emilie Thivierge: Writing – review & editing, Writing – original draft, Visualization, Resources, Project administration, Methodology, Formal analysis, Conceptualization. **Thuy Mai Luu:** Writing – review & editing, Validation, Software, Project administration, Investigation, Formal analysis, Data curation, Conceptualization. **Peter Rosenbaum:** Writing – review & editing, Software, Resources, Project administration, Methodology, Investigation, Data curation, Conceptualization. **Paige Terrien Church:** Writing – review & editing, Supervision, Resources, Investigation, Formal analysis, Conceptualization. **Rebecca Pearce:** Writing – review & editing, Validation, Resources, Investigation, Formal analysis, Conceptualization. **Annie Janvier:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Source of funding

None.

Data availability

No data was used for the research described in the article.

References

1. Fisch RO, Gravem HJ, Engel RR. Neurological status of survivors of neonatal respiratory distress syndrome. A preliminary report from the collaborative study. *J Pediatr*. 1968;73(3):395–403.
2. Jaworski M, Janvier A, Bourque CJ, Mai-Vo TA, Pearce R, Synnes AR, et al. Parental perspective on important health outcomes of extremely preterm infants. *Arch Dis Child Fetal Neonatal Ed*. 2022;107(5):495–500.
3. Pearce R, Synnes A, Lam MM, Richter L, Bacchini F, Jones M, et al. PARENTS' VOICE NETWORK; partnering with parents to change measurement and reporting of preterm birth outcomes. *Pediatrics*. 2024;154(5). https://doi.org/10.1542/peds.2024-067093. e2024067093.
4. Syltern J, Ursin L, Solberg B, Stoen R. Postponed withholding: balanced decision-making at the margins of viability. *Am J Bioethic*. 2022;22(11):15–26.
5. Janvier A, Barrington KJ. Delayed withholding: disguising withdrawal of life sustaining interventions in extremely preterm infants. *Am J Bioeth*. 2022;22(11):43–46.
6. Rosenbaum P, Gorter JW. The 'F-words' in childhood disability: I swear this is how we should think!. *Child Care Health Dev*. 2012;38(4):457–463.
7. WHO. ICF classification of functioning, disability and health. 2020, Available from: https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health.
8. Canadian Premature Babies Foundation. The Parents Voice Project, 2020. Available from: https://www.cpbf-fbpc.org/cnfun.

9. Richter LL, Janvier A, Pearce R, Bourque CJ, Church PT, Luu TM, et al. Parental and medical classification of neurodevelopment in children born preterm. *Pediatrics*. 2025;155(2), e2024066148.
10. Synnes A, Chera A, Richter LL, Bone JN, Bourque CJ, Zhang-Jiang S, et al. Redefining neurodevelopmental impairment: perspectives of very preterm birth stakeholders. *Children (Basel)*. 2023;10(5):880.
11. Saigal S, Stoskopf BL, Feeny D, Furlong W, Burrows E, Rosenbaum PL, et al. Differences in preferences for neonatal outcomes among health care professionals, parents, and adolescents. *JAMA*. 1999;281(21):1991–1997. https://doi.org/10.1001/jama.281.21.1991.
12. Janvier A, Bourque CJ, Pearce R, Thivierge E, Duquette LA, Jaworski M, et al. Fragility and resilience: parental and family perspectives on the impacts of extreme prematurity. *Arch Dis Child Fetal Neonatal Ed*. 2023;108(6):575–580.
13. Milette AA, Richter LL, Bourque CJ, Janvier A, Pearce R, Church PT, et al. Parental perspectives of outcomes following very preterm birth: seeing the good, not just the bad. *Acta Paediatr*. 2023;112(3):398–408. Oslo, Norway : 1992.
14. Callahan KP, Katheria AC, Luu TM, Pearce R, Janvier A. Integrating parent voices into research at the extremes of prematurity: what are we doing and where should we go? *J Perinatol*. 2024. https://doi.org/10.1038/s41372-024-02165-1. Advance online publication.
15. Pearce R, Synnes A, Lam MM, Richter LL, Bacchini F, Jones M, et al. PARENTS' VOICE NETWORK. Partnering with parents to change measurement and reporting of preterm birth outcomes. *Pediatrics*. 2024;154(5), e2024067093.
16. Synnes A, Lam MM, Ricci MF, Church P, Simard MN, Zwicker JG, et al. How to measure patient and family important outcomes in extremely preterm infants: a scoping review. *Acta Paediatr*. 2024;113(6):1228–1235.
17. CanChild. F-words in childhood disability, 2020, Available from: https://canchild.ca/en/research-in-practice/f-words-in-childhood-disability.
18. Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med*. 1999;48(8):977–988.
19. Church PT, Dahan M, Rule A, Janvier A, Stewart JE, Maypole JS, et al. NICU language, everyday ethics, and giving better news: optimizing discussions about disability with families. *Children (Basel)*. 2024;11(2):242.
20. Chevallier M, Barrington KJ, Terrien Church P, Luu TM, Janvier A. Decision-making for extremely preterm infants with severe hemorrhages on head ultrasound: science, values, and communication skills. *Semin Fetal Neonatal Med*. 2023;28(3), 101444.
21. Haward MF, Lantos J, Janvier A, POST Group. Helping parents cope in the NICU. *Pediatrics*. 2020;145(6). https://doi.org/10.1542/peds.2019-3567. e20193567.
22. Feudtner C, Walter JK, Faerber JA, Hill DL, Carroll KW, Mollen CJ, et al. Good-parent beliefs of parents of seriously ill children. *JAMA Pediatr*. 2015;169(1):39–47. Jan.
23. Moore S, Cattapan A. Women's reproductive health and "failure speak". *CMAJ*. 2020;192(12). E325–E326.
24. Janvier A, Barrington KJ, Aziz K, Bancalari E, Batton D, Bellieni C, et al. CPS position statement for prenatal counselling before a premature birth: simple rules for complicated decisions. *Paediatr Child Health*. 2014;19(1):22–24. PMID: 24627651; PMCID: PMC3938216.
25. Cummings J, COMMITTEE ON FETUS AND NEWBORN. Antenatal counseling regarding resuscitation and intensive care before 25 weeks of gestation. *Pediatrics*. 2015;136(3):588–595.
26. Lemyre B, Moore G. Counselling and management for anticipated extremely preterm birth. *Paediatr Child Health*. 2017;22(6):334–341.
27. Griswold KJ, Fanaroff JM. An evidence-based overview of prenatal consultation with a focus on infants born at the limits of viability. *Pediatrics*. 2010;125(4):e931–e937.
28. Gaucher N, Payot A. Focusing on relationships, not information, respects autonomy during antenatal consultations. *Acta Paediatr*. 2017;106(1):14–20.
29. Haward MF, Payot A, Feudtner C, Janvier A. Personalized communication with parents of children born at < 25 weeks: moving from doctor-driven to parent-personalized discussions. *Semin Perinatol*. 2022;46(2), 151551.
30. Gaucher N, Nadeau S, Barbier A, Janvier A, Payot A. Personalized antenatal consultations for preterm labor: responding to mothers' Expectations. *J Pediatr*. 2016;178:130–134. e7.
31. Haward MF, Gaucher N, Payot A, Robson K, Janvier A. Personalized decision making: practical recommendations for antenatal counseling for fragile neonates. *Clin Perinatol*. 2017;44(2):429–445.
32. Janvier A, Barrington K, Farlow B. Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. *Semin Perinatol*. 2014;38(1):38–46.
33. Janvier A, Mercurio MR. Saving vs creating perceptions of intensive care at different ages and the potential for injustice. *J Perinatol*. 2013;33(5):333–335.
34. CanChild. F-words tools Available from: https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability/f-words-tools.
35. Thivierge E., Luu T.M., Bourque C.J., Pearce R., Jaworski M., Barrington K., et al. Function over diagnoses: parents of extremely preterm infants give recommendations to clinicians about their information needs. Arch Dis Child Fetal Neonatal Ed. 2025 May 27:fetalneonatal-2024-328249. doi: 10.1136/archdischild-2024-328249.
36. Handtohold.org. 23 things NICU parents need to know and remember 2021 Available from: https://handtohold.org/23-things-nicu-and-preemie-parents-need-to-remember, seized May 29th 2025.
37. Miller L, Imms C, Cross A, Pozniak K, O'Connor B, Martens R, et al. Impact of "early intervention" parent workshops on outcomes for caregivers of children with neurodisabilities: a mixed-methods study. *Disabil Rehabil*. 2023;45(23):3900–3911.