

Parental perspective on neonatal outcomes

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WHO defines a preterm birth as a birth that occurs before 37 weeks of gestation. Annually 15 million babies worldwide are born preterm and 1 million of these babies die.¹ Advances in medical technology have seen the boundaries of viability extended to 22 weeks of gestation but with these advances comes the need for more specialised medical care for this growing cohort of preterm infants who, as a result of their early birth, are at increased risk of acquiring morbidities and lifelong complications associated with preterm delivery.

'WHAT DOES A PRETERM BIRTH MEAN FOR THE AFFECTED FAMILY?'

Preterm birth is an unexpected event for the majority of affected families. It deprives them of the joy of pregnancy, denies them of their expected birth plan, shatters dreams and future expectations but most of all, it disempowers them of their anticipated parenting role which can have lifelong consequences for the family unit.

A family in the aftermath of a preterm birth finds themselves unwittingly immersed in a foreign world where complex medical equipment, technical jargon and high-pitched alarms are the norms. Parents relinquish control of the care of their most precious gift to strangers for what can, in some instances, be many months and are forced to re-evaluate every aspect of the life they had anticipated for their new baby.

Parents of preterm infants are no different from any other group of parents, wishing their child good health and to lead a normal, fulfilling life, reaching his/her full potential.

The reality is that many preterm infants continue to experience the consequences of their early birth throughout their lives^{2 3} and the sequelae for the extended family unit can be dramatic and life altering.

Those who have 'travelled the journey' are best placed to tell the story...

For far too long research has been carried out on patients instead of with patients. The value of the rich experiential resource that patients and families can bring to the research table needs to be fully acknowledged and embraced by researchers to ensure that future neonatal research is meaningful and effective for patients and their families.

An outcome is the measured effect that an illness or treatment has on an individual.⁴ Patient-centred outcome measures place the patients, their families and carers at the heart of decisions concerning the most valuable criteria in health assessment; they improve and refine care; they improve our fundamental understanding of living with the sequelae of a condition and have the potential to be of value alongside clinical outcomes. A 20-year review of outcomes literature⁵ reveals that many research outcomes measured, relate to transient life episodes, with the result that a large percentage of the research carried out bares little real-world lifelong application for patients and their families and highlights the need to develop agreed core outcome sets to measure and compare.

Preterm birth is not an isolated event; it is a journey that lasts a lifetime and which can have a profound and lasting effect on the child and their family. As a parent of a 12-year-old child born at 25+6 weeks, I have witnessed the deconstruction of my parenting role by a set of circumstances outside of my control, in addition to navigating the myriad of emerging developmental issues that can arise long after discharge from neonatal follow-up.

Researchers must embrace the process of lifelong consultation with patients, not only to acquire a complete and in-depth impression of the impact of preterm birth on the patient, but to ensure that short-term, long-term and overarching research outcomes and endpoints are prioritised towards issues that can seriously impede the patient's enjoyment of life and curtail his/her potential; issues that are determined by the patient, not for the patient?



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Outcomes are fluid in nature and depending on where the patient and family is on their journey, can change, reflecting their changing life circumstances, that is, my 12-year-old ex-preemie when recently asked what she would like to change in her life responded 'I wish that I could eat food and cycle a bicycle with my friends' (she suffers from dyspraxia, sensory processing disorder and oral aversion). At first glance, one might assume that the second issue is transient in nature but the potential life-long impact on my daughter's self-esteem, confidence, social skills and overall sense of well-being is far reaching.

Outcomes that matter most to patients and their families are most definitely of a global aetiology, focusing on independence, quality of life, social integration and the family unit yet they continue to remain secondary to research funders.

Neonatal outcomes are multisystem in nature and cannot be viewed in isolation if the true outcome is to be evaluated from the perspective of the patient or the family. The unique lived perspective they bring to the research discussion points to the need for a patient participatory approach and a multidisciplinary, defined and coordinated approach to future research to ensure that the direction of research addresses those areas of most concern to families:

- ▶ Will my child be capable of independent living?
- ▶ Will my child be able to participate in normal daily life?
- ▶ Will my child remember the pain and separation of those early days in the neonatal Unit?
- ▶ Will my child be socially adept?
- ▶ What are the long-term health sequelae?
- ▶ How will our family recover from the preterm delivery?

For families new to the world of preterm birth, outcomes are short term in nature, that is, survival, as the family attempts to process the trauma of the early delivery and cope with the unanticipated emotional and psychological burden. Over time, the realisation of the potential lifelong sequelae that can follow a preterm delivery becomes an ever-increasing concern² as families struggle

to comprehend the vast array of multisystem health issues that can arise. Families are oftentimes ill equipped to recognise emerging developmental issues, some of which are so subtle in nature that only a trained eye can recognise them, with the result that emerging issues go undetected during that important window when intervention might help alleviate the seriousness of the issue. Additionally, the general lack of public awareness among educators and community-based healthcare providers, of the multitude of sequelae associated with preterm birth creates another barrier to identifying needs and accessing supports.²

The benefit of focusing on meaningful outcomes provides the platform for determining the supports that patients and families will require to ensure that preterm infants can reach their full life potential and that the fallout for the family unit is minimised.

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