

Outcomes from the other side

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Abstract

Parents and individuals who were born preterm rarely contribute to research study design in order to ensure that outcomes are reported that are of relevance to them. In this article we explore aspects of the measures we use and the lived experiences of three individuals with experience of having a very preterm birth or being very preterm themselves. Their experiences tell us that follow up needs to be more than 2 years, that prematurity needs to be more widely acknowledged in education and that adult services need to consider the consequences of being born early. There are encouraging signs that these important issues are becoming recognised. Individuals designing outcome studies should ensure that these important voices are heard, and their perspectives captured in such studies.

Decisions about what are significant impairments and concepts of disability in the medical literature are primarily professional judgements. Whereas we take care to develop outcome measures that researchers and clinicians consider important, it is common for parents, and now individuals who were born very preterm to report back that to their mind these are not the major issues. One excellent example of this is the use of quality of life measures, where in practice most individuals who have what we might think of as serious impairment, that would compromise their quality of life, actually report similar results to those without. There is also a problem with unevenness in our categorisation of impairment – is a hearing loss requiring aids of a similar import to cerebral palsy, or to moderate cognitive impairment?

Having definitions of outcome categories is a useful and valuable shorthand for the prevalence of conditions that cause impairment; internationally this was originally set out by the World Health Organization (WHO) in their International Classification of Impairments, Disabilities, and Handicaps published in 1980, which defined criteria for each.¹ This was straightforward and could be assessed across a range of domains. In the UK, mindful of different systems for reporting outcomes, a working group was established to define what was important in defining health status at 2 years, so it could be used as an outcome for studies following preterm birth.^{2,3} This group took the view that conditions that were important would be with the child and their family for life; thus they defined a category of severe disability, describing those impairments that were considered to lead to severe life-long disability, and to a large extent they ignored the social construct of “handicap”. There were of course impairments that were not severe that were bundled together and termed “other disability”. In parallel, many other groups developed measures termed variously as neurodevelopmental handicaps, disabilities or impairment (often abbreviated to NDH or NDI). These definitions were more inclusive and represented outcomes that might be attributable to our care, although this itself has proven difficult to establish on a 1:1 basis. Most studies report this category now, sometimes divided in to severe and moderate. This led to a revision of the UK definition which itself was further divided into severe and moderate impairments that together comprised NDI.⁴ Even this did not capture all measurable impairment; these others were termed “mild”.

And this, in terms of current categorisation, is where we are today – except that there is concern about the use of many of these terms and categories to make decisions about limiting life support, that there is uncertainty about the extent to which we can predict lifelong outcome from infancy in order to make robust appropriate decisions or to guide advice to parents about prognosis, and, finally, that there is concern about how obstetric and neonatal teams perceive these outcomes (often without direct experience of them).⁵⁻⁸ Whatever the pros and cons of each definition, most individuals who graduate from neonatal units after very (<32 weeks of

gestation) or extremely (<28 weeks of gestation) preterm birth do not have neurodevelopmental impairment and today the frequency of severe impairments is reassuringly low.

Furthermore, we often extrapolate from the infant classifications into childhood and adult life without considering the impact that each category has on the individual. If we continue to use such classifications, even as shorthand to compare populations, we should consider how to include the lived experience of the individuals we are evaluating. It would seem that one classification cannot fit all ages.

The science and enquiry into the later effects of prematurity has also grown such that we now have a much greater understanding of the behavioural and learning profile of individuals born very preterm through to adult life, as addressed throughout this issue. Many of these profiles are not severe enough to necessarily lead to medical or educational intervention, or even to trigger any definition of 'impairment', but to the individual they are important where present and may compromise their progress.

Additionally, we are challenged by a concentration on neurological development while we are aware that prematurity has implications for all body systems, for example respiratory and cardiovascular conditions.⁹ The WHO had recognised deficiencies in their original classification and revised it to include other aspects of functioning and that were important in the International Classification of Functioning, Disability and Health (ICF).¹⁰ This has framework been used to describe outcomes for preterm populations¹¹ and is described in detail in this issue.¹²

Thus, there are ways of reporting outcomes that have some face validity with professionals but what are the experiences of people who experience extreme prematurity? The James Lind Alliance has developed joint professional-patient priorities in research, which have helped guide priorities in funding. One priority setting partnership has addressed preterm birth,¹³ a valuable way to decide what is important using a broad spectrum of individuals. In contrast, when drawing up guidance for resuscitation at extremely low gestational ages, few countries have included parents in the process.¹⁴ The inclusion of parents and participants in designing research studies brings immediately a more appropriate set of outcomes and should be considered in each study. Priority setting in outcome evaluations is urgently needed to ensure that our long-term studies are relevant to our graduates and their parents.

In this paper, the reflections of three individuals are presented to put perspective on the lived experience of outcomes described through to adult life. They are necessarily personal views but help to place the articles in this issue in context.

Sarra Hoy is the mother of a child born at 29 weeks of gestation and just making his way in school at the moment. Alexandra Peacock was born at 24 weeks in 1994 and is now teaching geography in secondary school. Juliëtte Kamphuis was born at 28 weeks in 1980 and has lived with BPD. They will tell their own stories.

Sarra's story

I am very much aware other families will have witnessed the darkest depths of a neonatal experience and their lives will have been vastly altered as a result of prematurity. When I write this, it is not because I think my situation has been novel or unique but on the contrary, because I now understand my experience, in clinical terms, to have been a rather standard run of the mill one, with an excellent outcome. For me personally, it has been one the greatest challenges of my life.

So, what is an outcome for a parent of a premature baby? In the first instance, it quite simply takes the usual hopes, dreams and aspirations of pregnancy, motherhood and for your unborn child and summarily dismisses them.

Instead of pondering what cot to buy, I quite suddenly found myself crouched over an incubator looking at an impossibly frail baby. I was overwhelmed and absolutely convinced all was lost. Doctors did their best to reassure me, with carefully phrased advice which gave no guarantees of outcomes. I however, took no comfort from the statistics that weighed heavily in our baby's favour. I was unable to envisage there could be anything other than a negative outcome and that belief stayed with me for many, many months. The once alien and clinical surroundings in a neonatal unit quickly become familiar but one never feels comfortable or contented. There is not one moment when the panic and anxiety in your chest quietens or the screaming stops.

The well-rehearsed and repeated words of wisdom are that a neonatal journey is like a rollercoaster; full of ups and downs. That implies an element of fun. No, in reality there is no thrill to be taken from unexpected changes of direction, moments of horror followed by (possibly) a moment of calm, during which you dare take a breath. Each step forward is one step closer to home, but also one step higher to fall.

That fear of what lies ahead continues for long periods, even after discharge. Overwhelming fears can limit one's ability to 'parent' whilst on the unit. I often wonder how these fears affected my ability to bond, to be a mother and whether I have avoided projecting my concerns onto my child. I believe extra emotional support for parents at this stage is essential. We mustn't underestimate the level of shock and trauma a person has experienced immediately prior to finding themselves on a neonatal unit. What may be ordinary to the staff who see it every day, remains extraordinary for the family experiencing it.

After two months, we left the neonatal unit with our 4lb baby. We got home and placed him in the bedside cot. For the first time in his life, there was silence. No machines. No beeps. No white noise in the background. No gentle swish of nurses going by. No familiar clunk of the double doors realigning in the corridor. It should have been a peaceful moment to breathe a sigh of relief. But the silence revealed short, rasping efforts of breath that filled the room and then stopped. Silence. Then it would start again. Was he struggling to breathe? How could I not know? We had been parents for two months but felt wholly inadequate and lost. I was trying to balance the fear for my baby's health against being labelled as a fussy mother, who "could not cope".

Here is another outcome of a neonatal stay. It skews your view of what is 'normal'. I'd seen my baby struggle to breathe many times before, albeit within the safety of a hospital environment. We had learned resilience through adversity, where our darkest fears were a realistic prospect. It felt normal to watch your baby and be constantly weighing up the chance of him dying that day.

We muddled through somehow. The health visitor arrived amidst assurances that she specialised in premature babies although she'd "never seen one this small" and struggled to correct his age on the charts in the little red book. Experiences like this serve to confirm what we had realised from day one - that as a preterm parent, no rules apply to you. You are the exception to every rule. Just like the antenatal classes you didn't attend, like the newborn clothes that don't fit, like the baby showers you didn't get, like the breastfeeding that was actually on an electronic pump, via a tube, like the car seat that was far too big, like the cry-it-out method which would never have been appropriate for your baby. The list goes on. It is isolating and lonely.

This is why the follow up appointments with a neonatologist are so important. Not just for the child but for the family too. It is a link to the familiar; the qualified professional to give a reassuring nod and provide assistance when required. Our hopes rested with these visits. We would lurch from one appointment to another, to be reassured for a short time, only until the next when more concerns had accumulated.

Life continued like this after discharge. We were full of hope and wonder about what we had experienced but dogged by fear of what the future held. We celebrated what our baby had achieved, yet with hindsight I realise we were still in the thick of it. Several emergency hospital admissions a year was 'normal' for us. Through trial and error, I continued with a varying degree of success to balance the angst of making an undue fuss with not getting help quickly enough.

Everything was heading in the right direction; crawling, gait, physio and speech and so graduation from the "programme" was inevitable. While those children who have more complex needs continue to be assessed under specialist monitoring, the children who are deemed fit and well are discharged at two years old from paediatric care. It is a wonderful milestone, a positive outcome

and a moment you have been working toward. However, my expectation that our prematurity journey would conclude on discharge was misplaced and of course naive. In reality, it is only the beginning of a new chapter of preterm birth. As the following years stretched out, it became apparent that things are not quite as simple as the “two year catching up period” we had been told about.

The current system of discharge at 2 suggests a child is either ok or they’re not. There is no follow up or support from that date on, for children who have been discharged. For a parent of a preterm child who is no longer in the system, it is a worrying time. With no more clinical guidance, parents are left to navigate the next few formative years themselves, until the child enters the school system, where new and ongoing issues may be identified.

One of the consequences of being born preterm is that children are more likely to have special educational needs. How would a parent recognise the development of a cognitive or behavioural difficulty? The weight of concern about the long-term effects on health and development are profound. For parents, these worries do not disappear upon discharge at aged two.

We are told every child is different and will do things at their own pace but how should parents be guided through this phase? Preterm parents are accustomed to using a “corrected age” method, but without clinical guidance, it is hard to understand what is to be expected when applying it to social and emotional development. It is hard to know where to look for advice. Friends, with no understanding of prematurity are all experts and say “they all catch up by 2”; family desperately want to reassure you say “he’s come so far”. Even as the parent, it is hard to adequately explain the significance of what you see, to warrant making a doctor’s appointment.

Parents find themselves in limbo again where normal guidelines don’t seem to apply. There is a disconnect between the time of discharge until starting school. Parents are faced with not wanting to make a fuss, but in need of reassurance and advice.

Having recently come through these intervening years, from aged 2 until starting school at 5, I have learned there are many subtle idiosyncrasies and challenges where support would, in some ways, be better placed at that stage rather than during the first two years.

Having spoken to several families who have trodden a similar path, I have been reassured to hear them mention their experiences and concerns. There is a long list of subtle differences that make your preterm child stand apart from the rest. Eating, sleeping, toileting, playing, communication, group participation, social behaviour, inattentiveness, excessive attentiveness, sensory skills, too loud, too quiet, coordination, ability to learn new skills, an unusually compliant, well behaved child, a child who cannot sit still, to mention but a few. The continued support until the age of two is an excellent way to ensure no child with physical problems falls through the gaps. But evidence of

emotional and social development is only seen after this, when it can become apparent that behaviourally there is a much greater delay than you appreciated.

It is staggering to think of the number of families experiencing this, with no assistance or guidance available to them. For three years until they start school, parents are left to guess at how best to support their children during a crucial stage of development. If a stay in NICU can affect me as the mother for so long, it stands to reason it would have long lasting effects on my child too, and certainly beyond the age of two. Additional support for parents is essential beyond two and for those families who may appear to have had a straightforward experience. I have learned that first impressions can be deceiving; and it is only by digging down a little deeper that the real situation become clear.

Starting school is a huge milestone for many such families, including ours. To see your child starting mainstream school, with his peers, is a moment you never dared to dream back in those dark neonatal days. Yet we didn't mention prematurity to our child's teachers. Having passed that critical two-year milestone, it felt foolish to mention it, for fear of being the fussy mother again. No standard rules had applied to us so far, so why should this be any different?

Alexandra's Story

I was born in January 1994 at 24 weeks, weighing 1lbs 3oz and was given a 30% chance of survival. I was looked after there for the first 10 weeks then transferred closer to home for a further six weeks until I went home weighing 4lbs 4oz. As a pre-term baby there are many risks of developing disabilities and special needs which my mother was told about when I was born. They told her that I could have a brain bleed, problems with heart valves, cerebral palsy, delays in learning and social skills as well as blindness due to high oxygen dependency. Despite this, I do not have any disabilities or special needs, defying what many of the doctors believed back in the nineties. This is also evidenced in many of the tests I undertook as a toddler, where I was shown to be reaching and exceeding all the milestones close to the point where children born full-term would reach them.

Throughout my childhood and into adolescence I was often the smallest and most petite of all my classmates; at the beginning of secondary school, aged eleven, I was still wearing aged four to five clothes. As well as this, my BMI for a long time was classed as underweight. Now at the age of 26, I am classed around average height for a British woman at five feet, four inches, have a BMI of 19.4, though still consistently slim. The only medical issue I have is with small ear canals and eustachian tubes which mean I cannot hear 100% and had to have grommets inserted twice. Though this has not affected me much as I only can't hear quieter high-pitched sounds.

During my childhood it was never common knowledge in school that I was premature, unless I was to tell me people as my 'fun fact about me'. This meant that generally I was treated no different to other students in the class, though in secondary school some students would comment on how small I was. This did have an emotional effect on me as I had to keep telling people I didn't eat a lot which became frustrating, but not to the point where it had a significant effect on my mental health. Interestingly, as a young adult I hate it when people say to me that they think I have lost weight.

I have some difficulties with maths whereby it takes me longer to complete maths problems and struggle to complete them in my head quickly. If I cannot clearly see the relationship between the sets of numbers that I am using, I struggle, and it can take me a long time. When teaching I can often identify students who I think were born premature as I can see similarities between myself and them at the same age.

When I reflect on my childhood and school life having been a premature baby, I would like to have spoken more about my prematurity so teachers and other children could have understood a little more. Conversely, I would hope that this would not have meant I was treated any differently, which for me now as a teacher, is the most important part. Treat every student the same regardless of their start in life.

I would like to let people know that despite being extremely pre-term, I have managed to achieve the same things as most full-term babies, and in some respects more. I have been to university twice, gaining a BSc Geography and a PGCE, lived and studied abroad for a year in Montana, USA, travelled to countries like New Zealand, learnt to drive, achieved 9 GCSES A-B, 2 A-Levels in Geography and Biology, an AS-Level in Chemistry.

Juliëtte's story

In 1980 I was born by spontaneous labour after 28.5 weeks of gestation (weighing 1250 grams, 37.5cm) as the second child of my parents and having a 10-month older brother. Directly after my birth I was resuscitated due to respiratory arrest. The regional hospital I was born had no special expertise and the facilities to care for very preterm newborn infants. I was transferred to the neonatal intensive care unit of an academic hospital 130 km away. Of course, a terrible and emotional experience for both of my parents. My mother was left alone at the regional hospital and had only briefly seen her newborn baby, while my father, as strongly advised by the paediatrician, accompanied me during the transport as there was a high risk that I would not survive the journey. Like many very preterm infants, I developed severe respiratory distress syndrome, was intubated and given mechanical ventilation. My hospital stay was further complicated by suffering from a variety of medical conditions and undergoing medical procedures, such as multiple lung collapses,

infections, surgery for patent ductus arteriosus, exchange transfusion for severe jaundice, and transfusions for anaemia and hypo-albuminemia. The duration of high oxygen concentrations, mechanical ventilation and prolonged oxygen dependency caused lung-injury in the form of severe bronchopulmonary dysplasia, which was treated with corticosteroids. Given the circumstances at that time it was estimated that my survival rate was very low and adverse outcome was predicted at survival, such as having multiple disabilities.

After 4 months in hospital I was discharged home for the very first time, however I was re-hospitalised several times mostly due to respiratory infections or for feeding problems. Despite being born very preterm, I developed well, and I reached psychomotor milestones alongside my full-term peers; there was no follow up after 5 years of age, although my lungs remained my weakest point.

Growing up I experienced some minor consequences of preterm birth, being more sensitive to loud noises which made me feel uncomfortable as a toddler (I still prefer a quieter surrounding) and perhaps at elementary school some difficulties with fine motor skills (I didn't have very neat handwriting at the beginning but this improved with time) and with maths (I received supplemental homework). The latter definitely improved when I was allowed to use a calculator (mid adolescence) and it turned out that I was good at the logic behind maths, only not fast enough to do calculations in my head; I went on to obtain a BSc in biochemistry/biotechnology. I did not experience any reading difficulties and as a 1st grader I started reading books meant for the class above me. At elementary school I was, when it comes to scores, an average student and never repeated a class, although I did suffer from severe performance anxiety that probably affected my scores.

As a young child I was a very social and people-oriented person, I had just the bad luck of being bullied a lot starting from age 5 until 14, perhaps due to being smaller in size than my peers and not standing up for myself, therefore I was an 'easy target'. And of course, this doesn't help with feeling good in your own skin and interacting with your peers. At middle school I remember sometimes being teased for getting good scores. I was already trying to fit in so hard that I attempted lowering my scores on purpose; I was successful because I almost had to repeat a class. One of the best decisions that my parents made was to move to another location (for which I am very grateful) and I started at another school at the age of 14. My parents, especially my mother, prepared me for this occasion very well and how to stand up for myself to prevent being bullied again. At the new school I had no trouble in making friends, I was socially accepted and even my scores improved again to very good.

Physically I was very active and my parents encouraged me to do sports, starting from age 6, although I experienced some difficulties due to respiratory problems, feeling breathlessness after

swimming in a chlorine pool or performing intermittent action sports (such as handball and tennis), which I did throughout my whole childhood till adolescence. Symptoms of shortness of breath were also induced by weather conditions, such as fog, or for example smoke. Even though, I did not complain much about it, accepted it as my “normal”, and I didn’t see a physician or use medication until I became a young adult.

My respiratory symptoms became more severe at the age of 25, being breathlessness continuously for several months and I was referred. One of the first questions I asked was whether my symptoms related to being born preterm and having had BPD? The lung physician admitted she had never seen a very preterm young adult before, diagnosed asthma, and treated me with inhaled corticosteroids and bronchodilators, although my symptoms did not improve. I thought that these were triggered due to my working environment, therefore I sought support from an occupational physician, although my complaints were not taken very seriously from the start. The occupational physician wanted me to stop taking my prescribed medication for several weeks to determine the cause of my symptoms, refused to contact my lung physician to discuss this strategy, and even said “since you have experienced shortness of breath for such a long time and are used to it, it does not really matter if it is prolonged for several weeks after quitting your medication” – well it did matter to me! It felt awful, feeling out of breath and not completely being able to do the things I loved in life. Performing sports, participating in social activities with friends and family, and my working life, all were negatively influenced. Meanwhile I experienced 4 years of breathing difficulties including having to frequently take sick leave from work. The indoor air quality at work was investigated and demonstrated to be ‘poor’. At the age of 29, the occupational physician wanted to start the process for declaring me as having occupational disability, but I refused. I reasoned that my respiratory complaints would improve after switching to another employer, as they did and reduced my symptoms by half. I had to adapt my lifestyle as much as possible avoiding triggers and kept myself in good physical condition. Even though, I still kept experiencing prolonged induced respiratory complaints, for example a common cold could lead to shortness of breath for several months. I requested a second opinion. The last lung physician took her time, ran new tests, looked into my medical history, listened well to my story and thoughts, and searched for medical literature on the outcome of preterm born adults with BPD. She concluded that my condition may appear like asthma, with bronchial hyperreactivity, although there was no inflammation and therefore no need to use inhaled corticosteroids. The diagnosis is not asthma, but a chronic lung disease due to being born preterm. I consider my severe myopia and food intolerances minor issues, since they are solvable, by wearing glasses/lenses and adapting food habits.

Nowadays, in the Netherlands preterm infants are followed-up by a paediatrician till the age of 8. Perhaps, we should question whether this should be longer, since in my case I developed more severe respiratory symptoms as a young adult.

I experienced the lack of knowledge about premature born adults with BPD in health care. Perhaps it would have made a difference, if I was followed-up longer by a physician from childhood into adulthood, especially for my lung health. It may would have helped in gaining more knowledge about my lung development in time, getting the right diagnosis sooner and earlier receiving the right care. It may have reduced unnecessary health care costs and all the side effects I experienced from taking unnecessary medication and perhaps it would have altered the choices I made in my life. I welcome that, at the end of 2019, the Erasmus University Medical Center started its first outpatient clinic for preterm born adults with BPD.

Considering my predicted outcome as a preterm infant it could have been tremendously different and I have been very lucky developing so well against all odds. Influences like the environment I grew up in, having a loving family with supporting parents must have helped, even though there was no supporting system and resources for my parents at that time. Not every preterm grows up in such a supporting environment and is fortunate to develop well, as I did.

Research has shown that most preterm born infants adjust remarkably well during their transition into adulthood. Although short- and long-term adverse events from preterm birth labelled as “minor” or “major” are often made from the researcher’s perspective, individuals should be able to judge their own severity. Thus if we want to fully understand the impact of preterm birth and what is needed in healthcare for preterm born infants, we should include the perspective of individuals born preterm (e.g. who are now adolescents or (young) adults) and parents more often in the process of research design and development of guidelines.

Conclusions

Doctors do spend a lot of time talking to parents about what are effectively relatively low risk albeit important problems for individuals that are born very preterm, and often the aspects of prematurity that have the greatest impact for individuals are not those we have really thought about. Most extremely preterm children do not have what we define as neurodevelopmental impairment. Many do, but not all, and the system is only geared to identifying these difficulties in young children.

The challenge of parenting a developing preterm pre-schooler as described by Sarra is rarely addressed, but it is at this precise age that executive processes that will underpin their learning – such as attention or inhibition – are critically differentiating. Follow up services are slowly

recognising the support needed before going to school and particularly for the extremely preterm, who are likely to have the greatest cognitive challenges. Understanding the effect of prematurity on school age development is important and teachers need to understand this, as described by Alexandra. Belatedly there are now specific learning packages for teachers who are supporting preterm children, to try to address this and that have proved extremely popular with teachers and parents alike¹⁵⁻¹⁷, now reaching over 11,000 users (Johnson S personal communication May 2020). Perhaps we should be encouraging parents to identify very preterm children to teachers, if nothing else to encourage them to learn about their potential problems. Juliëtte makes an eloquent case for ensuring that the effects of prematurity are understood by adult physicians, equally important; a birth history should be part of every new consultation and adult physicians are now beginning to set up focused clinics to concentrate their expertise.

As care in the perinatal and neonatal period improves, long-term outcomes are not improving as fast as survival, if at all as yet.¹⁸ These outcomes are consequential. It is critical that we develop appropriate neonatal, preschool and school based interventions to optimise the long-term potential for this important group and repay our investment in their early care.

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