The Family’s Role in Long-Term Outcomes After NICU Care

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Dr. Saroj Saigal obtained her medical degree and pediatric training in India. She did her neonatal fellowship at the Universities of Edinburgh, McGill, and McMaster, and joined the pediatric faculty at McMaster University, Division of Neonatal-Perinatal Medicine, as a neonatologist in 1973, and was the Director of the Neonatal Follow-up Program for high-risk infants (1973 -2013). Dr. Saigal has been Professor of Pediatrics since 1984, and is currently Professor Emerita at McMaster, and continues to run the follow-up clinic as well as her ongoing research. Dr. Saigal and her colleagues have followed one of the few population-based cohorts of extremely low birthweight infants longitudinally from infancy to adulthood, and she has published extensively on the same. She and her collaborators have now completed a further follow-up study on their mental health and cardiovascular and metabolic sequelae at a mean age of 32 years. Dr. Saigal has been involved as a collaborator in several perinatal clinical trials. She is also the co-founder of ‘Adults born Preterm International Collaboration’ (APIC), a network that facilitates collaboration and sharing of data with investigators interested in the long-term health and disease of this vulnerable population. Dr. Saigal has held several leadership positions in the Canadian Pediatric Society. She is the recipient of many awards, among them: the Senior Scientist Career Award from the Canadian Institutes of Health Research (2000-2005); the Canadian Pediatric Society’s prestigious Distinguished Neonatologist Award, the Society’s highest award for neonatology (2005); the Landmark Award from the Section of Perinatal Pediatrics of the American Academy of Pediatrics (2009); and the Douglas K. Richardson Award from the American Society for Pediatric Research (2011), for her lifetime achievement as a clinical investigator who has made substantive contributions to Perinatal and Pediatric Healthcare Research. Dr. Saigal is internationally recognized for her studies that focus on the quality of life and consequences of having been born extremely prematurely. She has recently published a book for a general audience, “Preemie Voices,” a collection of letters that provides a description of life from the perspectives of adults who were born very prematurely (Friesen Press, November 2014).

Saturday, October 3th Breakout Session
The Family’s Role in Long-Term Outcomes After NICU Care

Objective:
Discuss the “life-time for recovery” and the critical role of families in enhancing their infants’ outcomes both in the NICU and in the community.
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Follow-up: Who, why, when and how

- We need to work together as neonatologists, parents, allied health professionals, and community workers to optimize the care and outcomes of the child and family.
- What can we learn from each other?

In this interactive session:
we request your input, especially that of the PARENTS

Importance of Early human development

- Infancy is a period of great opportunity to grow and learn, and also great risk with deprivation.
- The first 3 years comprise a long period of immaturity and dependence, and also of dramatic physical and mental developments.
- These developments are building blocks for adult cognitive and emotional functioning.
- Prematurity is a significant added risk.

Human Brain Development - Synapse Formation

ETHICAL VIEWPOINT

- ‘Neonatal intensive’ care should not cease at discharge from the NICU.
- FUP is mandatory to provide clinical and support services to optimize the outcome of both the child and the family.
- The best interest of the parents and child are paramount.

DISCLOSURE

I have no financial relationships to disclose, or conflicts of interest to resolve
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Talking Points
- Do parents feel that follow-up of high-risk infants is important and helpful to them? Does it create ‘performance’ anxiety?
- Is it taxing and costly for the families to keep frequent appointments?

Parents’ perspective
- FUP should include physical, cognition, behavioural and emotional health, social skills, education, and quality of life.
- FUP services should provide advocacy for families for treatment services for disabilities, developmental lags, early intervention services, and assist in funding sources.
- Provide anticipatory guidance to parents for future life events at various stages in a child’s life e.g. school readiness, screening for developmental disorders and behavioral problems.
- Monitor and support parental mental health.

Parents as Partners
- Parents can offer valuable information about their child’s development.
- We can capitalize on the observations of parents to provide an effective method for early detection of developmental and behavioral problems.
- We believe that when pediatricians incorporate parental data, it is likely that clinical impressions will increase in accuracy.

Talking Points
- Follow-up is very expensive – are the resources better spent elsewhere? If so where? Home care / intervention?
- What would parents like for their ‘ideal’ follow-up visit?

Parents’ Role at School-age
- Follow your child’s progress: meet with classroom teacher at regular intervals.
- Seek early assessment for behavioral and learning problems by qualified personnel, and be aware that there are long waiting lists.
- Become a ‘partner’ with the teacher in the shared common goal for your child’s success.
- Will my child get adequate support from school services?
- What can I do to help my child at school?
Parents as Advocates

- Parents have the best interest of their child and are most knowledgeable about their strengths and difficulties.
- Parental concerns are not always completely respected by health professionals and educational agencies.
- Parents should be proactive and ensure that the concerns about their child are addressed without much delay.

Delayed school entry for preemies?

Jaekel, Dev Med Child Neurol, 2015;18

- A Bavarian study showed that missing one year of learning because of delayed start, was associated with poorer performance on standardized tests at age 8.
- Other reports show that even ‘summer born’ children who are young for their year, also typically do worse at GCSEs and are less likely to get into university.
- In an ideal world, parents should have the right to opt for what they think would work best for their child, rather than rigid regulations. Some school boards.......

Early Childhood Education

CANADIAN STUDY
Fraser Mustard: Early Years Study

'The main recommendation was that children as young as 2-years-old should start receiving formal education, due to the "avalanche of evidence". This education should be community-based, and voluntary, leaving parents to decide how much time they want their children in these programs.'

To Inform or Not to Inform the Teacher....
Marlow N, Johnson S, Arch Dis Child 2007;92:945

- Parents are sometimes reticent to inform the teacher about their child’s prematurity, because of concerns of low expectations, differential treatment, and ‘labeling’.
- Because of the high prevalence of LD among very premature infants, even those without disabilities, the teacher should be aware, so as to provide anticipatory guidance, and early recognition and remediation of potential problems.
- However, many teachers and school boards may be unaware of LD problems in preemies and should be provided with the relevant information.

Talking Points

- What would neonatologists like to know / do / learn about FUP?
- What is the best minimum and maximum duration of FUP?

Neonatologists’ perspectives

- To obtain outcome data for audit for future directions for treatment and to influence decisions for interventions.
- To study the consequences of treatment through RCT or cohort studies, and to generate hypotheses for future research or interventions.
- Although service and research may proceed together, parents should be clear on what they consented for the research component, and receive info on results.
- Parental cooperation is invaluable for such questions.
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Duration of follow-up of premature infants
- Short-term: first year of life
- Long term:
  - Preschool
  - School age
  - Adolescence
  - Young adulthood
- Middle-age?
- Old-age?

Assessment measures: evolution
- Initially the focus was narrow, and mainly on the neurodevelopmental status
- Later, broader considerations of overall morbidity, accomplishments, self-perception, quality of life and future aspirations considered.
- Now, the focus is on the ‘aging’ premature infant: CVS and metabolic sequelae, psychiatric disorders, visual problems, and even reproduction.

Where do our interests and responsibilities end? Cradle to death?

Childhood vs adult outcomes
- Young children and adolescents were subjected to multiple ‘laboratory’ tests assessing disparate cognitive, motor, and other skills. The lower scores paint a pessimistic picture and overestimate the level of future ‘problems’
- At adulthood, we took a broader approach to ‘real life functioning’ without the tyranny of IQ and other tests!

Saigal & Rosenbaum, Sem Fetal and Neo Med, 2007

Longer term perspectives
- Contrary to our expectations, at young adulthood, the premature group showed remarkable achievements. This attests to the extraordinary ‘resilience’ of the survivors.
- The future of premature children has to be looked at from a lifespan perspective as ‘recovery’ may not be evident until adulthood
- Longer-term follow-up of newer cohorts is essential.

Luciana, Dev Psychopathol;2003;15:1017-47

Plasticity of the developing brain
- Human brain development is relatively slow permitting adaptation and plasticity to “override” the adverse neonatal events
- Plasticity critically depends on the environment in which the child is raised
- Transactional Model proposed by Sameroff & Chandler in the 1960s: dynamic interplay between the child’s biology and the child’s environment.

RS – in her own words
“Today, I am 31, employed full-time in a job that allows my strengths to shine. Despite my short stature and certain aspects of my autism, I am still proud to be me… I wear my differences like a badge of courage….. I won the battle and the war against prematurity, and if these mild deficits are the price to pay for being alive, then I can live with them!”

BW 600g at 26 weeks gestation, 1981
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Focus on Ability (Ableism)
not Disability

Everyday Griefs and Joys

“When Vincent was 4 days old, we were told that he had had a grade-4-IVH….Gary seemed to understand that this event would mean a life-long disability…. but all I wanted to know was, would he live? Nothing else mattered to me.”
Anne Casey, Mother, Founder of Parents of Premature Babies International Network, Australia. The Lancet Supplement 2001

A Complete Human Being

“Nobody plans for or expects to have a disabled baby; you receive no training, but…. we have to learn to live with the situation…. At times I’ve felt devastated, exhilarated and challenged. Never dull, never boring, however, never to be asked for, but once there, not to be missed.”
Tony McDonald, Mother of a 27 year-old with Downs Syndrome
The Lancet Supplement 2001

Functioning & Disablement: Model of the ICIDH – 2001 (adapted)

Health condition (Disorder/disease)

Body structure and function (Fitness)

Activity (Function)

Participation (Friendship)

Contextual

a) Environmental (Family factors)
b) Personal (Fun)

HYPOTHETICAL HEALTH STATES

“Jamie”

Less severe disability. Totally independent in all areas of life.

“Chris”

Some daily supports needed.

“Pat”

Severe disabilities. Totally dependent on caregivers. Sometimes unhappy, in pain.

“Sandy”

Serious disability. Totally dependent on caregivers. Sometimes unhappy, in pain.

Talking points

• Will my child with a disability say “Why did you save me?”
• Will my child be happy or suffer from discrimination?
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It’s worth remembering that people with disabilities can go on to do amazing things, and that perhaps a better term for disabilities would be **different abilities**, because we are all human beings and are unique in our own ways.”

Ron Federchuck
1978; 760g; 25 wks
(unilateral blindness)

“I’m not sure I would say that I am the person I am today because of my disability, but rather in spite of it. I may not be climbing mountains or winning Olympic medals, but I have not let cerebral palsy stop me from leading the full and independent life that I have always wanted.”

April Laramey
1978; 980g; 27wks

**ABILITY: Technology used by a blind and deaf person**

“How do I manage?”

- I use a computer to read and write, using Zoomtext, a Magnifier/ScreenReader and a Large Print Keyboard.
- To read books and class material I use a camera called the Flick. To read regular print such as newspapers I use a Video Magnifier.
- For leisure reading I read DAISY books that are audio books published in the CNIB’s Library.
- I am also learning Braille as I will eventually be fully blind.
- To get around I use a white cane, awaiting my Guide Dog.
- For everything else, I use intervenors – they are my eyes and ears in class, church, leisure activities, shopping etc.

Michelle Smudes (near blind and deaf)

**Disability paradox**


- When the personal perceptions are elicited from patients, they are often discordant with the ‘objective’ health status as rated by health professionals, or as viewed by society – “Disability Paradox”.
- The high QL reported by some respondents could be due to ‘secondary gain’ which occurs when individuals with impairments adapt to their new condition, **reinterpret** their lives and **reconstitute** personal meaning in their social roles.

**Siblings – Talking Points**

Parents go through a lot of guilt during the NICU stay about their other children.

What impact does the birth of a preemie have on the siblings?