Preschool outcomes in infants born less than or equal to 25 weeks gestational age: An integrative review of the literature

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My advisors:

- Dr. Wendy Hall, PhD
- Dr. Manon Ranger, PhD

The families at BCWH NFU Clinic

OUTLINE

- What was the purpose of my study?
- Why was this important to me and parents?
- How did I go about the study?
- What did I find?
- What can we do with that information?

What was The Purpose of the Study?

1. To synthesize the available evidence about the outcomes of EPT infants at preschool age.

2. To integrate the literature with outcomes of EPT infants from BC Women's Hospital NFU clinic.

3. To critically analyze the literature for it's usefulness for nurses working with families.

Why is this important?

- The uncertain outcomes for preterm infants is a significant stressor for parents (Green et al., 2015).
- HCW have limited knowledge regarding survival, disability and long-term outcomes (Blanco et al., 2005; Janvier et al., 2007).
- Nurses belief that outcomes are random emphasizes the need for HCWs to be aware of outcome data.
- Hope is one of the highest needs for parents with acutely ill children and lapses in communication risk damaging hope (Kirschbaum, 1990).

Whittemore and Knafl's (2005) integrative review methodology

Used a distinct type of literature review methodology that integrated multiple:

Definitions of outcomes

1. neurodevelopmental outcomes
2. Functional outcomes
3. parent/teacher reports of outcomes.

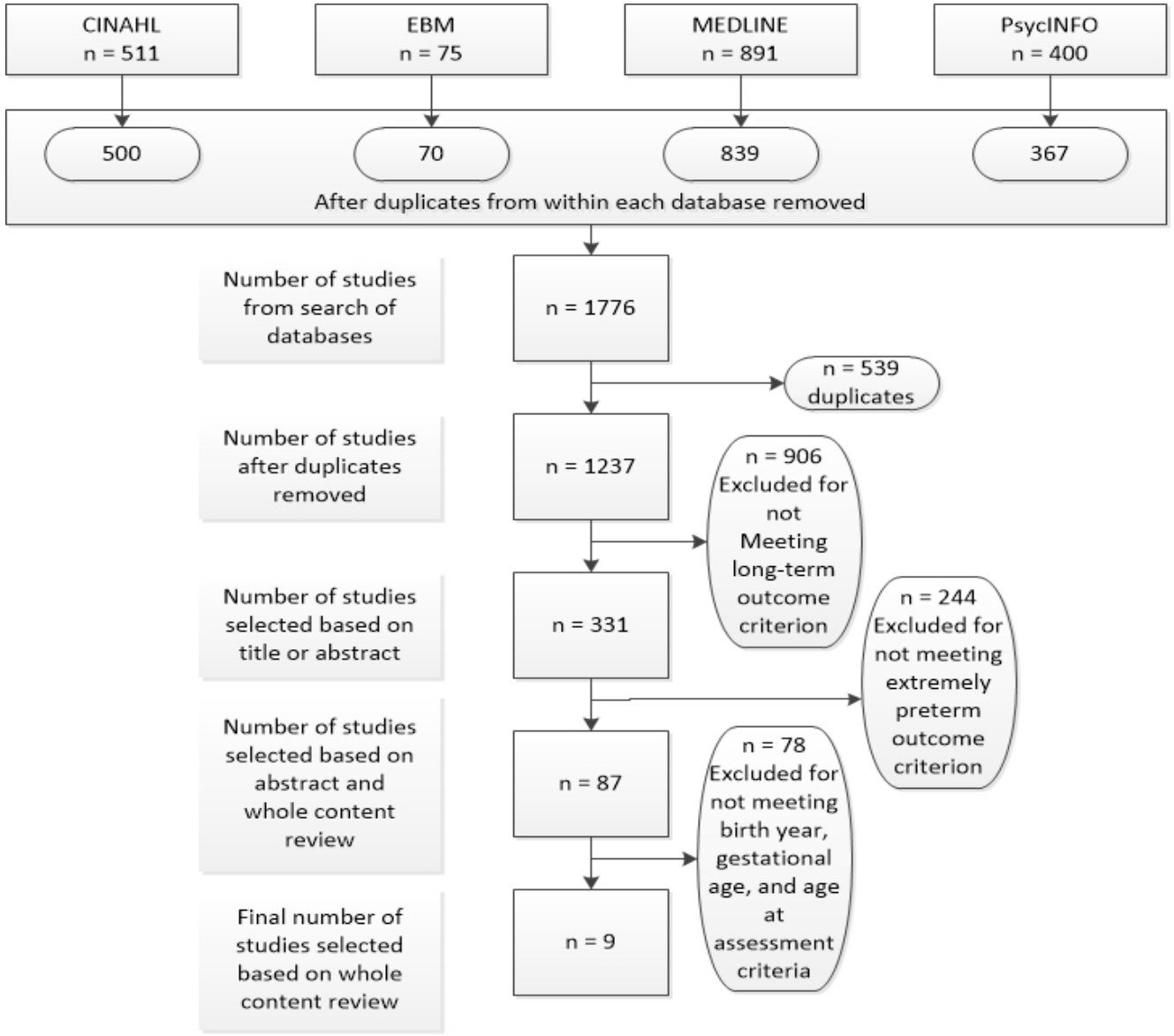
Types of evidence

1. quantitative and qualitative data
2. studies on parents perspectives
3. non-experimental studies

Multi-Step Process:

1. Ascertain overall quality of the evidence
2. Compare study elements
3. Extracted major study findings
4. Integrated the findings from BCWH
5. I created patterns and documented 4 themes

ARTICLE SELECTION PROTOCOL



Outcome Domains assessed in each publication

Author(s), Year and Country	Survival with or without impairment	Impairment Rates	Developmental Quotients	Cognitive Function	Motor Function	Growth	Health	Behaviour	Sensory-Communication Function
Baron et al. (2011) United States				x				x	
De Groote et al. (2007) Belgium		x		x	x	x	x		
Ishii et al. (2013) Japan	x	x.		x.	x.				x
Kerstjens et al. (2012) The Netherlands			x						
Kytnarova et al. (2011) Czech Republic		x			.	x			
Leversen et al. (2011) Norway		x		x	x				x
Moore et al. (2012) England	x	x	x		x				
Ochiai et al. (2014) Japan			x						
Zlatohlavkova et al. (2010) Czech Republic	x.								
BCWH Neonatal Follow-Up Program 2014-2015 Biennial Report (2017), Canada		x							

What did I find in the Integration of the findings?

<u>Overall Delays</u>

1. EPTs had significantly more difficulty in all identified areas of development.
2. EPTs who scores in the **normal** range scored significantly lower in cognition, language and motor domains.
3. Highest prevalence of delays were found in cognitive index, then language, then motor index.
4. 2 studies looked at growth and found EPTs to exhibit some catch up growth by 3 years and 5 years respectively.

What did I find in the Integration of the findings?

Impairment Rates

1. Severe impairments estimated between 11% and 14.5%
2. Moderate to severe impairment estimated between 30% and 35%
3. 2 studies looked at rates of CP found that to be between 13% and 14%
4. ≤ 25 weeks GA had higher rates of moderate and severe impairment than ≤ 27 weeks GA

What did I find in the Integration of the findings?

Gaps

- Behaviour
- Health Outcomes
- Protective factors
- Parent's perception of outcomes
- Quality of Life
- Family resiliency

Integration of the findings - Themes

Correlates of Outcomes

All studies described factors related to outcomes in their results.

Factors are categorized as: maternal, perinatal, infant, neonatal morbidities and treatments.

- **Antenatal Steroid**
- **Lower gestational age**
- **Male sex**
- **Multiples**

Integration of the findings - Themes

Comorbidities

- 1/3 of dataset demonstrated multiple areas of disability in EPT born preschoolers
- Severe impairments, milder impairments and delays co-occurring in neuromotor functioning, visions and hearing, cognitive development and motor development.
- Multiple areas of hidden deficits

Integration of the Findings – Message Framing

Author, Date & Country		Stated Aims		Conclusion	
	Favourable	Neutral	Adverse	Favourable	Adverse
Baron et al. (2011) United States		Performance	Impairment		Delays and immaturities
De Groote et al. (2007) Belgium	Health	Neurodevelopmental outcome			Deficient development and impairment/poor outcomes
Ishii et al. (2013) Japan		Neurodevelopmental outcomes	Mortality		Death or NDI
Kerstjens et al. (2012) The Netherlands			Delay		Delay
Kytnarova et al. (2011) Czech Republic		Growth		Catch up	Microcephaly
Leversen et al. (2011) Norway		Cognitive and motor function	Disability	Impairment free	Poor outcomes
Moore et al. (2012) England		Outcomes		Survival and survival without disability	Impairment
Ochiai et al. (2014) Japan	Survival	Neurodevelopmental outcome		Survival	Impairments
Zlatohlavkova et al. (2010) Czech Republic	Survival/outcome free of major disability		Mortality	Survival and survival without major disability	Impairment
Neonatal Follow-Up Program 2014-2015 Biennial Report (2017) Canada	Normal		Impairment Abnormal		None

Integration of the findings - Themes

Reporting and Interpreting Outcomes

Specific issues for integrating data:

- variability in control groups
- denominators of survival
- definitions of impairment
- categorizing outcomes for gestational age or birth weight
- choices of assessment tools and edition
- age at assessments
- choice of corrected age vs chronological age for reporting test scores.
- heterogeneity of cohort (geographically defined vs multi centre vs single centre, comparison of birth weight vs gestational age)
- different treatment policies in delivery room, active medical intervention and health care practices (Saigal & Doyle 2008; Zeitlin & Ancel, 2011).
- follow-up rates

Reporting and Interpreting Outcomes

Table 5. Impairment Definition by Publication

Study	Motor Impairment	Hearing Impairment	Vision Impairment (VI)	Development/Cognition Impairment
Baron et al. (2011) United States				Impairment: **DQ scores <85** (1 SD below mean)
De Groote et al. (2007) Belgium	Severe: Requires assistance to perform ADLS, unable to walk without assistance, cannot sit independently	Severe: Uncorrected hearing loss with amplification	Severe: blindness or light perception only	Severe/Moderate: **DQ score <70** Mild: DQ 70-85 Normal: DQ > 85 (within 1 SD of mean)
Leversen et al. (2011) Norway	Severe: **CP GMFCS Level 4-5** Moderate: CP GMFCS Level 2-3 Mild: CP GMFCS Level 1	Severe: Deaf Moderate: bilateral amplification Mild: mild hearing impairment no aids	Severe: Blind Moderate: severe VI Mild: refractive errors, strabismus	Severe: IQ <55 (<3 SD below mean) Moderate: IQ 55-70 Mild: IQ 70-85 Normal: IQ >85 (within 1 SD of mean)
Moore et al. (2012) England	Severe: **CP GMFCS Level 3-5** Moderate: CP GMFCS Level 2 Mild: CP GMFCS Level 1	Severe: Profound SNHL not helped by aids Moderate: bilateral amplification	Severe: Blindness Moderate: functional VI Mild: refractive errors, strabismus	Severe: IQ <55 (<3 SD below mean) Moderate: IQ 55-70 Mild: IQ 70-85 Normal: IQ > 85 (within 1 SD of mean)
Ochiai et al. (2014) Japan				Moderate or Severe: **DQ score <50** Mild: score 50-70 Normal: >70

Integrated results within context of greater literature

<u>EPT in normal range remain disadvantaged</u>:

Term born have higher mean scores that usual reference means, underestimating the true disadvantage experienced by EPT (Leversen, et al., 2011).

EPT born children experience high prevalence and low severity of disabilities and educational problems at school age (Kerstjens at al., 2012)

Integrated results within context of greater literature

Corrected vs Chronological age:

- only half of the studies specified whether CCA vs CA was used.
- When CCA is used, term group still performed significantly (0.7SD) above the preterm group means.
- In a review of CCA vs CA a significant differences in cognitive scores at 4 years, and height and weight at 3 years was found (D'Agostino 2010).
- Importance of balancing available services without overburdening referral system and creating undue parental anxiety (Wilson and Cradock, 2004).

Integrated results within context of greater literature

Drawing conclusions about cognitive impairments when overall developmental tests are used:

Global tests such as ASQ, BSID-II and III and KSPD are intended to expose developmental delay and are not predictive of cognition at school (Canals et al., 2011; Columbo & Carlson, 2012).

Comorbidities within the context of greater literature

- Australian cohort of "apparently normal" EPT children with IQ >84 with without disabilities at 8 years, found:

  42% EPT diagnosed with DCD vs 8% of term kids

  30% EPT had scores in keeping with severe DCD vs 0% of term kids

  (Goyen & Lui, 2008)

- Canadian cohort of "impairment free" EPT with verbal and performance IQ>84 at 4.5 years found:

  65% had one or more learning disabilities, compared with 13% of their term counterparts. verbal functioning accounted for the learning disabilities in term children visual-special, visual-motor and verbal functioning accounted for the performance in math and reading (Synnes, 2010)

- "Preterm behavioral phenotype" (Anderson, 2014; Johnson & Marlow, 2014)

Message Framing within the context of greater literature

Terminology and wording used in the literature shapes the readers perception of the data, results, conclusions and take home messages.

- Two studies that described unimpaired outcomes and characteristics of EPT infants provided optimistically framed hypothesis and balanced conclusion stating that nearly 1/3 of EPT infants had unimpaired outcomes, specifically describing that children's cognitive scores shifting to lower end of the normal range, (Gargus et al., 2009; Kumar et al., 2013).

- A Canadian study of stated their results optimistically reporting that 83.5% of EPT infants born between 2009 and 2011 were free of significant neurodevelopmental impairment at 2 years of age, balanced with the findings that 46% of the children met the criteria for milder impairments in motor, cognition, language or sensory-communication domains.

Message Framing within the context of greater literature

Hope is concisely identified as a central feeling of mother of preterm infants

- Mother's appreciated nurses who focused on encouraging hope and found hope was easily destroyed by negative attitudes or words (Plaas, 2007).
- Lack of balanced disclosure was described as hindering parent's involvement in their child's care and parent's ability to find hope (Charchuck & Simpson, 2005).
- HCP do not need to share parent's hope, but do need to recognize the importance of hope (Charchuck & Simpson, 2005).

Promoting Positive communication about outcomes

1. Acknowledging potential for healthy development
2. Recognize parents need for hope
3. Offering a balanced perspective of outcomes
4. Pair outcome data with appropriate interventions geared at supporting optimal outcomes

Guidelines for Reporting Outcomes of EPT Births.

1. Researchers should include context of study, including: study dates, geography, and population source (i.e. differences in outcomes of in born vs out born)
2. The point of inception for the study should fit with the aim of the study (admission to NICU vs discharge from NICU)
3. Outcome findings should be reported stratified by gestational age
4. Researchers should account for treatment decisions and guidelines at the individual centers such as delivery route and selective vs active resuscitation outcomes
5. All outcomes terms should be described, specifically aggregate and component outcomes should be described and reported.
6. Studies should be designed with a reference group and assessors should be blinded to eliminate preconception bias (Flynn effect- progressive increase in IQ scores measured over time)
7. Studies should be reporting statistics with precision including 95% CI for better informed decisions and making comparison of studies.

(Rysavy et al., 2016)

Reporting and Interpreting Data within the context of greater literature

What can look for?

- Methodology, data collection, interpretation and reporting should be consistent with reporting guidelines
- Data should be analyzed, interpreted, presented with conclusions and crafted messages to support appropriate understanding of the data
- Unit specific data is most practical to ensure applicability to the population of interest

Future Goals

- Audit is one of the 5 established standards of NFU clinics
- Definition of Audit: " The systematic study and **reporting** of neonatal outcomes with the intent of making changes to improve future outcomes" (Sauve & Lee, 2006, p.268).

1. Knowledge translation
2. Applying reporting guidelines
3. Interventions aimed at improving outcomes

Summary

- Multiple areas of impairments and delays across all developmental domains
- HCWs need to be aware of various factors that affect integrating and interpreting results
- Unit specific and regional data is most valuable outcome data
- Further exploration of caregiver's perception of outcomes and what is important to caregivers.
- Focus on evidence-based interventions that support optimal outcomes and functioning

Questions?

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Link to SPAR project in Circle and
https://dx.doi.org/10.14288/1.0366977

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