

A QUALITATIVE EXPLORATION OF HOW CHILDREN BORN PRETERM TRANSITION TO PRIMARY SCHOOL: AN INSTRUMENTAL MULTIPLE CASE STUDY

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15 million babies are born preterm globally per year (1 in 10), a worldwide epidemic (Canadian Premature Babies Foundation, 2020). In Canada, 30,000 babies are born prematurely each year (Canadian Premature Babies Foundation, 2020).

Prematurity is the leading cause of neonatal morbidity and mortality. Infants who survive have higher long-term morbidity rates than infants born full-term (Purisch & Gyamfi-Bannerman, 2017; WHO, 2012).

Once preterm babies are school age, known health impediments (e.g., hearing impairment) may affect their school performance. Other health outcomes of being born preterm (e.g., Specific Learning Disorder [SLD]) may only become apparent once the child is in school and fails to keep up with their peers, particularly in reading and math. Several studies have concluded that children who were born preterm have lower cognitive test scores (Brydges et al., 2018; McBryde et al., 2020), increased behavioural problems (Ask et al., 2018; Jin et al., 2019; Loe et al., 2019), and have lower academic performance scores in the domains of reading and mathematics (Jansen et al., 2020; McBryde et al., 2020).

This research study was a multiple case study with a constructivist approach. A constructivist case study approach seeks to interpret, understand, and explore several socially constructed phenomena in human activity (Howell, 2012). A constructivist approach aims to understand all the nuances of the phenomena of interest to obtain clarification and insight into the situation, namely the facilitators and challenges these children and their parents have encountered (Howell, 2012).

This study examined children and their circle-of-care members' experiences of having a preterm infant with health challenges and the children's transitions into primary public school. The study consists of eight case studies. For this study, I define the circle-of-care members as close family members and friends of the child. Members can include the parents, grandparents, and significant others who are not family, for example, babysitters and professionals, including home support personnel, teachers, learning assistants, guidance counsellors, physicians, and public/community health nurses. Data was collected and analyzed through semi-structured interviews (22 total), demographic information (on 8 families), document analysis (13 documents), and a home visit (1 visit, direct observation).

Goals/Objectives:

Research Question: How does a child born preterm (who currently has one or more disabling health challenges) and their parents adapt to the child entering the public school system?

Research Objectives:

1. To investigate the factors within the school, their community, and the province that helped and/or hindered their child's ability to achieve the best possible educational outcomes.
2. To determine if the school's location within the province (urban versus rural) made a difference in how the child transitioned into school.
3. To explore if more supports are available for the child/family depending on where they live (urban versus rural).

Demographic Information:

Eight families agreed to be interviewed. At the end of all interviews with the parents, demographic data was collected.

4 families lived in urban areas of NL, while the other 4 families lived in rural areas of the province.

Direct Observation:

Due to the COVID-19 pandemic, public health restrictions, and instructions from Memorial University of Newfoundland and Labrador during data collection, only one home visit was completed. This visit happened in the fall of 2019, prior to the pandemic beginning.

During the visit, I used my observation guide to help direct me to observe specific things during the visit; this included general family dynamics and the general condition of the home, as well as who was present, who was interacting with the child, and whether there were any safety concerns for the child. After the visit was complete, I wrote field notes regarding my experience, including my thoughts and feelings regarding the visit

Interviews:

All children in this study were born between 24 weeks to 36 weeks and spent between a few hours to four and a half months in the NICU in St. John's, NL. The health challenges varied and included autism spectrum disorder, anxiety, attention deficit hyperactivity disorder, hearing impairment, diabetes, specific learning disorder (reading and math).

I used the voice-centred relational method to analyze interview data. An overarching theme of transitions was identified, with three significant transitions identified for most if not all families. I have broken my analysis into three distinct phases of transition. They include (a) the transition of expecting to have a healthy baby/child and having a preterm baby/child who has health challenges, (b) the transition of leaving the NICU and going home, and lastly, (c) the transition of having your child with health challenges attend public school.

Document Review:

I used the steps outlined by O'Leary (2014) for this analysis. I began by looking for relevant documents on the Newfoundland and Labrador English School Districts website and the Government of Newfoundland and Labrador's Department of Education's websites.

I also reviewed the *NL Building's Accessibility Act* and the *Accessibility Act* because, in my interviews, two families brought up the issues they had gone through regarding not being able to enter certain businesses with a wheelchair. The documents that I reviewed were pertinent to the stories told to me during the interviews.

Knowledge that emerged from this study includes families of children that are born preterm find follow up appointments time-consuming. Appointment times were not coordinated between specialities and sometimes parents had to visit the hospital multiple times in a week to see different specialities. These families also spoke about the financial burden they experience. These parents spend a large amount of money on mediations and equipment for their children including braces and wheelchairs. In addition, they have to cover the cost of services like tutoring that can help their child be successful in school. Also, the cost of travel to and from the hospital also needs to be paid and while some of these costs may be covered by different plans/programs, the parents have to pay upfront, fill in the necessary paperwork and wait for reimbursement.

Another finding was that the resources/services that many of these children need are not known to most parents, the parents in my study found out about them through word of mouth from other parents. Also, the power of insider knowledge- some parents and grandparents in my study were nurses and teachers. With their insider knowledge they were aware of policies, procedures, medical conditions and tests, which lessened their stress, and they knew what to expect, and what to ask for.

Some other knowledge that was gained from this study was the power of resilience. These children are fighters and go through so much in their lives. They fight to stay alive. Their resilience is amazing,

In addition, meetings with school was also important. Many parents in this study met with the school prior to the school year starting to ensure that the services and resources their child needed were put into place.

Urban vs rural school living- Parents interviewed spoke about the school regarding it being small or large, urban or rural, and the benefits and downfalls of living in these areas.

Lastly, supports are needed for these children and families, one example is that more IRT's (instructional resource teachers) are needed in schools and some children need more time with them throughout the school day.

My study highlighted the many challenges faced by families included in my study. All families coped well with their children entering public school. While some encountered more challenges than others, their children have adapted well overall with the help of their circle of care members. This dissertation's findings include both benefits and drawbacks to attending urban versus rural schools, the empowerment of insider knowledge, and the need for more information regarding the services/resources available to these parents in this province. Lastly, it found that financial help is needed for these families. This project has numerous recommendations aimed at supporting the transition from home to school and ones that would be helpful to families that have children born preterm and have a health challenge.

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