A phenomenological exploration of mothers with intellectual disability and their experiences of making infant-feeding decisions

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Abstract

Mothers with intellectual disability (ID) are less likely than mothers without ID to breastfeed their infants, however little literature addresses infant-feeding decisions among this population. This manuscript-based thesis presents a study exploring the experiences of mothers with ID and their infant-feeding decisions. Four mothers with ID were interviewed. Data analysis examined two elements of the experience: making and carrying out decisions. Three sub-themes of making infant-feeding decisions emerged: being familiar with benefits of breastfeeding, owning the initial decision, and preparing for infant-feeding. Two sub-themes of carrying out infant-feeding decisions transpired: facing challenges and receiving support. Conclusions propose that the mothers felt most empowered during the prenatal period, yet opportunities to prepare them for possible challenges were missed. Health professionals should understand the learning needs and motivation behind infant-feeding decisions, and adjust prenatal education accordingly. Research implications highlight the need to explore the impact of social support on infant-feeding decisions.

Résumé

Les mères ayant une déficience intellectuelle sont moins susceptibles d'allaiter que les mères sans déficience intellectuelle. Cependant, les recherches sur les décisions entourant l'alimentation des nourrissons dans cette population sont peu nombreuses. Le présent mémoire expose les résultats d’une étude portant sur les expériences de mères ayant une déficience intellectuelle par rapport aux décisions entourant l'alimentation de leur nourrisson. Quatre mères ayant une déficience intellectuelle ont été interviewées. L'analyse de données porte sur deux éléments de l'expérience : la prise de décision et la mise en pratique de cette décision. Trois sous-thèmes par rapport au processus de prise de décision sont apparus : la connaissance des avantages de l'allaitement, la confiance par rapport à la décision initiale, et la préparation. Pour ce qui est de la mise en pratique de la décision, deux sous-thèmes se sont imposés: comment surmonter les défis, et recevoir de l'aide. Nous concluons que les mères se sentaient adéquatement préparées pendant la période prénatale, mais que la préparation fût, à certains égards, inadéquate pour surmonter certains défis pratiques. Les professionnels de la santé devraient comprendre la motivation et les besoins sous-jacents aux décisions entourant l'alimentation des nourrissons, et devraient ajuster l'information prénatale. À la lumière des résultats de notre étude, nous soulignons l’importance d'explorer l'impact des groupes d’entraide sur les décisions entourant l'alimentation des nourrissons lors de recherches ultérieures.

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Preface and Contribution of Authors

The research project reported in this manuscript based thesis was led by me. The study was conceptualized and designed by me, with guidance from Dr. Delphine Collin-Vézina and Dr. Marjorie Aunos. I conducted and transcribed all of the interviews. I analyzed the data, and Dr. Aunos read the transcripts as a secondary reader in order to provide feedback on my analysis. The manuscript was written by me, with feedback provided by Dr. Collin-Vézina and Dr. Aunos.

Conferences and Publication

Preliminary results of this study were presented at the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) 2015 North Americas Regional Congress. An abstract of the final manuscript has been accepted as a paper presentation at the IASSIDD 2016 World Congress. Additionally, the manuscript was submitted in November of 2015 for consideration for publication in a special issue on parents and parenting with intellectual disability in the Journal of Applied Research in Intellectual Disability (JARID). The manuscript included in this thesis was revised based on blind peer-review and resubmitted to JARID in March 2016.

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CHAPTER 1: BACKGROUND

Introduction

International health organizations such as UNICEF and the World Health Organization (WHO) have come to recognize breastfeeding as the ideal infant-feeding method. Asserting that breastfeeding is optimal for the health of mother and child, both organizations recommend exclusive breastfeeding[1] for the first 6 months of life and continued breastfeeding after the introduction of solid foods until the child is 2 years old and as long as mother and child desire thereafter (UNICEF, 2015; WHO, 2011). In alliance with the international bodies, Health Canada and the Québec Ministère de la Santé et des Services Sociaux (MSSS) have published the same recommendations along with guidelines at their respective governmental levels (Health Canada, 2015; MSSS, 2011a).

In 2001 the province of Quebec developed a breastfeeding policy to be implemented in provincial health settings entitled: *L'allaitement maternel au Québec: Lignes directrices* in an effort to improve breastfeeding rates in the province (MSSS, 2011b). Following this publication, the rate of initiating breastfeeding among mothers in Québec rose significantly from 76% in 2003 to 89% in 2012 (Statistics Canada, 2013). However, initiation of breastfeeding and duration of breastfeeding are very different phenomena. Every month post birth shows drastic reductions in the breastfeeding rates from day one, with only a small proportion of mothers exclusively breastfeeding for the recommended 6 months (Haiek, Gauthier, Brosseau, & Rocheleau, 2007; Health Canada, 2012b, Langlais, 2009; Neill, Drouin, Tremblay, & Québec,

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[1] Exclusive breastfeeding is defined as when the infant is fed only breastmilk and no other liquids or solids, with exception of vitamins or medications.

2006; Statistics Canada, 2013). Additionally, there are notable differences in the characteristics of mothers who breastfeed for longer. Lower income, lower education level, younger women, and single women have been reported to be less likley to breastfeed for the recommended 6 months (Dennis, 2002; Health Canada, 2012b; Ryan, Wenjun & Acosta; Statistics Canada, 2013; Stoltzer, 2010). This suggests that while health policies can have a positive impact on breastfeeding rates, there are variations across demographic groups that warrant closer examination of particular individual and socio-cultural factors in order to further improve future policy and practice.

To date, one such group that has been largely excluded from breastfeeding research is mothers with intellectual disability (ID). Parents with ID are more likely than their peers without ID to face risk factors such as: low-income, social isolation, prejudice, and poorer health (e.g. Aunos, Feldman, & Goupil, 2008; Glaun & Brown, 1999; IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008; Llewellyn, McConnell & Mayes, 2003; McConnell & Llewellyn, 2002). Given the documented health impacts of breast milk, researchers on pregnancy outcomes among mothers with ID have very recently begun to include information on breastfeeding in their findings. This research is beginning to suggest that mothers with ID are less likely to breastfeed than mothers without ID (Goldacre, Gray & Goldacre, 2015, Hindmarsh, Llewellyn and Emerson, 2015; Mitra, Parish, Clements, Cui & Diop, 2015). However no studies attempting to further explain these findings were found.

The research presented in this manuscript-based thesis sought to fill the gap in knowledge by exploring the first hand experiences of mothers with ID faced with making and carrying-out infant-feeding decisions. To frame the study presented in this manuscript-based thesis, I provide a literature review consisting of three sub-sections. First I examine literature regarding the health impacts of breastfeeding for mother and child to understand the basis behind breastfeeding recommendations. Next I explore the risk factors of vulnerable populations who have been shown to be less likely to breastfeed. Finally, I present the specific population of mothers with intellectual disabilities (ID) to contextualize the rational of this study. Following the manuscript, conclusions and implications for the field of social work are discussed.

Literature Review

Breastfeeding and Health. Research regarding the effects of breastfeeding is not a new area of interest. However, research studies over the years have produced some conflicting findings and these studies generally consist of observational studies, which pose some limitations on the generalizability of the findings. Due to the nature of the phenomenon it is not possible to study the effects of breastfeeding using randomized-controlled trials, which can lead to biases and suggestions of correlations rather than causal data. Despite these limitations, there is enough evidence to suggest that there are benefits to breastfeeding, although the extent of these benefits is not yet fully understood. Research has consistently demonstrated that breastfeeding is associated with better short term and long term health outcomes for mothers and infants (Horta, Bahl, Martines, & Victoria, 2007; Ip et al., 2007).

In 2007, the Tufts-New England Medical Center Evidence-Based Practice Center performed an extensive review for the Agency for Healthcare Research and Quality (AHRQ) in the United States with the goal of summarizing and evaluating the literature concerning the relationship between breastfeeding and maternal and infant health outcomes in developed countries (Ip et al., 2007). They included 43 primary studies on infant health outcomes, 43 primary studies on maternal health outcomes and 29 systematic reviews or meta-analyses that covered over 400 individual studies. The authors addressed specific health issues that they deemed relevant to the people of developed countries and discussed the association of any noted effects to the type of feeding (mostly breastmilk, mostly formula, or mixed feeding) and duration of breastfeeding. They also evaluated the methodological quality of the individual studies and the systematic reviews and meta-analyses that were included and added controls for possible confounding factors where possible. The authors' analyses revealed that breastfeeding is associated with a reduction in rates of acute otitis media, non-specific gastroenteritis, severe lower respiratory tract infections, atopic dermatitis, asthma in young children, obesity, type 1 and type 2 diabetes, childhood leukemia, sudden infant death syndrome (SIDS) and necrotizing enterocolitis. However, the authors noted that the studies in which a positive association between breastfeeding and infant cognitive development was made, there was no adjustment to account for maternal intelligence, thus no conclusive statement could be made.

In regards to maternal outcomes, Ip and colleagues (2007) noted that women who had breastfed were less likely to develop type 2 diabetes, breast cancer or ovarian cancer. They also reported that the risk of postpartum depression increased in relation to early cessation of breastfeeding or not breastfeeding. The authors noted that there was no association between lactation and osteoporosis found, and evaluations of studies regarding maternal weight loss showed that there were many factors other than breastfeeding that had bigger impacts on weight loss after pregnancy.

Researchers have continued to explore the specific benefits related to breastfeeding and to support and further clarify the associated benefits. In 2015, Acta Paediatrica published a special issue entitled: Impact of Breastfeeding on Maternal and Child Health. The special issue is comprised of systematic literature reviews and meta-analyses that explore the health impacts of breastfeeding. Methodological limitations and a general reliance on cross-sectional retrospective studies are acknowledged, while maintaining that the included reports support the need for continued efforts to promote breastfeeding as the optimal infant-feeding method (Grummer-Strawn & Rollins, 2015).

Within the special issue, the articles examining child outcomes, breastfeeding was again found to protect against childhood acute otitis media until the age of 2 years old, and the protection increased with exclusive breastfeeding and longer breastfeeding duration (Bowatte et al., 2015). Rates of infant and child mortality are reported to be higher among infants and children who were not breastfed exclusively (Sankar et al., 2015). Rates of obesity and type 2 diabetes in children were decreased by breastfeeding (Horta, Loret de Mola, & Victoria, 2015a). Horta, Loret de Mola and Victoria (2012b) also re-examined the question of an association between breastfeeding and performance on intelligence testing. The authors controlled for publication bias and noted that while the studies that controlled for maternal IQ showed a smaller benefit from breastfeeding, the benefit remained. Evidence that breastfeeding is associated with lowered risk of childhood asthma was reported (Lodge, et al., 2015). Lodge and colleagues reported evidence that breastfeeding can protect against eczema and allergic rhinitis, however the associations were weak.

One article in the special issue reviewed studies that looked at maternal outcomes (Chowdhury, et al., 2015). The authors looked for effects on breast cancer, ovarian cancer, osteoporosis, type 2 diabetes, lactational amenorrhea, postpartum depression, and postpartum weight change. Findings reported that breastfeeding is associated with lower rates of breast and ovarian cancer, and type 2 diabetes. Amenorrhea, the absence of menstruation, is associated with exclusive or predominant breastfeeding. The authors report that evidence for an association with osteoporosis, postpartum depression, and weight loss is lacking.

Research consistently demonstrates that there are some benefits to be derived from breastfeeding. However, there are often conflicting results in regards to some specific elements. It is possible that some of the conflicting evidence can be explained by individual or socio-cultural characteristics of the mothers involved.

Psychosocial Risk and Protective Factors. The research suggests that there are psychosocial factors related to the likelihood of pursuing breastfeeding. Several studies have linked breastfeeding rates to factors such as mother’s age, income, education level and types of support received. This section provides examples of such studies.

In a review of studies on breastfeeding initiation and duration rates, published between 1990 and 2000 it was reported that unsupported women who are young, low-income, or are members of an ethnic minority are least likely to breastfeed (Dennis, 2002). Dennis also noted that support from non-professionals and the mother’s partner is positively associated with breastfeeding while professional support can be negative when the information provided is inaccurate or inconsistent (Dennis, 2002).

Ryan, Wenjun and Acosta (2002) compared responses on infant-feeding patterns and mother socio-demographic information from 1996 and 2001 taken from a large national survey performed periodically in the United States. There were 744 000 questionnaires in 1996 and 1.4 million questionnaires mailed in 2001. The authors do not specify how many responses were received and all the data is provided in percentages. An overall increase in breastfeeding initiation rates were found comparing the data from 1996 to the data from 2001. Despite a large increase in the initiation of breastfeeding among black women under 20 years old, who had no education past high school, were unemployed and participated in the United States Women, Infants, Children (WIC) program[2], white, college-educated women over the age of 25 who were not participants in the WIC program remained more likely to initiate breastfeeding and to still have been breastfeeding when the infant reached 6 months of age.

Adding further support to the previous findings, Taveras and colleagues (2003) also found that breastfeeding discontinuation was higher among mothers with lower education levels, lower income, being a single mother or being a first time mother. The authors also reported that mothers with more depressive symptoms at 2 weeks post-partum were less likely to be breastfeeding at 12 weeks post-partum. Contrary to some previous research, they found that encouragement from a healthcare professional increased the likelihood of breastfeeding at

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[2] Women, Infants and Children is a U.S. federal assistance program for healthcare and nutrition of low-income pregnant women, breastfeeding women, and infants or children under the age of five.

12 week post-partum. Among the participants who had initiated breastfeeding, a return to school or work was the strongest predictor of the cessation of breastfeeding.

Given the evidence suggesting that mothers within particular demographics are less likely to breastfeed, some studies have focused on particular groups. In a recent qualitative study from the United States, Stoltzer (2010) explored the infant-feeding decisions of 100 women who were participating in the WIC program for low-income families. Of the 100 women, 74 had chosen to bottle-feed infant formula. The three most common reasons given for choosing to bottle-feed were: work or school obligations prevented them from breastfeeding, bottle feeding was more convenient and their self-reported inability to produce enough breastmilk. When asked who or what was the biggest influence on the decision to bottle-feed the most common response was “me”, followed by the doctor, and then their own mother. Among the mothers who chose to breastfeed, the three most common reasons were: it is best for baby, provides nutritional benefits to the baby, and is less expensive. The mothers who chose to breastfeed indicated that they were most influenced by their mother, their medical provider or books.

A 2012 study explored breastfeeding decisions among adolescent mothers. The researchers interviewed 16 adolescent mothers who had decided to breastfeed using a phenomenological approach (Nesbitt et al., 2012). Nesbitt et al. recruited mothers between the ages of 15 and 19 years old who were able to speak English fluently, were the biological mother of a child 12 months of age or younger and had made at least one attempt to breastfeed their child. The study revealed that the decision to breastfeed was generally made prenatally and made by the mother with some influence by their partner’s and family members’ opinions. Several influences on continued breastfeeding were also named; impact of breastfeeding on relationships, availability of social support, physical demands of breastfeeding, mothers’ knowledge of breastfeeding benefits and practices and mothers’ perceived comfort in breastfeeding.

Mothers with Intellectual Disability. Mothers with ID are reported to have greater exposure to social determinants of health, are affected by institutional discrimination and may struggle more than mothers without ID to express their needs and feel understood by health professionals (Llewellyn, 2012). However, recent research suggests that while general health among parents with intellectual impairments is demonstrated to be poorer than parents without intellectual impairment, controlling for socio-economic factors mostly eliminates this finding (Emerson, et al., 2015). As discussed in the proceeeding section of this thesis, psychosocial factors such as low-income and low-educational attainment have been identified as negatively impacting on breastfeeding rates.

To date, no research could be found that explored infant-feeding decisions among mothers with ID. However, researchers are beginning to report lower breastfeeding rates among mother with ID than the general population (Goldacre, Gray & Goldacre, 2015; Hindmarsh, Llewellyn & Emerson, 2015; Mitra, Parish, Clements, Cui & Diop, 2015). This study is the first to focus on infant-feeding among mothers with ID directly. The manuscript within this thesis (Chapter 4) provides a more detailed literature review in regards to research concerning this particular population.

Study Rational

Purpose. This study aims to begin filling the gap of knowledge in the area of infant-feeding among mothers with ID by understanding the experience of being a mother with ID faced with making infant-feeding decisions.

Objectives. The first objective of this study is to understand first-hand experiences of mothers with an intellectual disability in regards to infant-feeding method decisions. The second objective is to understand the mothers' perceptions of informal and formal supports they received when carrying-out their decisions.

Research Questions. This study is informed by the methodology and design of Nesbitt and colleagues on infant-feeding decisions among a sample of Canadian adolescent mothers without ID (Nesbitt, et al., 2012), with certain adaptations to address the particular needs of mothers with ID. As an exploratory, qualitative study, the research questions were not developed to test a hypothesis, but rather to explore the experiences of mothers with ID in regards to their infant-feeding decisions. Two research questions guided the design of this study:

1. How are infant-feeding decisions perceived among mothers with ID?
2. How is breastfeeding support perceived by mothers with ID?

Ethical Considerations. This study was approved by the Research Ethics Boards of Comité d’éthique de la recherche conjoint destiné aux centres de réadaptation en déficience intellectuelle et en troubles envahissants du développement (CÉRC/CRDITED) as well as the

McGill University Research Ethics Board. The consent procedure is particularly important in this project because the participants recruited are considered to be from a vulnerable population. To ensure that informed consent is obtained the researcher discussed the project and consent with the participant prior to the interview. The study was explained using the Participant Information Form (Appendix A). The consent form template was downloaded from the CÉRC/CRDITED website. The consent form was translated to English because the participants were Anglophone. The consent form includes six questions to ensure the participant's comprehension of her participation. All participants answered all of the questions correctly. The form was signed by the participant and the researcher. The participants were given a copy of the consent form (Appendix B).

CHAPTER 2: THE PHENOMENOLOGICAL APPROACH

Brief Overview

Phenomenological research is a qualitative approach that explores the lived experiences of a group of individuals in relation to a particular concept or phenomenon, in the search of the universal essence of said phenomenon (Creswell, 2013). Thus, phenomenological research focuses on the description of the participants' experiences rather than a description of their actions or behaviours (Polkinghorne, 1989). The researcher aims to understand *what* was experienced as well as *how* it was experienced (Moustakas, 1994). "Phenomenology is the *first* method of knowledge because it begins with "things themselves"; it is also the final court of appeal" (Moustakas, 1994, p. 41).

The roots of phenomenology trace back to the philosophical ideas of Edmund Husserl (1859-1938) regarding the subjective openness in science (Moustakas, 1994). Moustakas explained that Husserl's transcendental phenomenology offers three processes: epoche, transcendental-phenomenological reduction and imaginative variation. In the first stage, epoche, the researcher brackets out his or her personal experiences with the phenomenon attempting to eliminate pre-suppositions. The second stage, transcendental-phenomenological reduction, consists of the development of a textural description of the essence of the phenomenon. The final stage, imaginative variation, produces a structural description of the connection between what is experienced and how it is experienced (Moustakas, 1994).

Husserl's descriptive phenomenology preceded Heidegger's (1927-1962) interpretive phenomenology: Hermeneutic phenomenology (Laverty, 2003). Hermeneutic phenomenology also aims to understand lived experiences, however, the process of understanding differs. Where Husserl believed that the researcher must release all preconceived notions to view a phenomenon as though for the first time, Heidegger claimed that a person's pre-understanding is referenced in order to understand new concepts (Laverty, 2003).

Others have also expanded on the views of Husserl, describing somewhat different perspectives of phenomenology (Creswell, 2013). One framework in particular, Interpretive Phenomenological Analysis (IPA), provides a structured approach to study design and data analysis, which other forms of phenomenological research often lack. IPA specifically aims to explore individual narratives of the participants in order to provide a detailed analysis of the perceptions of the individuals being interviewed (Smith & Osborn, 2003). Concepts from IPA were drawn upon to inform the data analysis in this study.

Positioning Myself

Phenomenological research sometimes includes a process referred to as *epoche* (Moustakas, 1994) in which the researcher brackets out his or her personal experiences with the phenomenon attempting to eliminate pre-suppositions. Creswell (2013) notes that bracketing cannot remove the researcher from the process completely, however, it can serve two purposes: The researcher uses bracketing to acknowledge his or her own experiences in order to partly set them aside, and allows the readers a frame of reference so that they may judge to a certain extent, the influence of the researcher's experiences on the study. IPA does not require a bracketing process, arguing that it is through the researcher's biases that he or she makes sense of others' experiences (Fade, 2004). Fade explains that when using IPA, the researcher may choose to acknowledge his or her role in the interpretative process, though this is not a required step. I conducted the current research with reflexivity as an important component in the project development and analysis, therefore I decided to include a section on my personal experiences with breastfeeding prior to engaging in this research.

My personal interests in parenting and breastfeeding developed due to my experiences with motherhood. While I had worked with children with disabilities and their parents prior to becoming a parent myself, my understanding of the family system shifted as I experienced motherhood first-hand. My experiences with breastfeeding could be considered typical. Like many mothers I faced challenges early on, especially with my first child. I was sore, unsure if the baby was getting enough milk, questioned the amount of spit up and the length of time between feedings. A public health nurse visited my home a couple of days after the baby was born, but my difficulties and questions did not start until a couple of weeks later so I did not need much help when it was offered. My doctor asked if I planned to breastfeed, but offered no follow up information. My mom had not breastfed me for long and I was the first among my group of friends to have a baby, so I turned to the internet for help. I found online forums and connected with other mothers who had lived similar experiences. I navigated the information and support systems available and built myself a network. The birth of my second child brought new and different perspectives. While I was much more confident in some aspects of breastfeeding, new contexts meant new learning curves. I returned to school when my youngest was 8 months old. Unlike with my first, I had to figure out daycare, feeding schedules and expressing my milk while away from him at school and in field placement. The online network I had built myself was still very much present throughout all of these transitions.

My first field placement of the Bachelor of Social Work program took place in perinatal services within a public health organization situated in a neighbourhood with a large immigrant population. In this setting, I was struck with both the commonalities along with the stark differences in the challenges faced by the women of this community. Some mothers faced social isolation, others paired that with language barriers. I was approached by a nurse about becoming a breastfeeding peer support volunteer within a chapter of Nourri-Source that was being developed in the community. Nourri-Source Federation is a Quebec non-profit organization. Their mission is to support breastfeeding via local groups and a pairing service that matches an experienced and trained mother with a new mother seeking support with breastfeeding (Nourri-Source, 2016). I had not heard much about this organization prior, being fortunate enough to have the skills and opportunities to find other resources when I needed personal support. The nurse who had been developing the initiative was unexpectedly transferred, and I took lead of the project, hoping to help the women in the community find locally the type of support that I had found online. There were challenges along the way, but a year later, I left the group in the hands of four motivated mothers from the community as I began my graduate studies. Four months into my master's degree, I took a position as a professional social worker in a service that provides support for mothers with ID, and that paved the way for this research project.

My personal experiences with breastfeeding and breastfeeding peer support influenced my interest in studying infant-feeding decisions among mothers with ID. In the development of this research study, I discovered something interesting. No matter the context, professional, academic or social, when I was asked about my topic area by another mother, the conversation consistently led into a discussion of their personal experiences with breastfeeding or infant-feeding decisions. The information was always volunteered; I never asked about personal experiences during these conversations and I rarely spoke of my personal experiences prior to initiation of the topic by the other person. I found this to be true very often when speaking to fathers as well; they would share the story of their wife's experiences as they perceived them. From these conversations I concluded that there is a general desire to share experiences and decided that if I were to begin exploring infant-feeding decisions among mothers with ID, the most logical place to start is by asking them to share their experiences.

CHAPTER 3: THEORETICAL FRAMEWORK

The theoretical frameworks that guide this research were not explicitly chosen, but rather acknowledged on the part of the researcher. That is to say, I did not make a conscious decision to use any particular theory or lens when designing and implementing this research, instead I reflected upon the existing literature and my manner of understanding it and two predominant concepts became clear. Ecological systems theory and a disability interpretive lens form the theoretical basis of this research.

Ecological Systems Theory

Ecological systems theory considers the interactional influences of multiple environmental systems in human development (Bronfenbrenner, 1986). Bronfenbrenner's theory describes bi-directional influences between multiple levels; the microsystem, the mesosystem, the exosystem, the macrosystem and the chronosystem. The microsystem considers the interactions within the immediate environment of the individual. For a child, this could include their immediate family as well as their school or daycare environments. The mesosystem refers to the interactions between the components of the microsystem; for example, the implication of the child's parents with the school. A parent's mesosytem may include whether their workplace has family-friendly policies. The exosystem includes environments that impact the individual, without necessarily having direct interaction. For example, a situation at work can impact on how the parent interacts with their child, or the financial stability of the family. The macrosystem refers to the largest influencing system in the individual's life including cultural values and governing laws. The final system, chronosystem, takes into account the effect of passing time, including development and life transitions.

Research has consistently demonstrated that parenting competence is not determined as a function of the parent's IQ, but rather is impacted by ecological factors such as parental health, parental relationship characteristics and family income (e.g. Booth & Booth, 1993; Feldman, 2002; Mickelson, 1947; Tymchuck & Feldman, 1991). An interactional model of parenting by persons with intellectual disabilities was developed based on the ecological systems theory and is often used within the literature on this population (Feldman, 2002). The model describes the influence of multiple interacting factors on parenting and child development; factors such as history, parent and child characteristics, income, housing, living environment, availability of informal and formal supports, as well as social and cultural influences such as stigma and policy.

Disability Interpretive Lens

In addition to the ecological systems theory, a disability interpretive lens was used in the approach to conducting this research. The disability interpretive lens views disability as human difference as opposed to human defect (Creswell, 2013). The disability interpretive lens is based on the social model of disability, which frames disability as being the result of inaccessible social environments or structures; in contrast to the medical model which focuses on rehabilitation or repair of the shortcomings of an individual (Heyer, 2007). Disability literature demonstrates a trend in the movement away from a medical model understanding of disability to a more social model perspective (Mackelprang, 2010). One example of research that has applied a disability lens is a study that examined how a typical hospital environment is not necessarily well suited to meet all of the needs of an individual with Autism (Iannuzzi, Kopecky, Broder-Fingert & Connors, 2015). Given aforementioned research indications that mothers with ID face challenges in expressing themselves and being understood by healthcare professionals in other areas, a current focus on mothers' perceptions of the accessibility of resources to support their infant-feeding decisions is justified. Using a disability interpretive lens, the current research was designed to explore how mothers with ID experience the decision-making process and their support needs. The study aims to explore the experiences in order to begin informing future research and practice on how best to accommodate the needs of mothers with ID in making and carrying out infant-feeding decisions.

CHAPTER 4: MOTHERING WITH AN INTELLECTUAL DISABILITY: A PHENOMENOLOGICAL EXPLORATION OF MAKING INFANT-FEEDING DECISIONS

Abstract

Background: Mothers with intellectual disability (ID) are less likely than mothers without ID to breastfeed their infants, however there is little literature that addresses infant-feeding decisions among this population. This study explores experiences of mothers with ID in making and carrying-out infant-feeding decisions. **Methods:** Using a phenomenological approach, in-depth interviews were conducted with four mothers with ID. **Results:** Analysis focused on two elements of the experience of making infant-feeding decisions: making infant-feeding decisions and carrying out infant-feeding decisions. Three sub-themes of making infant-feeding decisions emerged: being familiar with benefits of breastfeeding, owning the initial decision and preparing for infant-feeding. Two sub-themes of carrying out infant-feeding decisions transpired: facing challenges and receiving support. **Conclusions:** The prenatal period was a crucial time for the mothers regarding infant-feeding decisions. It is the time in which they felt the most decision-making power, yet opportunities to prepare for possible challenges were missed.

Keywords: breastfeeding, infant-feeding, intellectual disability, mothering, phenomenology

Introduction

Up to now, research in the field of parents and parenting with ID has evolved according to three phases (Llewellyn, Mayes & McConnell, 2008). The first phase included studies that focused on the heredity of intellectual disability. While some heritability of general intelligence was found, studies reported that most children of parents with ID have normal intelligence (e.g. Ainsworth, Wagner & Strauss, 1945; Mickelson, 1947). Consequently, concern shifted away from preserving the genetic quality of the human species, to examining whether people with ID have the competence to parent appropriately (MacLean & Aunos, 2010; Taylor, 2010). The second phase produced evidence that parents with ID present with diverse strengths and weaknesses, and that they are capable of learning parenting skills when the teaching is adapted to their personal learning needs (e.g. Budd & Greenspan, 1985; Feldman, 1994; 2010; Tymchuck & Feldman, 1991).

Throughout those studies it was consistently demonstrated that parenting competence was not determined as a function of the parent's IQ, but rather is impacted by ecological factors such as parental health, parental relationship characteristics and family income (e.g. Booth & Booth, 1993; Feldman, 2002; Mickelson, 1947; Tymchuck & Feldman, 1991). The third phase of parenting with ID research then drew attention to the impact of the everyday contextual factors lived by parents with ID and their families (Llewellyn, Mayes & McConnell, 2008). Parents with ID were found to be more likely than their peers without ID to face risk factors such as: low-income, social isolation, prejudice, and poorer health (e.g. Aunos, Feldman, & Goupil, 2008; Glaun & Brown, 1999; IASSID Special Interest Research Group on Parents and

Parenting with Intellectual Disabilities, 2008; Llewellyn, McConnell & Mayes, 2003; McConnell & Llewellyn, 2002). The importance of support that is competence-enhancing has been demonstrated (Aunos & Feldman, 2002; Tucker & Johnson, 1989) but issues related to the social inequalities surrounding parents with ID, has revealed the need for detailed exploration of elements such as maternal and infant health (McConnell, Llewellyn, Mayes, Russo & Honey, 2003).

So, possibly a fourth phase, focused on mother and infant health has emerged. Elements such as mothers with ID being more likely to experience pre-eclampsia, giving birth prematurely, and more likely via caesarian section, compared to mothers without ID, are now known (McConnell, Mayes & Llewellyn, 2008; Höglund, Lindgren & Larssen, 2012a). The health of infants is also studied with evidence that babies of mothers with ID are at a higher risk of being stillborn, of dying perinatally and of being considered small for gestational age (Höglund, Lindgren & Larsson, 2012b).

With a spotlight on health, consideration of infant feeding decisions becomes pertinent. Breastfeeding is recognized in Canada and internationally as optimal for the health of both mother and infant and exclusive breastfeeding is recommended for the first 6 months of an infant’s life and continued breastfeeding after the introduction of solid foods for as long as mother and child desire (Health Canada, 2004; Ministère de la Santé et des Services Sociaux, 2011; World Health Organization, 2011). These recommendations were influenced by an abundance of research regarding the relation between breastfeeding and the health impacts on mothers and children. For example, a frequently referenced, extensive review was conducted for the Agency for Healthcare Research and Quality (AHRQ) in the United States with the goal of summarizing and evaluating the literature concerning the relationship between breastfeeding and maternal and infant health outcomes in developed countries (Ip et al., 2007). Their review of over 80 primary studies and 29 systematic reviews or meta-analyses revealed several meaningful associations between breastfeeding and certain health outcomes. Regarding infant outcomes, breastfeeding was linked to a reduction in acute otitis media, non-specific gastroenteritis, severe lower respiratory tract infections, atopic dermatitis, asthma in young children, obesity, type 1 and type 2 diabetes, childhood leukemia, sudden infant death syndrome (SIDS) and necrotizing enterocolitis. Regarding maternal outcomes, the authors noted that a history of having breastfed was related to a reduced risk of type 2 diabetes, as well as breast and ovarian cancer. They also reported that the risk of postpartum depression decreases in relation to longer duration breastfeeding.

Given the documented health impacts of breast milk, researchers with an interest in mothers with ID have very recently begun to include information on breastfeeding in studies that explore pregnancy outcomes among this population. To our knowledge, three recent studies were found to have reported that breastfeeding rates are lower among mothers with ID than the general population. In the first, researchers examined archived data from 245 007 births between 1970-1989 in England to explore pregnancy characteristics and birth outcomes of mothers with ID. Of the sample, 217 mothers with ID were identified using the International Classification of Disease (ICD) codes for ‘mental deficiency’ and ‘mental retardation’. Among their findings it was revealed that 33% of newborns to mothers with ID were breastfed at discharge from the hospital, compared to 70% of newborns to mothers without ID (Goldacre, Gray & Goldacre, 2015). More recent data from Massachusetts the United States also revealed that babies to mothers with intellectual and developmental disabilities (IDD) were less likely to be breastfed at discharge from the hospital than babies born to mothers without such diagnoses (Mitra, Parish, Clements, Cui & Diop, 2015). Mitra et al. reviewed pregnancy outcomes from 916 032 births; of which 703 were to mothers with IDD as per the ICD-9-CM code. They reported that 49% of mothers were breastfeeding at time of discharge from the hospital, compared to 77% of mothers without IDD. Hindmarsh, Llewellyn and Emerson (2015) looked at maternal health and developmental outcomes of 9 month olds infants of mothers with intellectual impairment. Using data from the Millennium Cohort Study (MCS) in the United Kingdom, the authors found that infants of mothers with intellectual impairments were less likely than babies of mothers without, to have been breastfed for longer than a month's time.

Although the literature is beginning to suggest that mothers with ID are less likely to breastfeed, there is an absence of research looking at why that appears to be the case. Mention of breastfeeding as a natural process and the desire to breastfeed for as long as possible was made within a qualitative study from Sweden examining motherhood among women with ID (Höglund & Larsson, 2013). In this study participants stated that "explicit and implicit threats about losing custody of the child did not appear to negatively influence how women with ID breast fed and cared for their newborn children" but there was no mention of factors that did influence infant-feeding decisions.

The current research aims to begin filling in the gap of knowledge with regards to infant-feedings decisions of mothers with ID. This project will lead the way for future inquiry by presenting an analysis of the experiences of infant-feeding decisions from the mothers' perspectives. The first objective of this project is to understand first-hand experiences of mothers with an intellectual disability in regards to infant-feeding method decisions. The second objective is to understand the mothers' perceptions of the available supports to support the implementation of their infant-feeding decision. The currrent research is informed by the methodology and design of a study by Nesbitt and colleagues on infant-feeding decisions among a sample of Canadian adolescent mothers without ID (Nesbitt, et al., 2012), with certain adaptations to address the population at hand.

Method

Design

This research study aims to understand the common significance of the perceptions and experiences of mothers with ID when faced with making and carryingout infant-feeding decisions. Considering the gaps in knowledge regarding infant-feeding decisions among mothers with ID, an approach focused on the perceptions of those experiencing the event was chosen for this study. Phenomenology is a qualitative approach that is used to explore the lived experiences of a group of individuals in relation to a particular concept or phenomenon, in the search of the universal essence of said phenomenon (Creswell, 2013). The researcher aims to understand *what* was experienced as well as *how* it was experienced (Moustakas, 1994). Phenomenology was chosen as the approach for this research because it is exploratory in nature and thus well suited to the purpose of understanding the overall significance of the participants' experiences with regards to infant-feeding decisions. Concepts from Interpretative Phenomenological Analysis (IPA) were drawn upon to inform this study. IPA is a phenomenological approach that combines Edmund Husserl's ideas of understanding the components of experiences or phenomena with Martin Heidegger's interpretive approach of hermeneutics as well as with idiography; the in-depth analysis of individual experiences (Pietkiewicz & Smith, 2014). IPA aims to explore individual narratives of the participants in order to provide a detailed analysis of how the participants make sense of particular events or experiences (Smith & Osborn, 2003). Although phenomenology is not intended to provide generalizations to larger population groups, it will help as a first step in beginning to understand how infant-feeding decisions are informed and made among mothers with ID.

Participants

Four mothers with a mild ID were recruited to participate in the study. Purposeful sampling was employed to ensure that all of the participants have experienced the process of making infant-feeding decisions and met inclusion criteria, which were as follows: (1) The participants were 18 years or older. (2) The participants were receiving services from the local rehabilitation centre, thus having met the eligibility criteria of a formal diagnosis of an intellectual disability as per the American Association on Intellectual and Developmental Disabilities (2011) criteria. (3) The participants had given birth within the last 6 years. (4) The participants were apt to consent, meaning that mothers meeting all first three criteria but who are under legal curatorship or tutorship were excluded. Due to the specificity of the inclusion criteria for participating mothers, recruitment of a large number of eligible participants was expected to be difficult, thus a small sample size of 4-6 participants was expected for the purposes of this initial exploration of the topic. Additionally, this respects the IPA approach in which studies commonly use small sample sizes so as to ensure detailed analysis of each participant's described experiences (Smith & Osborn, 2013). A summary of participant characteristics can be seen in Table 1.

Ethics

This project was approved by the Research Ethics Boards of Comité d'éthique de la recherche conjoint destiné aux centres de réadaptation en déficience intellectuelle et en troubles envahissants du développement (CÉRC/CRDITED) as well as the McGill University Research Ethics Board prior to beginning the recruitment process. All data gathered from the participants is kept confidential and pseudonyms are used in the report to protect the identity of the participants. Identifying information of third parties spoken of by the participants is likewise omitted for reasons of confidentiality.

Procedure

Participants were met with on one occasion in a mutually convenient, private location. One participant was interviewed in a private office; three participants were interviewed in their respective homes. The meeting began with the presentation of the research project to the participant where their role and their rights to consent were explained. The participants consented to having the interviews audio recorded. Once the consent procedure was completed the interview followed.

During the interview each participant was asked to speak in depth of her experiences with making infant-feeding decisions and the support received during the early infancy period. The interview was semi-structured and took approximately 30-60 minutes. The interview was guided by four broad, open-ended questions with follow-up questions as needed to clarify or obtain further information. Refer to table 2 for the interview guide. The questions used for this research were based on those from Nesbitt et al.'s study (2012) where a similar methodology was used to explore breastfeeding decisions among adolescent mothers. Adaptations to the research guide were made to generalize the questions to infant-feeding decisions as opposed to being breastfeeding specific. Introductory sentences were provided for the questions as a way of presenting the topic and facilitating the participants' understanding of what was being asked. Follow-up questions were used for clarification and to ensure sufficient depth of the responses. The interview process was complete when it is considered coherent, rich in details and the mother had confirmed that it represents the truth of her experience. Interviews were audio recorded.

Data Analysis

The interviews were transcribed from the audio recording for the purposes of analysis. During the interview the researcher used summary and interpretive statements to allow the participant to correct any misconceptions as a member checking strategy to enhance overall data credibility. The first author conducted all interviews and analysed the transcripts. IPA is a dynamic process where the researcher plays an active role in understanding the phenomenon as the participants experienced it, and then interpreting those perceived experiences to explore whether there is further meaning to be derived from the experiences (Pietkiewicz & Smith, 2014). The analysis began with reading, re-reading and note taking to familiarize the content. The transcript was then broken down and codes were assigned to significant statements, line by line. This initial coding process was repeated two times to ensure that all significant data was coded and that the codes were as accurate as possible. For example, a participant's statement of "It was an easy decision" was initially coded as 'easy decision'. After subsequent readings of the transcript and a better understanding of the data that code was interpreted to 'feeling confident in her decision.' Following the initial coding procedure, clusters of common codes were organized into themes that helped to describe the context of the two elements of making infant-feeding decisions. Table 3 provides an example of how codes were clustered into sub-themes, in relation to the element of making infant-feeding decisions. The discovered themes were then interpreted to describe the essence of the experiences of mothers with ID while making and carrying out infant-feeding decisions. Themes discovered from within each interview were compared and common themes were drawn out from the comparison. Due to the subjective nature of qualitative data analysis, the first author consulted the second author throughout the coding process to verify the emerging themes.

Results

The focus of the data analysis within a phenomenological study is generally to understand the common essence of the participants' experiences. In accordance with the IPA focus on narratives within the analysis, a brief description of each mother's situation and experience is provided to highlight that the commonalities are drawn from four very different trajectories through the same event of making infant-feeding decisions. Pseudonyms are used to protect confidentiality.

Description of participants

Gillian. Gillian is a single mother of a four year old son. The child's father was involved in the child's life for a short period of time, but was not involved at the time of the interview. She initiated breastfeeding in hospital and had also introduced infant formula prior to discharge from the hospital. Gillian fed her infant both breastmilk and infant formula approximately 1 and a half months, at which point she switched entirely to using infant formula. She experienced maternal health complications after the birth of her son that required hospitalization and separation from her infant for a period of several weeks. Gillian expressed that her complications impacted her attempts to breastfeed. She spoke of her mother and her brother as sources of support.

Paula. Paula is the mother of a 2 year old son. She has been in a relationship with the child's father for many years. They live together and he is very involved in the care of the child. Her mother, siblings and in-laws are also involved in her family life on a regular basis. Paula spoke about informing herself about breastfeeding in order to increase her chances of succeeding. She breastfed her son until he was approximately 13-14 months old. The occasional supplementation of infant formula was used early on, but was discontinued once difficulties with breastfeeding were overcome.

Emma. Emma is a single mother of a 4 year old daughter and a 2 month old son. She has the support of her mother. Emma's first child, her daughter, was born premature and she expressed that she was never given the option to breastfeed because the infant was cared for in the Neonatal Intensive Care Unit. Emma stated that she expected to try to breastfeed her son, but found it very difficult. She introduced infant formula within the first couple of weeks and had switched to exclusively using infant formula by the end of the first month.

Amy. Amy is the mother of a 2 year old daughter. She is in a relationship and lives with the child's father. Amy decided to use infant formula from the birth of the child because of personal discomfort with the idea of showing her body to others. She did not initiate any form of breastfeeding. Amy states that her partner participates in caring for their child, including feeding but that she prepared the bottles for him.

Elements of the decision making process

In analyzing the data drawn from the stories of these four mothers with ID, two elements to the decision making process were explored; the experience of making infant-feeding decisions and the experience of carrying out the decisions made. Each of these elements revealed common themes that help explain how the participants experienced this phenomenon.

Making infant-feeding decisions. All of the participants expressed having made an initial decision in regards to infant-feeding method during the prenatal period. Three of the four participants made a decision to initiate breastfeeding and the fourth chose to exclusively use infant formula from birth. The initial decision must be considered within a largely theoretical context. Only one of the mothers in the sample had multiple children, thus allowing for some personal lived experience to influence a prenatal decision with the second child. Three dominant sub-themes of this element regarding making infant-feeding decisions emerged;

familiarity with basic benefits of breastfeeding, ownership over the initial decision and prenatal planning.

Theme 1: Being familiar with benefits of breastfeeding. All of the mothers who were interviewed were aware of certain benefits derived from breastfeeding. Generally, the mothers expressed basic understanding focused primarily around the concepts of healthier and better for baby. Paula provided the most detailed understanding of health benefits:

> So uh I just want – I thought breastfeeding would just be like, would be like healthier because you have their natural um, like, I don't know how to say the word (laughs) but like… He'd get all your immunities because you don't have an immune system when you're born. (Paula)

The mothers who expressed that they wished to breastfeed identified infant health benefits as an influencing factor behind their decision to do so. In addition to the health benefits of breastfeeding, Gillian named a financial impact of breastfeeding as well. "It's more healthier and better for the baby. And just probably cheaper I guess because you don't have the formula." Amy also expressed that she was informed of both health and financial advantages of breastfeeding, though they did not impact on her decision to use infant formula.

The mothers described both formal and informal sources of information regarding the benefits of breastfeeding. "Friends, family members say 'oh that's the best milk than ever to keep them from having – being sick, having a cold and all those stuff'… even the doctor [said the same]" (Emma). When asked where she heard about the benefits of breastfeeding, Paula explained that her knowledge of her own mother's experiences influenced her decision to breastfeed her son. "Just from personal, like 'cause um my mom breastfed me and when she had to stop I started getting really really really sick." Paula later spoke of the hospital staff's position of promotion of breastfeeding. Of the four participants only Amy expressed that breastfeeding information came exclusively from formal sources. She explained, “He [the doctor] would say to me it’s healthier and cheaper but … he said ‘ok, it’s your choice.’” Amy stated that she has friends who breastfeed and friends who use infant formula, but stated that none of them spoke to her about feeding decisions.

Theme 2: Owning the initial decision. Although the mothers spoke of being informed of the recommendation to breastfeed, the concept of personal choice was strongly present in the described experiences. With only one exception, all of the mothers perceived their initial feeding decision to be their own, even when they consulted with friends, family or professionals during the decision making process. Exceptionally, Emma explained that her first child was born prematurely and was cared for in the NICU for several months before she was able to be discharged.

> Uh with the girl one, with [daughter’s name], she was a premie so she she stay away for a long time so if I would continue she was uh three months already. [By then] there was nothing coming out, no milk. (Emma)

In this situation, Emma expressed not being given an option to breastfeed however with her second child Emma perceived that the choice was her to make.

> Well the first – with the first one the child, I didn’t actually think because
>
> you’d have to drink milk and stuff, those stuff was kind of new to me so I didn’t really know, didn’t look at it that way, but with [son’s name] now, I decided that I want to breastfeed... (Emma)

Gillian explained that her friends validated that the decision was hers to make, despite some negative experiences they shared with her. “My friends, they knew [that I wanted to breastfeed] but they said it’s very hard to breastfeed and it’s time consuming and, you know. But that’s their choice not mine… my choice was different.” In discussing the role of the doctors in her decision making, Paula emphasized that despite the professional recommendations, the choice remains in the hands of the mother. She recognized that other mothers could make a different decision than her own.

> Well they said breastfeeding was usually the best. Encouraging. My doctor encouraged me well ’cause it was the General Hospital and they try to like get everybody to breastfeed – but if they don’t want to, they don’t want to – they [the doctors] can’t say no, but they try to get you to breastfeed. (Paula)

Even with information coming from varied sources, depending on the individual support network of each mother, the choice of what decision to make was perceived in a positive manner to be the responsibility of the mother.

Theme 3: Preparing for infant-feeding. While all of the mothers expressed ownership over the decision of how to feed their infant, the preparation for how this decision would be carried out and the expectations associated with the decision differed between the mothers.

Paula and Gillian, who were both adamant that they wanted to breastfeed, sought out information in order to be prepared. “No I decided that on my own but I tried to learn as much as I can about it before I gave birth.” (Paula) Both mothers spoke of attending prenatal education classes on breastfeeding. “Doctors and (pause) I don’t know I went to the [community organization] too, they had courses on different things you know that you needed before the baby was born.” (Gillian) Despite the conviction behind their decision both mothers held different expectations in regards to how they thought breastfeeding would work out.

Gillian remarked that she was not sure she would be able to breastfeed, but had brushed off concerns thinking that she probably would not have any challenges. Paula described experiencing worry about the potential physical pain associated with breastfeeding. “A lot of people have a lot a lot of difficulties, I was a little like scared but I knew I could do it if I really really tried.” She spoke of paying particular attention when learning about breastfeeding, so as to knowing the signs of problems and when to seek support. “I knew that you weren’t supposed to have pain or bleeding and a lot of people have pain and bleeding and they said that if I have pain, I’m not doing it right.”

Amy, who was firm in her decision to use infant formula, approached her local social assistance office for support with purchasing the milk and the bottles prior to the baby’s birth. Emma, on the other hand, said that she had not given the decision much explicit consideration. Her description of the decision making process differs from that of the others in that she was not committed to an infant-feeding method from the start; she was willing to try breastfeeding. “Well, I didn’t – I didn’t actually plan, I just like go ahead… to try to breastfeed.” Emma did not seek out any information regarding breastfeeding prior to the baby’s birth.

Carrying out infant-feeding decisions. All of the mothers who chose to breastfeed experienced challenges with following through on their decision. Some were more prepared than others to face those challenges. Two dominant sub-themes transpire: facing challenges and receiving support.

Theme 1: Facing challenges. All of the mothers who initiated breastfeeding experienced unexpected challenges with following through on their decision. The individual reactions to these experiences were varied. Emma remembered breastfeeding as stressful and difficult. When discussing how her son had problems with latching, Emma described her experience as follows:

> Stressful… Stressful for the baby too like he crying 'ahhh!' … The doctors the – well the nurses, not the doctors the nurses. They show you how to breastfeed like you have to bring his mouth up to it and stuff like that, you have to – I just said, you know what? This is hard

Emma introduced infant formula and expressed that mixed feeding reduced her levels of stress.

> It was less stressful, because if I'm giving him the breast it's more stressful than giving him half and half, like you know like after giving the breast, you just give more in the bottle, if you want you can still give him the breast.

Emma explained that she soon switched completely over to using infant formula "because the bottle more easier."

Paula, who actively learned about the possible problems went on to succeed at reaching her breastfeeding goal despite some challenges early on.

> uh yeah, I w- the first few days he had no suction so it was very very difficult to breastfeed because he had he couldn't suck so we had to do it through a tube. I would have to like pump, put it in like a little cup and then take a syringe and like a little tube thing and try to put my finger in it, and so he wasn't eating – getting enough so we had to give him bottles at one point. He was – I just wanted to bottle feed him just for his health. 'Cause I was scared that he was going to lo – that he was losing too much weight.

When asked what she did next; after introducing some infant formula due to weight gain issues she replied:

> I don't know I just kept pushing myself and trying to – my mom and the nurses said um like I should keep trying if I really want to do it. Because when he started sucking that uh uh that I could still breastfeed.

She later added "A lot of people have a lot a lot of difficulties, I was a little like scared but I knew I could do it if I really really tried."

On her end, Gillian's challenges with breastfeeding began in the hospital with difficulty getting the baby to latch. Gillian expressed that the nurses at the hospital made the decision that her baby required infant formula. Gillian said "well they told me when I go home like I could breastfeed like if the [public health nurse] comes you know. It's not going to stop just because of like a tiny bit, you know." Gillian's attempts to give her baby breastmilk included hand expressing into a coffee cup, because the electric pump that was provided by the public health nurse was not working. Gillian's challenges were further compounded by a post-partum infection that required her to be hospitalized and separated from her infant for approximately a week and a half. Gillian explained that she tried to continue to breastfeed when she was back home, but that the medical equipment she required interfered with her breastfeeding.

> Well it was – it was bad because I had all wires everywhere so somebody would have to put him there 'cause I can't really you know – with the wi– I was attached to like ah some machine so I can't exactly go everywhere with it

Gillian expressed feeling as though the decision was no longer in her control. "I just like really wanted to but it's not my fault that I had an infection or you know."

Theme 2: Receiving support. The mothers were all aware of where to access some support services, such as public health nurses or community organizations, but they were utilized to different degrees.

The health care system in Quebec provides in-home visits by a nurse to all mothers, once discharged from the hospital. The mothers expressed dissatisfaction with some of the breastfeeding support they did receive. They expressed feeling as though they weren't being heard and that their specific support needs were not being met. Gillian struggled to feel helped both prior and post discharge from the hospital. In reference to the hospital nursing staff she stated "You'd call them to help you and like to - I guess to latch and get him to latch on and they were all busy everywhere else". She continued to feel unheard when the public health nurse visited her home. "Like, I was telling her the machine the pump wasn't working and she didn't believe me or something like you know?" Emma also expressed feeling as though the public health nurse lacked an interest in helping her. "[I felt] like she didn't want to show it to me, that she didn't want to show me how to do it. She just want me to just read the paper."

During the interviews, the mothers clearly identified their support needs. In regards to breastfeeding support there was a general consensus around modeling being necessary as a teaching tool. "I just wanted them to show me, but they would explain it to me and explain it to me and they would show me paper… and I'm like, I don't want you to *explain* it" (Paula). Emma explained, "paper is different than she showing it to you, because paper you have to read them, when she showing it to you she show you directly." Modeling as a preferred learning tool was referenced when discussing prenatal education as well. Paula expressed having learned a lot from a video that was shown during her prenatal courses and Gillian from a demonstration with a doll.

Contrary to the experiences of the mothers seeking support for breastfeeding, Amy expressed satisfaction with the written material provided to her to support her around bottle-feeding. “The doctor gave me a little chart or something…uh, how much to give her, and what size to give her when she get older and stuff like that.” Amy indicated that she kept this chart handy and referred to it often. Emma and Gillian both also expressed that when it came to preparing formula, the written instructions sufficed, whereas with breastfeeding they required a different approach. Emma spoke of the lack of step by step instructions in the written material for breastfeeding. “It doesn’t really say ok do this, do that, do that. But the bottle said ok warm up the water, blah blah blah blah”

Discussion

The objective of this study was to explore the essence of the experience of mothers with ID when faced with infant-feeding decisions, as a means to begin to understand the particular needs of this population. The mothers who participated in this study expressed the desire to provide the best possible beginning for their infants while respecting the balance between the infant’s needs and the mother’s needs. The general concept of breastfeeding as the ideal infant-feeding method was present in the mothers’ discourses. Other research has suggested that mothers (not specifically mothers with ID) internalize the ‘breast is best’ message so deeply that a fear of infant formula developed (Sheehan, Schmied & Barclay, 2010). The mothers in this study, however, did not express such fears, but rather an emphasis on the concept of choice emerged. In past studies, mothers with ID have expressed that health professionals or family members can undermine decisions they make for themselves or their baby (Höglund & Larsson, 2012). In this study, mothers felt strongly the choice was theirs to make, that is, until after the baby was born and they were faced with challenges they were not equipped to handle on their own. In these situations the mother expressed that the infant-feeding decision was no longer entirely hers to make; when the baby was premature and placed in NICU, when the baby had difficulty latching in the hospital and when maternal health complications impeded on the physical process. It cannot be known whether these difficulties could have been avoided, but attention is drawn to the prenatal period as an opportunity to reach women while they are feeling empowered as mothers and prepare them for possible challenges to come.

The importance of educating mothers during the prenatal period is further emphasized by understanding the experiences of how the mothers in this study faced challenges with breastfeeding after the baby was born. The energy invested by each mother into preparing for infant-feeding during the prenatal period was similar to the energy invested into seeking support when faced with challenges. Paula, who was determined to arm herself with as much information as possible prior to the baby's birth, went on to breastfeed her child for over a year. Gillian attended some prenatal classes but stated that she did not pay much attention to the idea that she may have difficulties with breastfeeding. When faced with obstacles she didn't reach out for more support despite knowledge of other services available to her. Emma who decided that she would "try to breastfeed", switched to infant formula as soon as she perceived breastfeeding to be difficult. Low level of commitment to breastfeeding has been reported to be associated with shorter breastfeeding duration (Nesbitt, et al., 2012). Nesbitt and colleagues describe two categories of adolescent mothers who "try" to breastfeed: those who feel there is an expectation to and those who are worried about possible complications. In this study, the mothers spoke of both familiarity with breastfeeding promotion by health professionals and of owning the decision herself. There is a discrepancy that exists in the idea that mothers have a choice to make, but that one option is promoted as better than the other. Breastfeeding has been associated with the idea of being a “good” mother (e.g. Murphy, 1999; Marshall, Godfrey & Renfrew, 2007), thus a mother who might not want to breastfeed may try because she thinks it looks better to have tried and failed than to have not tried at all. Health professionals working with mothers with ID should spend time getting to know her during the prenatal period; come to understand the motivation behind her infant feeding decisions and adjust the focus of the education accordingly. This study further supports the need for evaluations of the type, quality and suitability of perinatal supports for mothers with ID as identified by McConnell et al. (2003).

The mothers in this study expressed their learning needs. They described a preference for modeling over images or written text when being educated on breastfeeding. They voiced the need for more individualized support than what they generally received. Interestingly, different needs were identified for support with the use of infant formula. When it came to preparing infant formula, the mothers conveyed that there were fewer challenges and that written materials were a sufficient support. This difference may be due to the differing nature of the feeding methods. Breastfeeding is a relatively abstract process without clear, concrete instructions to follow. This is compounded by the fact that mothers cannot see how much milk their baby is getting at each feeding so it may be more difficult to determine how things are going. The mothers in this study who breastfed described feeling unsure about how much milk the baby was getting, whereas with infant formula, the instructions are concrete and readily available on the can. Uncertainties such as these may make the mothers feel less in control, less empowered about their infant-feeding decision. Further exploration into the reasons behind why such differences are seen is required.

Past research has demonstrated that parents with ID tend to seek support from their partner and their family members prior to seeking professional support (Llewellyn, 1995). The findings of the current study did not provide consistent information on how mothers with ID utilize their informal support networks with regards to infant feeding decisions. Future research to explore the impact of social support on infant-feeding is warranted.

This study focused narrowly on infant-feeding decisions, one aspect of the overall experience of mothering. It is important to remember that a mother's infant-feeding decisions are impacted by other postnatal experiences and personal needs (Sheehan, Schmied & Barclay, 2010). The topic of infant feeding among mothers with ID requires more study in order to better inform practice. For example, greater understanding of when formal versus informal support systems are the most impactful on creating positive infant-feeding experiences would provide some indication of where to focus future research and practice efforts.

Limitations

While phenomenology is well suited to the purpose of this study, the focus on the detailed experiences of a small number of women is a limitation in that the findings cannot be generalized to describe the population as a whole. Additionally, due to the narrowness of the subject, only one interview was planned. Though further interviews would likely have resulted in much repetition they may also have led to more comfort on the part of the participant and thus even greater depth to the description of their experience. More extensive research on the infant-feeding support needs of mothers with ID is required.

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Conflict of interest

The authors declare that there is no conflict of interest.

Table 1 Participant Information

Name (Pseudonym)	*Approx. Age*	*Relationship status*	*Number of children*	*Gender of child(ren)*	*Age of child(ren) at interview*
Gillian	40's	Single	1	Boy	4 years
Paula	30's	Cohabitating	1	Boy	2 years
Emma	30's	Single	2	Girl; Boy	4 years; 2 months
Amy	20's	Cohabitating	1	Girl	3 years

Table 2 Interview Guide

Intro: All pregnant women must think about how they want to feed their baby. Let’s talk about when you were pregnant. **Q 1**: Tell me about how you planned to feed your baby.
Intro: Now let’s talk about after the baby was born. **Q 2:** Tell me about your experiences breastfeeding/formula feeding your baby.
Intro: Let’s talk about the people in your life, such as friends and family members, who were involved in your feeding decisions. **Q 3:** Tell me about how friends or family members affected your experience with breastfeeding/formula feeding.
Intro: Let’s talk about how professionals, such as doctors, nurses or workers, were involved in your feeding decisions. **Q 4:** Tell me about any professionals affected your experience with breastfeeding/formula feeding.

Table 3 Example of clustering codes into subthemes

Being familiar with benefits of breastfeeding	**Owning the initial decision**	**Preparing for infant-feeding**
Identifying health benefits of breastfeeding Identifying financial benefits of breastfeeding Identifying pros and cons of breastfeeding	Feeling confident in her decision Wanting to breastfeed Decision was her own	Awareness of possible challenges Seeking information • Consulting with partner • Consulting with mother • Consulting with sister • Consulting with workers

CHAPTER 5: CONCLUSIONS, LIMITATIONS, IMPLICATIONS AND FUTURE DIRECTIONS

Conclusions

The purpose of this study was to begin filling the gap of knowledge by understanding what it means to be a mother with ID faced with making infant-feeding decisions. This study advances knowledge in the areas of parenting with ID and breastfeeding by providing some insight into the common experiences of mothers who have faced these particular decisions. The mothers who participated in this study expressed the desire to balance their infant's needs with their own needs in order to provide the best possible beginning for their infant. Consistent with the concepts of ecological systems theory, the study was designed and the analysis conducted with consideration given to the impact of the various contextual factors within the mothers' lives. Through the disability interpretive lens, the mothers' abilities and learning needs were considered in relation to whether support services were perceived as providing adequate adapted support, as opposed to considering whether their disability caused them to be unable to pursue their infant-feeding decision.

Limitations

As is the case with qualitative research in general, the results of this study cannot be generalized to the rest of the population. It should also be noted that because the participants were recruited from a service that addresses the particular needs of parents with ID, these four mothers may be more aware of their limitations and learning needs than mothers with ID who are not receiving services. This may further limit generalizability, though it may also add to the richness of the data due to the participants' cognizance of this element in their daily lives.

Limitations to the methodology of this study were noted within the manuscript. Upon further reflection, a combination of a more structured survey style component to complement the semi-structured interview may have yielded additional information that was missed due to flow of the conversation.

Additionally, as a less experienced researcher, I felt that the limited sample size of this study may have impacted on the quality of the information gathered from the interviews. I found myself more confident in my interviewing skills with each subsequent interview. I imagine that more interviews would have allowed me to become even more at ease and have allowed me to delve deeper into the themes as they emerged.

Implications for Social Work Practice

Breastfeeding is a topic that is often studied in healthcare context and may be overlooked in the field of social work. However arguments have been made that promote the implication of social workers within this domain. “Breastfeeding is a physiological behavior enacted within complex social, psychological and cultural influences” (Hurst, 2007, p. 209). Hurst reasons that social workers have an important role to play in supporting new mothers in receiving best practice information in regards to breastfeeding. She proposes that social workers who work with pregnant women and new mothers, should be aware of local health services and peer support or community services in order to refer to them as necessary and as a function of the mother’s individual needs. Social workers have the skills and training required to explore infant-feeding decisions with pregnant women and new mothers within the context of the socio-cultural factors involved. Thus, social workers may have an easier time understanding the need to discuss a woman's concerns and the meaning she attaches to her experiences, than some other medical professionals. However, social workers also develop familiarity and expertise within the specific services of their work. Social workers who are experienced in working with pregnant women and new mothers may not be familiar with disability studies and may benefit from specialized training, reading and subsequent reflection of their practice when working with parents with ID.

Direct implications from this study for practice are limited given its descriptive, qualitative nature. However, in understanding the experiences of these four mothers, Hurst's statements are supported. Infant-feeding decisions must be understood within the context of both the common and the individual experiences. The prenatal period is highlighted as a time when women are feeling the most empowered about their decisions and as such it provides professionals the opportunity to explore their expectations and prepare them for possible challenges to come. Many of the mothers in this study identified that they felt unheard or a lack of interest on the part of their worker. This study provides social workers, along with other professionals, an opportunity to consider their approach when working with mothers with ID. It is important that social workers identify, with the mother, how she learns best and adapt their interventions accordingly. Involving the mother in this process would allow her to feel as though her voice is heard and will ensure that adaptations are personalized. For example, the mothers in this study emphasized that modeling and videos were more helpful in learning about breastfeeding than picture-type visual aids.

Implication of social workers in infant-feeding decisions can be understood using the ecological systems theory. At the micro level, social workers can support the mother in understanding her personal motivations and making an informed infant-feeding decision by adapting to her personal learning needs. Through understanding the mother's family, friend or work networks (or the mesosystem and exosystem levels), social workers can identify support needs, and connect the mother to programs. As needed, social workers can advocate for adapted resources within the health and community resources and work collaboratively with other professionals. At the macro or policy level, social workers can be involved in influencing health policies that take into account individual or socio-cultural factors in breastfeeding promotion.

Implications for Future Research

This study broached the topic of infant-feeding decisions among mothers with ID by exploring of the experiences of four women. While the understanding of the common themes that emerged from their stories is informative, more research in this area is necessary in order to generalize findings and impact on the development of infant-feeding education and support programs. Research exploring the experiences and perceptions of the health and social service professionals who work with mothers with ID during the perinatal period would provide another perspective to the topic.

Research exploring different types of infant-feeding support among mothers with ID is also warranted. Some evidence has suggested that the decision to breastfeed is influenced more by the mother's family and peer support network than by their health care professionals (e.g. Chapman, Damio, Young & Perez-Escamilla, 2004; Dennis, Hodnett, Gallop & Chalmers, 2002; Dix, 1991; Mickens, Modeste, Montgomery, & Taylor, 2009). Additionally, research demonstrates that parents with ID tend to seek support from their partner and family members prior to seeking professional support with parenting issues (Llewellyn, 1995). Taken together, these findings highlight the need for future research to explore the influences of formal and informal support systems on infant-feeding decisions among mothers with ID.

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Appendix A: Participant Information Form

Participant Information Form

You are invited to participate in a research project titled “Mothering with an intellectual disability: A phenomenological exploration of making infant-feeding decisions”. This research is being done by Amanda Guay, a master’s student from McGill University.

The purpose of this research is to understand your experiences when you were deciding how you were going to feed your baby. Your story will help us better understand what mothers like you go through when faced with this decision.

If you want to participate, someone will interview you where you feel comfortable. A worker or friend you trust may accompany you, if you would like.

Your participation in this research is voluntary. This means that you do not have to take part. If you choose to, you can stop participating at any time without any negative impact on you, your family or the services you receive.

Your name will be kept secret. In other words, no one will know that it is you talking about your parenting experience. The information collected from the interviews will be kept in a safe and secure location.

As a part of the research, there will be a written report, where your name will not be included.

Within the interview, you will be asked to talk about experiences with feeding your baby. You will be asked to talk about your experiences in detail. You can take your time talking and you can take breaks if you need. You can also stop any interview at any time. If you feel that you would like to further discuss some of the issues with a professional, the researcher will arrange for a meeting. Telling your story also has benefits, as you are expressing yourself and sharing important parts of your life.

If you have questions, you can call the researcher, at any time, Amanda Guay, at (514) 363-3025 ext. 2273 or Dr. Delphine Collin-Vézina; delphine.collin-vezina@mcgill.ca.

Appendix B: Consent Form

Consent Form

Project title:

Mothering with an intellectual disability: A phenomenological exploration of making infant-feeding decisions.

Researcher:

Amanda Guay**,** MSW Student, under the supervision of Dr. Marjorie Aunos, Director of professional service at CROM and Dr. Delphine Collin-Vézina, professor in the School of Social Work at McGill University.

Project objectives:

This research will explore the experiences of mothers with an intellectual disability when they were deciding how to feed their baby.

Nature of your participation:

I understand that Amanda will interview me about my experiences with feeding my baby. I will be asked to talk about my experiences in detail. The researcher will plan for the interview to take 1 hour and a half. If I need a break or there is a lot to talk about and we decide that the interview cannot be finished in one meeting then a second meeting will be scheduled. The interview will be held in a place that is private and that is comfortable to me. It can take place in the office at CROM or in my home.

Financial compensation:

I understand that I will not be paid to participate in this research.

Advantages to participating in this research:

I understand that participating in this research will allow me to talk about my experiences and will help develop more knowledge so that other mothers can be supported in their decisions to feed their baby.

Disadvantages to participating in this research:

I understand that participating in this research may cause some difficulties. I understand that the interview will take some of my time. I understand that some of the questions might be personal and they may make me think of bad memories or may make me emotional. However, if I do not want to answer a question, I have the right not to. I can also take my time and take a break at any time during the interviews.

The right to stop participation at any time:

I understand that my participation in this research is a choice. I understand that I can decide to not participate in the research at any time. I understand that I do not need to tell Amanda a reason for wanting to stop. I understand that if I tell Amanda I do not want to participate in the research that it will not change any of the services I am receiving from CROM.

Confidentiality:

I understand that my answers will be kept a secret. No one, except for Amanda and her supervisors, will be able to identify my stories with my name or the names of my children. The interview notes will be kept in a safe and locked place. Paper notes will be shredded 5 years after the research project.

I understand that the interviews will be audio-recorded. Only Amanda and her supervisors will listen to the recordings of the interviews. The recordings will be kept on a computer that is locked with a password and will be completely deleted 5 years after the research project.

My responses will be kept secret. In the event that myself or my children are in danger, Amanda will have to tell the right person(s) about my experience, but I will be told beforehand.

Distribution and publication of the research results:

I accept that the global results will be included in a written report, journals and oral presentations. My name and the names of my children will not be included in these reports, articles or oral presentations.

Contact information:

If I have any questions, I can contact the researcher, Amanda Guay, at (514) 363-3025 ext. 2273; amandaguay@ssss.gouv.qc.ca or Dr. Delphine Collin-Vézina; delphine.collin-vezina@mcgill.ca at any time.

For all questions on my rights and my participation in the research project, I can contact Karoline Girard, coordinator of ethics in research for the CERC/CRDI-TED at (819) 376-3984 ext. 347; karoline_girard_csdi@ssss.gouv.qc.ca.

If the researcher does something that makes me feel uncomfortable or if she does not respect the conditions of my participation, I can make a complaint to: the complaints commissioner, Mr. Stuart Rechnitzer at (514) 363-3025 ext. 2203; srechnitzer.crom@ssss.gouv.qc.ca.

I understand that by agreeing to this research I do not give up any of my legal rights nor do I release the researcher (Amanda) or the institutions (CROM and McGill) from their legal and professional responsibilities.

Please answer true or false to each of the questions below.

The purpose of this study is to understand my experiences and experiences of mothers like me	**True**	**False**
I can choose whether I want to participate or not	**True**	**False**
I can ask to stop the interview at any time	**True**	**False**
I can change my mind, even after agreeing to participate	**True**	**False**
My name and my child's name will not be used in any written reports	**True**	**False**
My decision to participate or not, will not change any services I receive from CROM/WMRC	**True**	**False**

Declaration of participant:

I declare that I understand the consent form and I understand the nature of my participation in the research project.

I received a copy of the consent form to keep for my own records.

I accept to participate in the research to understand more about the mothers' experiences feeding their babies, done by Amanda Guay, master's student, under the supervision of Marjorie Aunos, PhD (CROM) and Delphine Collin-Vezina, PhD (McGill University)

Participant's name (printed letters): ___________________________

Participant's signature:______________________________________

Date: ______________________

Declaration of researcher:

I declare that I have explained the terms of this form to the participant and I have answered all questions related to the form and the project. I declare that I have clearly indicated that the participant may end participation at any time. I declare that I will respect the objectives of the study and the participant's confidentiality.

Researcher's name (printed letters): _________________________

Researcher's signature: ___________________________________

Date: _________________________