Feeding Infants with Down Syndrome

Master’s Thesis

Presented to
The Faculty of the Graduate School of Arts and Sciences
Brandeis University
Genetic Counseling Program

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In Partial Fulfillment
of the Requirements for
Master’s Degree

by
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May 2011
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Acknowledgments

My deepest gratitude goes to the mothers who answered the survey. Their responses gave richness to the data and provided new insight into this topic, and I thank them for taking the time and care to answer the questions fully. I am also in debt to my committee members who helped design the project and present the data. Thank you to Elaine Hiller, Angela Lombardo, Dr. Emily Davidson, and Dr. Barbara Philipp. Your expertise, interest, and attention carried me through this work. Finally, I greatly appreciate the various forms of support I received. Thank you to Beth Rosen Sheidley and the Brandeis Genetic Counseling Program for structural support. Thank you to Scott Motyka and Leslie Mandel for statistical support. Thank you to my classmates and family for practical and emotional support. This final product is shared by all of us and dedicated to the families of children with Down syndrome.
Abstract

Breastfeeding reduces the likelihood of selected adverse health outcomes such as postpartum depression in the mother and acute otitis media in the child. Learning to breastfeed can present challenges, however, and may become overwhelming to a parent. Infants with Down syndrome (DS) have physical features and medical issues that may complicate breastfeeding even further. While these characteristics have long been recognized, the experience of breastfeeding an infant with DS has not been previously assessed within the United States population. The purpose of the current study was to gather both qualitative and quantitative information pertaining to breastfeeding from mothers of children with DS. An online survey of 56 questions was posted on the websites of three different DS organizations. A total of 98 responses were collected. Rates of breastfeeding in this sample were found to be 84% for initiation (N=98) and 56% and 42% for duration to 6 and 12 months, respectively (N=78), all of which exceed the general population rates in the United States of 73%, 42%, and 21%. Previous breastfeeding experience, breastfeeding normality amongst the participant’s family and friends, birth order, and days spent in the hospital influenced breastfeeding, while congenital medical conditions, surgery, poor infant health, and belief in the capability of infants with DS to breastfeed did not. Substantial difficulty with breastfeeding was reported in relation to the diagnosis, however, which may have been partially the result of the reported inconsistency and deficiency of information that the participants were provided regarding breastfeeding an infant with DS. The overwhelming majority of
participants expressed the desire to breastfeed and described an increased motivation in response to the diagnosis, with the hope of improving their child’s health and development. These data provide more complete information that medical professionals may use when communicating with families of an infant with DS.
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Introduction

Just over 25 years ago, the Surgeon General held a workshop to evaluate breastfeeding trends, breastfeeding disparities, and federal comments on or programs directed toward breastfeeding. The workshop was ultimately used to make recommendations that would promote and support breastfeeding in the United States (Grummer-Strawn & Shealy, 2009). Research demonstrating the health benefits to both mother and child likely spurred this governmental focus. A woman who breastfeeds has a reduced risk of type 2 diabetes, breast cancer, ovarian cancer, and postpartum depression (Ip, 2007). A breastfed infant has a lower chance of developing atopic dermatitis, acute otitis media, childhood asthma, severe lower respiratory tract diseases, non-specific gastroenteritis, necrotizing enterocolitis, obesity, types 1 and 2 diabetes, childhood leukemia, and sudden infant death syndrome (Ip, 2007). Recognition of these advantages began to be published in the early 1980’s, and in 1989 the United Nations put forth a document stating in Article 24 that State Parties should take action “to ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in … the advantages of breastfeeding …” (Nations, 1989). This recommendation falls within the section regarding a child’s health and suggests that denying an infant the opportunity to breastfeed would lessen the quality of his/her health care. More recently, the United States government has specifically addressed breastfeeding in its program Healthy People, which identifies the most relevant health
issues for people in the United States. Among the goals for 2010 were that 75% of
infants initiate breastfeeding, 50% breastfeed for six months, and 25% breastfeed for 12
months (Scanlon, 2010). These same goals for 2020 have been increased to 81.9%,
60.6%, and 34.1%, respectively (Services). The message that “breast is best” has also
permeated consumer literature. As an example, the popular book What to Expect the
First Year cites the many physical and mental health benefits to both the mother and the
baby, provides advice for establishing and continuing breastfeeding, and strongly advises
to breastfeed whenever possible (Murkoff, 2003).

In opposition to these desirable health benefits and explicit recommendations,
however, stand a number of challenges. Lack of knowledge, social norms, poor family
and social support, embarrassment, lactation problems, employment, childcare, and
inadequate access to health care can negatively influence breastfeeding rates (Services,
2011). Efforts to reduce these barriers have dramatically changed breastfeeding in the
United States over the last 40 years. In the early 1970’s, only 26.5% of newborns
initiated breastfeeding and 5.4% were still breastfeeding at 6 months of age (Grummer-
Strawn & Shealy, 2009). An increase in breastfeeding for any length of time, from 60% to
77% percent, was observed for infants born during 1993-1994 compared to those born
during 2005-2006 (McDowell, 2008). More specifically, the national data for children
born during 2003-2006 show rates of 73.4%, 41.7%, and 21.0% for initiation, duration to
six months, and duration to 12 months, respectively (Scanlon, 2010). It appears that the
breastfeeding campaigns have encouraged more mothers to breastfeed their children, but
that this option still does not work for every family. There are huge disparities in
breastfeeding rates with regard to race, income, maternal age, maternal education, and
marital status, showing up to a 20% variance between different sub-groups (Prevention, 2010). No data exist, however, to address the potential disparities among infants with disabilities.

On top of prevailing demographic and social factors, mothers of infants with DS are presumed to face additional obstacles when breastfeeding, though this idea is relatively unexplored. Books that describe DS mention that these infants have more difficulty breastfeeding and comment that medical professionals may incorrectly tell new families that breastfeeding is not possible (Cunningham, 1996; Skallerup, 2008). Infants with DS certainly must meet a number of challenges. One study compared anomalies at birth in 2.5 million control infants to 2,894 infants with DS and found a higher incidence of the following in DS: hypotonia, cardiac defects, digestive system problems, eye cataract, respiratory system defects, genital differences, anomalies of the extremities, urinary system problems, hydrocephalus, hernia, and cleft palate (Torfs & Christianson, 1998). Research also shows that children with DS more frequently become sick (head/chest colds or stomach/intestinal illnesses), visit a medical office, go to the emergency room, and require surgery or other medical procedures (Schieve, Boulet, Boyle, Rasmussen, & Schendel, 2009). Any of these anomalies or health issues could interfere with breastfeeding. One book that covers breastfeeding in great detail includes a short discussion about DS, recognizing that some infants may struggle at first due to hypotonia, a small mouth size, a less demanding personality, cardiac defects, and intestinal problems (Newman, 2006). Evidence also exists that hypotonia, which is commonly associated with DS, can make breastfeeding difficult for any infant, especially since it impacts sucking behavior (Thomas, Marinelli, Hennessy, & Protocol, 2007).
along with several other disorders that impair neurologic function, can result in a depressed and poorly sustained sucking reflex, which requires intervention to successfully breastfeed (Danner, 1992). Taken together, the literature does indicate that infants with DS most likely must overcome a number of barriers before they can establish successful breastfeeding.

A few studies have looked at the breastfeeding rates of infants with DS and tried to identify the source of difficulties in establishing and/or maintaining breastfeeding (Al-Sarheed, 2006; Aumonier & Cunningham, 1983; Colon et al., 2009; Hopman et al., 1998; Murdoch, 1991; Pisacane et al., 2003; Weijerman et al., 2008). None of these analyzed the rates in the United States, however, and the results are not consistent from one group to the next in terms of breastfeeding rates and the characteristics of DS that affect breastfeeding. Mothers of children with DS have requested that medical professionals provide information about DS that is complete, accurate, balanced, and realistic and discuss fully the concerns most relevant to infancy when the diagnosis is made (Skotko BG, 2009). Currently, mothers often report negative experiences related to their child’s diagnosis because these criteria are not met (Skotko, 2005). The interaction between breastfeeding and DS would be an essential piece of information to share with families, but it is not well understood. The aims of this study were to gather perceptions regarding the ability of infants with DS to breastfeed, identify potential barriers to breastfeeding infants with DS, and learn about the experience of breastfeeding infants with DS.
Methods

Study Design

This was a cross-sectional study of mothers of children with DS that utilized a self-administered, anonymous online survey to quantitatively and qualitatively assess breastfeeding experiences, perceptions, and barriers in a United States population. The study was reviewed by the Brandeis University Institutional Review Board (IRB Protocol #11087).

Study Sample

The participants were recruited through the Massachusetts Down Syndrome Congress (MDSC), the National Down Syndrome Congress (NDSC), and the National Down Syndrome Society (NDSS). The MDSC and NDSC sent the link to the survey along with the recruitment notice to their members through an established listserv and the NDSS posted the survey along with the recruitment notice under the “research” page of their website. (Appendix A.) To be eligible for the study, the participants had to be the biological mother who gave birth to and raised a child with DS in the United States during the first 12 months of life. The mother also had to be 18 or more years of age at the time of the survey and able read English.
Data Collection

All participants completed the anonymous online survey available through the software Qualtrics. (Appendix B.) The survey contained a mixture of 56 qualitative and quantitative questions and was subdivided into five parts: screening, DS characteristics, understanding/support, breastfeeding, and demographics. The “screening” section ensured that only eligible participants answered the survey. The “DS characteristics” section gathered information regarding the child’s health at birth and during the first month of life. The “understanding/support” section ascertained the knowledge of the participant and her surrounding community regarding DS and breastfeeding, as well as the participant’s perceived support in breastfeeding. The “breastfeeding” section collected data about the experience of breastfeeding. The “demographics” section gathered general information. The survey was open for a total of four weeks from February to March 2011.

Data Analysis

The data were downloaded into and analyzed with the Predictive Analytics SoftWare Statistics 18 program. The frequency of responses for each quantitative variable was calculated. The relationship between breastfeeding and each quantitative variable was assessed using methods including the Chi-square test, Independent Samples T Test, and Pearson Correlation test. The qualitative comments from the participants about their experience were screened for recurrent themes by hand.
Results

Demographics

Demographic data are summarized in Table 1. Most of participants were over the age of 40 years, non-Hispanic white, well-educated, and had an annual household income of $50,000 or more. All of the participants were mothers of a child with DS, and most of these children were under the age of 10 years at the time of the survey and represented either the first or second birth to their mother.
Table 1: Demographic Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (N)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td>30-39</td>
<td>21</td>
<td>23.6</td>
</tr>
<tr>
<td>40-49</td>
<td>41</td>
<td>46.1</td>
</tr>
<tr>
<td>50-59</td>
<td>19</td>
<td>21.3</td>
</tr>
<tr>
<td>60-69</td>
<td>5</td>
<td>5.6</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>American Indian or Alaskan Native</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Asian</td>
<td>2</td>
<td>2.2</td>
</tr>
<tr>
<td>Black or African American</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Native Hawaiian or other Pacific Islander</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>white, Hispanic or Latina</td>
<td>3</td>
<td>3.3</td>
</tr>
<tr>
<td>white, non-Hispanic</td>
<td>86</td>
<td>94.5</td>
</tr>
<tr>
<td>other</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Highest Education Completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School/GED</td>
<td>5</td>
<td>5.5</td>
</tr>
<tr>
<td>Some College</td>
<td>8</td>
<td>8.8</td>
</tr>
<tr>
<td>2-year College Degree</td>
<td>7</td>
<td>7.7</td>
</tr>
<tr>
<td>4-year College Degree</td>
<td>36</td>
<td>39.6</td>
</tr>
<tr>
<td>Masters Degree</td>
<td>31</td>
<td>34.1</td>
</tr>
<tr>
<td>Doctoral or Professional Degree</td>
<td>4</td>
<td>4.4</td>
</tr>
<tr>
<td>Annual Household Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>under $20,000</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>$20,000-49,999</td>
<td>10</td>
<td>11.5</td>
</tr>
<tr>
<td>$50,000-99,999</td>
<td>30</td>
<td>34.5</td>
</tr>
<tr>
<td>$100,000-149,999</td>
<td>26</td>
<td>29.9</td>
</tr>
<tr>
<td>$150,000 or above</td>
<td>20</td>
<td>23.0</td>
</tr>
<tr>
<td>Child's Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>39</td>
<td>48.1</td>
</tr>
<tr>
<td>6-10</td>
<td>17</td>
<td>21.0</td>
</tr>
<tr>
<td>11-15</td>
<td>6</td>
<td>7.4</td>
</tr>
<tr>
<td>16-20</td>
<td>7</td>
<td>8.6</td>
</tr>
<tr>
<td>21 or older</td>
<td>12</td>
<td>14.8</td>
</tr>
<tr>
<td>Child's Birth Order</td>
<td></td>
<td></td>
</tr>
<tr>
<td>first</td>
<td>38</td>
<td>41.8</td>
</tr>
<tr>
<td>second</td>
<td>29</td>
<td>31.9</td>
</tr>
<tr>
<td>third</td>
<td>16</td>
<td>17.6</td>
</tr>
<tr>
<td>fourth or higher</td>
<td>8</td>
<td>8.8</td>
</tr>
</tbody>
</table>

Breastfeeding

Data on breastfeeding are presented in Table 2 and Figures 1, 2, and 3. 54.9% of participants had previous breastfeeding experience. 87.6% had planned on breastfeeding.
before they knew their child had DS, and this plan did not change after the diagnosis was made. 84% breastfed for more than one week. The proportion of participants breastfeeding to 6 months and 12 months was 56% and 42%, respectively. A variety of breastfeeding methods were used by the participants, including the traditional form (baby sucking directly at the breast), a cup, a bottle, a supplemental nursing system (baby sucking at the breast with a tube taped to the breast that connects with a container filled with milk), and other methods. The other methods reported by the participants were delivering breast milk by syringe, eyedropper, finger feeder, washcloth, and nasogastric tube.

Table 2: Breastfeeding Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (N)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous Breastfeeding Experience</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>50</td>
<td>54.9</td>
</tr>
<tr>
<td>no</td>
<td>41</td>
<td>45.1</td>
</tr>
<tr>
<td>Plan to Breastfeed before Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>85</td>
<td>87.6</td>
</tr>
<tr>
<td>no</td>
<td>9</td>
<td>9.3</td>
</tr>
<tr>
<td>undecided</td>
<td>3</td>
<td>3.1</td>
</tr>
<tr>
<td>Plan to Breastfeed after Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>85</td>
<td>87.6</td>
</tr>
<tr>
<td>no</td>
<td>10</td>
<td>10.3</td>
</tr>
<tr>
<td>undecided</td>
<td>2</td>
<td>2.1</td>
</tr>
</tbody>
</table>
Figure 1: Breastfeeding Rates

Did you breastfeed your child?
(N=98)

- 84%
- 9%
- 1%
- 0%

- yes
- one week
- no

Figure 2: Breastfeeding Methods

What methods of breastfeeding did you use?
(N=89)

- Traditional
- Bottle
- SNS
- Other
Data concerning the characteristics related to DS for the participants’ children are shown in Table 3, Figure 4, and Table 4. The diagnosis of DS was made after birth for 78% of participants’ children, 95.9% of the children had at least one congenital medical condition, and 6.2% of the children required surgery during the first month of life. The “other” medical conditions listed by the participants included pleural effusion, hypoglycemia, difficulty with thermoregulation, intrauterine stroke, thrombocytopenia, pulmonary hypertension, jaundice, low APGAR scores, pneumonia, hypermobility, and breathing issues. Out of the six participants whose children required surgery, four of the surgeries were reportedly for duodenal atresia and two for a cardiac defect. On average at birth, the children weighed 6.6 pounds, had 1.9 medical conditions, and stayed in the
hospital for 9.3 days. On average during the first month of life, the children stayed in the hospital a total of 10.2 days, visited a medical professional for illness 1.2 times, and became ill 0.6 times. Overall, the participants rated their children’s health during the first month of life at 5.09 on a scale of 1 (very unhealthy) to 7 (very healthy).

Table 3: Down Syndrome Characteristics Frequencies

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (N)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down Syndrome Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>before birth</td>
<td>20</td>
<td>22.0</td>
</tr>
<tr>
<td>after birth</td>
<td>71</td>
<td>78.0</td>
</tr>
<tr>
<td>Medical Condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>hypotonia</td>
<td>83</td>
<td>85.6</td>
</tr>
<tr>
<td>heart defect</td>
<td>49</td>
<td>50.5</td>
</tr>
<tr>
<td>digestive system problem</td>
<td>9</td>
<td>9.3</td>
</tr>
<tr>
<td>eye cataract</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>respiratory system defect</td>
<td>7</td>
<td>7.2</td>
</tr>
<tr>
<td>genital difference</td>
<td>6</td>
<td>6.2</td>
</tr>
<tr>
<td>extremity anomaly</td>
<td>6</td>
<td>6.2</td>
</tr>
<tr>
<td>urinary system problem</td>
<td>4</td>
<td>4.1</td>
</tr>
<tr>
<td>hydrocephalus</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>hernia</td>
<td>6</td>
<td>6.2</td>
</tr>
<tr>
<td>cleft palate</td>
<td>1</td>
<td>1.0</td>
</tr>
<tr>
<td>other</td>
<td>13</td>
<td>13.4</td>
</tr>
<tr>
<td>any condition</td>
<td>93</td>
<td>95.9</td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>6</td>
<td>6.2</td>
</tr>
<tr>
<td>no</td>
<td>91</td>
<td>93.8</td>
</tr>
</tbody>
</table>
Figure 4: Medical Conditions at Birth

Table 4: Down Syndrome Characteristics Averages

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Responses (N)</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Weight</td>
<td>97</td>
<td>6.56</td>
<td>1.2</td>
<td>3.06-8.94</td>
</tr>
<tr>
<td>Total Number of Medical Conditions</td>
<td>97</td>
<td>1.92</td>
<td>1.0</td>
<td>0-4</td>
</tr>
<tr>
<td>Days in Hospital after Birth</td>
<td>76</td>
<td>9.34</td>
<td>10.7</td>
<td>0-66</td>
</tr>
<tr>
<td>Total Days in Hospital during First Month</td>
<td>76</td>
<td>10.18</td>
<td>12.6</td>
<td>0-66</td>
</tr>
<tr>
<td>Number of Medical Visits for Poor Health</td>
<td>96</td>
<td>1.24</td>
<td>4.1</td>
<td>0-30</td>
</tr>
<tr>
<td>Number of Times Sick</td>
<td>95</td>
<td>0.55</td>
<td>3.1</td>
<td>0-30</td>
</tr>
</tbody>
</table>
Understanding/Support

The understanding of the impact of DS on breastfeeding was analyzed by asking the perceived capability of these infants to breastfeed. These data are summarized in Figure 5. Most participants believed that infants with DS fell between moderately capable and capable with regard to breastfeeding. Breastfeeding support was measured in a variety of ways. On average, the participants believed they received good support from the people around them, as shown in Figure 6. The average satisfaction the participants reported with the birth hospital’s support of breastfeeding fell between satisfactory and quite satisfactory. Of 92 participants who responded to the question, 31.5% were breastfed by their own mother. The average “normality” of breastfeeding among the participants’ family and friends was reported between normal and quite normal.
Figure 5: Belief in Capability to Breastfeed

![Belief in Capability to Breastfeed](image1)

Figure 6: Breastfeeding Support

![Breastfeeding Support](image2)
Relationships

There was no significant relationship between breastfeeding and maternal age, race, or education. A negative correlation of -0.224 existed between breastfeeding duration and annual household income (N=69, p=0.065). No significant relationship was found between breastfeeding and maternal age at the child’s birth nor the child’s age at the time of the survey. A positive correlation of 0.232 existed between breastfeeding duration and the child’s birth order (N=73, p=0.048). A participant who had previous breastfeeding experience was more likely to breastfeed for a longer period of time (t (71)=3.08, p=0.003).

There was no significant relationship between breastfeeding and timing of the DS diagnosis (before vs. after birth), a specific medical condition, the presence of any one medical condition, the total number of medical conditions, or requirement for surgery. A participant whose child weighed more at birth was more likely to breastfeed for a longer period of time (t (96)=2.49, p=0.015). A negative correlation of -0.251 and -0.253 existed between breastfeeding duration and days in the hospital at birth and days in the hospital during the first month of life, respectively (N=64, p=0.045 and N=64, p=0.044, respectively). No significant relationship was found between breastfeeding and the number of sick visits, the number of times the child became ill, or the participant’s rating of the child’s health.

There was a positive correlation of 0.365 and 0.267 between breastfeeding duration and belief in breastfeeding capability as perceived by the participant’s partner and by a lactation specialist, respectively (N=30, p=0.047 and N=52, p=0.055,
respectively). No significant relationship existed between breastfeeding and any other person’s belief in breastfeeding capability nor the average value of perceived capability for all persons. No significant relationship was found between breastfeeding and the level of support the participant received nor their satisfaction with the hospital’s breastfeeding support. A participant who was breastfed by her own mother was more likely to breastfeed for a longer period of time (\( t(72) = 2.14, p = 0.036 \)). A participant was more likely to breastfeed when the value of breastfeeding normality among their parents, siblings, and friends was high (\( t(76) = 2.32, p = 0.023 \); \( t(71) = 2.29, p = 0.025 \); and \( t(87) = 1.81, p = 0.074 \), respectively). A negative correlation of -0.450, -0.278, and -0.353 existed between the child’s age at the time of the survey and belief in breastfeeding capability of the obstetrician, nurses at the hospital, and nurses at the pediatrician’s office, respectively (\( N = 29, p = 0.001 \); \( N = 62, p = 0.029 \); and \( N = 35, p = 0.038 \), respectively). A negative correlation of -0.283, -0.222, -0.304, -0.228, -0.225, and -0.394 was found between the child’s age at the time of the survey and the level of support the participant received from her partner, parents, obstetrician, nurses at the hospital, nurses at the pediatrician’s office, and a DS organization, respectively (\( N = 70, p = 0.018 \); \( N = 57, p = 0.096 \); \( N = 49, p = 0.034 \); \( N = 70, p = 0.058 \); \( N = 45, p = 0.091 \); and \( N = 26, p = 0.046 \), respectively).

Qualitative Data

Throughout the survey, participants were given open-ended questions that further addressed their experience of breastfeeding. Certain themes became apparent in their
answers. In response to “Please explain how the diagnosis of Down syndrome did or did not affect your plans to breastfeed”, slightly over half (55%, N=89) of the participants reported that the diagnosis had no effect. About 15% of the participants discussed an increased commitment to breastfeed because of the diagnosis, hoping to improve their child’s health, give their child any advantage possible, and find a way to help their child themselves. The following two quotes serve as good illustrations:

_The diagnosis of Down syndrome actually encouraged me to breastfeed even more, because I knew that the nutrition was superior to anything else for him. I knew that he was at risk for different health issues, so I wanted to give him the best start possible._

_It made my decision stronger, knowing that it would give my son an advantage and would empower me in a situation that made me feel like I had lost some power, given the fact that my son had been born with Down syndrome. It was a good way for me to feel very useful to my son._

Another 12% of the responses explained that the diagnosis itself did not influence the decision to breastfeed, but the characteristics of DS (such as a heart defect, hospitalization, and surgery) made breastfeeding difficult. Finally, about 10% of the participants commented that the diagnosis prompted concern from themselves and their medical team that the child would struggle with breastfeeding.

The participants were then asked “Please describe the factors that influenced your decision to breastfeed or not. In other words, why did you breastfeed or not breastfeed?” There were a total of 96 responses, and many of them described multiple reasons for their decision, including improving their child’s health and development (67%), wanting to bond with their child (19%), having previous experience with breastfeeding (19%),
difficulty in establishing breastfeeding (12%), and the ease and low cost of breastfeeding (10%) Another 4% simply chose not to breastfeed. The selection of quotes below exemplifies these themes:

*I had breastfed my older two children successfully and always planned on breastfeeding my twins (one with Ds and one without). I think it's healthier for the child and the mother. I found it easier with my older two, and I appreciated the savings vs. buying formula.*

*I breast fed for many reasons, first for my baby's health, for the bonding experience, and lastly to help with her hypertonia in her month.*

*I wanted to do anything that would help my baby and I knew breast feeding would be good nutritionally, good for her immune system, good for the tone in her mouth and face and wonderful for our bonding, and in the end easier and very rewarding for me as a first time mother.*

*My child had a difficult time latching on and we just wanted him to come home from the hospital - if we had gone the breast-feeding route he would have had to have learned that before he came home.*

*I was not able to continue to breastfeed due to my daughter's inability to suckle properly. I am an experienced breastfeeding mother. She simply did not have the strength (most likely due to her heart defects) and I was unable to continue pumping after several months.*

After the participants rated how capable of breastfeeding they thought infants with DS were before they had their own child, the survey asked them to explain why they had this belief. Out of 76 responses, 28% of the participants wrote that they never had considered the effect that DS may have on breastfeeding. One participant commented:

*I didn't know any better, I guess. I knew that DS affected cognitive ability and intelligence, but I didn't think it affected as basic an activity as eating. I didn't*
know what low tone meant except that it meant he was floppier, but again -- I didn't know enough to know it affected his ability to nurse. It didn't seem to affect his ability to suck, so I never thought about it.

Two similar themes were that the participant had no knowledge of DS (25% of responses) or no knowledge that their child had DS (13% of responses), and therefore never even had a chance to make a connection between DS and breastfeeding. Another 18% of participants replied that they did their own research through books, the internet, and other parents of children with DS, while only 5% of participants reported that a medical professional provided them with information.

The survey also asked the participants to share what other people had told them about breastfeeding an infant with DS. The participants reported being informed that infants with DS cannot breastfeed (12%), breastfeeding would be difficult (32%), infants with DS may or may not breastfeed just like other infants (10%), and breastfeeding would eventually work if they kept trying (17%) (N=83). The following quotes show this variety:

I was told by the lactation specialist at the hospital that my daughter would not be able to breastfeed, to not even bother trying. Other medical specialists had little to say to encourage me.

When I first asked to breastfeed my baby, the nurse said,"Honey, babies w/DS usually can not breastfeed, b/c their low muscle tone, prevents them from being able to suck strong enough ."

Many mentioned that he may tire more easily and not be able to latch well, both of which were true at different times.
They told me that the ability was not absolute either way, that some children with DS were able to figure it out and had the tone to accomplish it and some might not be able to do it, really depended on each individual child, but that it was the right thing to try and work at it for awhile to determine if like other babies, it was just taking awhile, or whether or not the child really could not do it due to low tone

most of the professionals said, "don't give up...give her time."

my husband and the nurses/lactation specialist at the hospital seemed to think it was possible but would take time for baby to get the strength needed for it, to keep trying.

In another 18% of the responses, the participant reported having received a lot of support from a lactation specialist. Finally, 12% of the participants said that there had been no discussion with anyone about breastfeeding infants with DS.

The participants were additionally asked in the survey “Overall, how did you feel about your experience of breastfeeding? Why?”. In total, 86 of the participants answered the question, and related feelings of high satisfaction with or love of the experience (46%), the meaningfulness of breastfeeding for their own emotional connection and their child’s physical health (37%), difficulty with the experience (31%), and great disappointment in not breastfeeding or not continuing to breastfeed longer (16%). Most often, each response included a range of feelings, as the following examples show:

Extremely disappointed that I was unable to breastfeed. I believed that of all my children, she needed to breastfeed more than my other children, and my inability to breastfeed was actually more devastating to me than finding out that she had Down syndrome!
Extremely positive. It was a peaceful time for me to feel like I was contributing to my child something valuable. Her slow nursing made me slow down and think about what I did have instead of worry about what I didn't. It helped me adjust to the shock of having a special needs infant.

The most difficult thing I ever did. It took him five weeks to gain his birth weight back. He had terrible tongue thrust, inconsistent suckle, never let me know when/if he was hungry. It is also the most rewarding! By 5 months, he was at the 50% of a typical child in height & weight. He's never been sick and he's a year old. He's doing great! His jaw muscles are strong & no longer has tongue thrust. So glad I did it/am doing it!
Discussion

Literature addressing the experience of breastfeeding infants with DS is scarce, though a selection of studies outside the United States have documented research in this area. A few of these reported rates of breastfeeding, giving ranges of 45-90% for initiation, 21-55% for continuing for one month or more, and 31% for continuing to six months (Al-Sarheed, 2006; Aumonier & Cunningham, 1983; Colon, et al., 2009; Hopman, et al., 1998; Weijerman, et al., 2008). When comparing to control groups, however, these studies showed that infants with DS may breastfeed at lower, equivalent, or higher rates than infants without DS (Al-Sarheed, 2006; Aumonier & Cunningham, 1983; Colon, et al., 2009; Hopman, et al., 1998; Pisacane, et al., 2003; Weijerman, et al., 2008). In the current study, 84% of participants breastfed for more than one week. Of note, this value is above the Healthy People 2020 goal of a 81.9% breastfeeding initiation rate and the actual initiation rate in the United States of 73.4% for the general population. The duration of breastfeeding to 6 months and 12 months (56% and 42%, respectively) for this current study are also considerably higher than the general rates (41.7%, and 21.0%, respectively) in the United States. These data indicate that despite any challenges DS may or may not present, breastfeeding is most certainly possible for some families.

Previous studies have suggested what some of the challenges may be. Breastfeeding an infant with DS has been reported to be negatively associated with cardiac defects, shortage of information about DS, lack of support from the medical
community, and hospitalization, but not socioeconomic status (Al-Sarheed, 2006; Aumonier & Cunningham, 1983; Murdoch, 1991; Pisacane, et al., 2003). The current study tested these factors as well as several other factors hypothesized by these previous studies to impact breastfeeding. Here, the duration of breastfeeding was shown to be shorter when annual household income was high, the child was the firstborn, the participant had no previous breastfeeding experience, the infant spent more days in the hospital, the partner or lactation specialist believed these infants less capable of breastfeeding, the participant was not breastfed by her own mother, and breastfeeding was not considered normal among the participant’s family and friends. These results were expected based on previous research, with the exception of the trend involving income. Other studies have shown a positive relationship between breastfeeding and annual household income. The finding from this current study may be a consequence of the overall affluence of the study population. Interestingly, the study did not show a relationship between breastfeeding and the infant having one or more medical conditions, requiring surgery, nor becoming ill more frequently. Also, no relationship was found between breastfeeding and the participant’s or medical professionals’ belief in the capability of infants with DS to breastfeed nor breastfeeding support. The data suggest that breastfeeding depends much more heavily on a mother’s personal experience and social structure than anything specific to DS.

The responses gathered from the open-ended questions support this conclusion. About 70% of the participants maintained that the diagnosis of DS either did not change their plan to breastfeed or increased their commitment to breastfeeding. Some people may consider breastfeeding an infant with DS more important than breastfeeding a
typical infant because some of the health advantages directly relate to issues that are more prevalent in DS. In particular, the following conditions have both a lower incidence in breastfed individuals and a higher incidence in individuals with DS: atopic dermatitis, otitis media, childhood asthma, gastroenteritis, obesity, types 1 and 2 diabetes, and childhood leukemia (Ip, 2007; Roizen, 2003; Schieve, et al., 2009). Breastfeeding also protects against dental malocclusion, enhances oral motor strength and coordination, improves neurocognitive ability, and improves outcomes for congenital heart disease, all of which are issues seen in individuals with DS (Thomas, et al., 2007). The goal of improving health and development was introduced by a number of participants, supporting the idea that DS may in many cases encourage rather than inhibit breastfeeding.

The presence of DS cannot be discounted entirely, however. About 22% of the participants reported that the child’s condition either raised concern over the possibility of breastfeeding or actually interfered with the ability to breastfeed. Well over half of the participants used more than one method of breastfeeding, and several participants reported trying numerous and involved techniques, indicating that DS can present a genuine challenge to breastfeeding. Many participants discussed a high level of difficulty and expressed disappointment because they were not able to breastfeed as they would have liked. One previous study found that 84.6% of infants with DS experienced some impediment to sucking (Colon, et al., 2009). It seems, based on the data, that DS can truly be a significant factor in the experience of breastfeeding.

Because the current study group included mothers who gave birth to their infant with DS from a wide range of years, trends over time were examined by comparing the
child’s age to other variables. There was no indication that the overall rate of breastfeeding has increased or decreased in the last 30 years, though the small number of participants in some age brackets precludes a firm conclusion. It was observed that the perceived belief in breastfeeding capability held by obstetricians, hospital nurses, and nurses at the pediatrician’s office and the support of breastfeeding by partners, parents, obstetricians, hospital nurses, nurses at the pediatrician’s office, and DS organizations has increased over time. Currently, it seems that no consensus exists amongst medical professionals or the general public regarding the capability of infants with DS to breastfeed; participants reported comments that ranged from complete incapability to unhindered capability. Furthermore, very few of the participants received information regarding breastfeeding their infant from a medical professional and many participants never considered that DS could have an effect on breastfeeding. It is important that future research address the remaining barriers as well as successful strategies for breastfeeding infants with DS. This would better equip medical professionals to discuss breastfeeding with parents of infants with DS, allowing them to prepare appropriately and optimize their experience.

The current study, of course, has limitations. The sample size was small and geographically limited, with a majority of the participants residing in the Commonwealth of Massachusetts. The demographic was largely white, affluent, and well educated, relative to the general United States population. Survey recruitment may also have attracted a biased sample of particularly motivated participants and/or participants who had strong feelings, either positive or negative, about their breastfeeding experience. Finally, the survey focused on very specific topics that were predicted to influence
breastfeeding, but may have missed other important variables. Despite these limitations, however, the wealth of information generously provided by the participants gives new insights about the experience of breastfeeding an infant with DS. In addition, it provides foundational information for future studies involving larger and more representative groups of mothers. One might hypothesize, for example, that to the extent that the mothers in this study had difficulty navigating the complexities of feeding an infant with DS, mothers with fewer resources might have even less access to the support and information they need.
Conclusion

Breastfeeding an infant with DS is entirely possible for some families. Aside from increased time spent in the hospital, the features and potential complications of the diagnosis investigated in this study had no significant influence on breastfeeding. Factors that were found to correlate with breastfeeding stood independent of DS. Despite this, issues surrounding DS can introduce added complexity and difficulty to the process of breastfeeding, leaving the potential for frustration and disappointment with the entire experience. The presence of this adversity may carry substantial weight for families, as indicated by this study population that the diagnosis itself can generate both a strong motivation to breastfeed and negative memories of the experience. Medical professionals can and should play a primary role in helping mothers gain knowledge and support regarding feeding infants with DS, so that the ambiguity of the capability of infants with DS to breastfeed may be resolved and the issue may be discussed more concretely with families. The message to mothers of infants with DS should be that the diagnosis need not change their plans to breastfeed because many infants do have this capability. The process may still be challenging, however, so these families should be given accurate information, proper attention, and open support.
References


Appendix A: Recruitment Notice

Feeding Infants with Down Syndrome

Are you the mother of a child with Down syndrome? You are invited to answer survey questions about your experience of feeding your child when s/he was an infant. The goal of this study is to better understand how feeding is established in newborns who have Down syndrome and how future families may be helped with this process.
Appendix B: Survey

SCREENING

1. Do you have a child with Down syndrome?
   -yes
   -no \textit{(survey ends for this response)}

2. Do you have more than one child with Down syndrome?
   -yes \textit{(survey ends for this response)}
   -no

3. Are you the biological (not adoptive) mother of your child with Down syndrome?
   -yes
   -no \textit{(survey ends for this response)}

4. Did you give birth to and raise your child for the first year in the United States?
   -yes
   -no \textit{(survey ends for this response)}
DOWN SYNDROME CHARACTERISTICS

1. How far along were you in your pregnancy when your child was born? (Full-term babies are born at 40 weeks.)

   -enter weeks

2. How much did your child weigh at birth?

   -enter weight

3. At birth, did your child have any of the following issues? (Select all that apply.)

   -hypotonia (low muscle tone)

   -heart defect

   -digestive system problem (esophagus, stomach, intestine, pancreas, anus)

   -eye cataract

   -respiratory system defect (trachea, lungs)

   -genital difference (undescended testes, hypospadias)

   -hand, fingers, foot, or toe defect

   -urinary system problem (kidney, bladder, ureter)

   -hydrocephalus (“water on the brain”)

   -hernia

   -cleft palate (a deep groove in the roof of the mouth)
4. How many days did your child stay in the hospital after birth?

-enter days

5. In your opinion, how healthy was your child during the first month of life?

-chose # on scale, 1=unhealthy, 7=healthy

6. Did your child have surgery during the first month of life?

-yes

-no (skip Q7,8,9,10,11 for this response)

7. How many surgeries did your child have during the first month of life?

-enter number

8. What was the surgery (or surgeries) for?

-enter text

9. In your opinion, how serious was the surgery (or surgeries)?

-choose # on scale, 1=not serious, 7=very serious

10. How many days did your child stay in the hospital after surgery?

-enter days

11. When your child was in the hospital for surgery, how much time were you able to spend with him/her?
-choose # on scale, 1=none, we were totally separated, 7=all, we were together the whole time

12. During the first month of life, how many times did your child go to the hospital, emergency room, or urgent care for sickness (not birth or surgery)?

-enter times

13. During the first month of life, how many times did your child go to the pediatrician due to sickness (not a scheduled well-visit)?

-enter times

14. During the first month of life, how many times did your child get sick (significant congestion, very runny nose, ear infection, lung infection, vomiting, diarrhea, high fever...)

-enter times

**BREASTFEEDING**

The term “breastfeeding” includes the traditional method of the baby taking milk from the breast and non-traditional methods such as a supplemental nursing system (baby taking milk from a tube that is taped to the breast and is connected to a container filled with milk) or giving breastmilk from a cup or bottle.

1. Before you knew your child had Down syndrome, did you plan on breastfeeding?
1. Is breastfeeding part of your personal or family history?

-yes

-no

-I had not decided

2. After you knew your child had Down syndrome, did you plan on breastfeeding?

-yes

-no

-I had not decided

3. Please explain how the diagnosis of Down syndrome did or did not affect your plans to breastfeed.

-enter text

4. Did you breastfeed your child?

-no, I never tried (skip Q6,7,8,9,10 for this response)

-I tried, but did not continue for more than 1 week (skip Q6, 9 for this response)

-yes (for more than 1 week)

5. Please describe the factors that influenced your decision to breastfeed or not. In other words, why did you breastfeed or not breastfeed?

-enter text

6. For how many months did you breastfeed?
7. What methods of breastfeeding did you use? (Select all that apply.)

- traditional (baby independently taking milk from the breast)

- supplemental nursing system (baby taking milk from a tube that is taped to the breast and is connected to a container filled with milk)

- breastmilk in a cup

- breastmilk in a bottle

- other *(Q8 appears for this response)*

8. Please describe these “other” methods you used to breastfeed your child.

- enter text

9. How often did you supplement breastfeeding with formula?

- choose # on scale, 1=never and 7=very often

10. Overall, how did you feel about your experience of breastfeeding? Why?

- enter text

**UNDERSTANDING/SUPPORT**

1. Before your child was born, how capable did you think babies with Down syndrome were of breastfeeding?
2. Please explain why you thought this.

-enter text

3. When you discussed breastfeeding with the following people, how capable did they tell you babies with Down syndrome are of breastfeeding?

-choose # on scale, 0=did not discuss, 1=incapable, 7=as capable as other babies

-your child’s other parent

-your parents

-your siblings

-your friends

-your obstetrician

-nurses at the hospital

-your child’s pediatrician

-nurses at your pediatrician’s office

-a lactation (breastfeeding) specialist

4. Please describe what these people told you about breastfeeding a baby with Down syndrome.

-enter text
5. When your child was in the hospital at birth, how satisfactory was the area you were given to feed him/her? (Such as a private, quiet room.)

- chose # on scale, 1=very unsatisfactory, 7=very satisfactory

6. When your child was in the hospital at birth, which of the following items were available to you? (Select all that apply.)

- private, quiet room
- comfortable chair or bed
- pillows
- blankets
- breast pump and supplies
- bottles

7. Please explain why you were satisfied or dissatisfied with the setting for feeding your child in the hospital after birth.

- enter text

8. If your child was in the hospital for sickness or surgery, how satisfactory was the area you were given to feed him/her? (Such as a private, quiet room.)

- chose # on scale, 1=very unsatisfactory, 7=very satisfactory

9. If your child was in the hospital for sickness or surgery, which of the following items were available to you? (Select all that apply.)
- private, quiet room

- comfortable chair or bed

- pillows

- blankets

- breast pump and supplies

- bottles

10. Please explain why you were satisfied or dissatisfied with the setting for feeding your child during the hospital stay for sickness or surgery.

- enter text

11. How supportive of you breastfeeding your child were the following people?

- choose # on scale, 0=I did not want to breastfeed or I did not come in contact with these people, 1=not supportive, 7=very supportive

  - your child’s other parent

  - your parents

  - your siblings

  - your friends

  - other parents of a child with Down syndrome

  - a Down syndrome organization
-your obstetrician

-nurses at the hospital

-your child’s pediatrician

-nurses at your pediatrician’s office

-a lactation (breastfeeding) specialist

12. Please describe the good ways in which these people were supportive.

-enter text

13. Please describe ways in which these people could have been more supportive.

-enter text

14. Did your mother breastfeed you?

-yes

-no

15. How many of your family members and friends have breastfed their children?

-enter number

16. In your opinion, how normal is it to breastfeed among your parents, siblings, and group of friends?

-choose # on scale, 1=not normal, 7=very normal
DEMOGRAPHICS

1. What year were you born?

-enter year

2. What year was your child’s other parent born?

-enter year

3. What is your race? (Select all that apply.)

-American Indian and Alaskan Native

-Asian

-Black or African American

-Native Hawaiian and other Pacific Islander

-white, Hispanic or Latino

-white, non-Hispanic

-other

4. What is the highest level of education you have completed?

-less than high school
- high school/GED

- some college

- 2 year college degree

- 4 year college degree

- Masters degree

- Doctoral degree

- Professional degree

5. What is your combined annual household income?

- under 20,000

- 20,000-29,999

- 30,000-39,999

- 40,000-49,999

- 50,000-59,999

- 60,000-69,999

- 70,000-79,999

- 80,000-89,999

- 90,000-99,999
6. Is your child with Down syndrome a boy or a girl?
   - boy
   - girl

7. Is your child with Down syndrome older than 1 year of age?
   - yes *(skip Q6 for this response)*
   - no

8. How many months old is your child?
   - enter months

9. What year was your child born?
   - enter year

10. When did you learn that your child had Down syndrome?
-before birth

-after birth

11. Of your biological children, which birth was your child with Down syndrome?

-first

-second

-third

-fourth or later

12. Did you breastfeed another child (or children) before giving birth to your child with Down syndrome?

-yes

-no