

**Through a New Lens: The Impact of an Infant's Visual Impairments on  
Maternal Bonding and Maternal Identity During Feeding Time**

Master's Thesis

Presented to

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by  
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## ABSTRACT

### Through a New Lens: The Impact of an Infant's Visual Impairments on Maternal Bonding and Maternal Identity During Feeding Time

A thesis presented to the Department of Biological Sciences, Program in Genetic Counseling

Graduate School of Arts and Sciences  
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A significant amount of research has been conducted on children with visual impairments. Visual impairments may occur for a variety of reasons and are known to impact the relationship that a child forms with his or her primary caregiver, usually the mother. However, little information is known about how a young child's visual impairment impacts maternal identity or a mother's ability to bond with her child.

In this study, eight mothers with one child (under the age of three) with a visual impairment and at least one sighted child (over the age of three) participated in audiotaped interviews to explore how their child's visual impairment impacted feeding time and their bonding experience when compared to those experienced with their older, sighted child. Through the use of a semi-structured interview guide, participants were prompted to discuss issues related to feeding, bonding, maternal identity and response to diagnosis. Eight primary themes emerged from the interviews which focused on changes in maternal identity, response to the diagnosis, differences in maternal expectation and the extent to which mothers depend on mutual gaze during feeding time to establish feelings of closeness.

The mothers who participated in our study reported that the lack of mutual gaze and reciprocal emotions significantly impacted the bonding process. However, they developed strategies for relying on other senses to increase feelings of closeness with their child. The degree to which mothers felt that their child's visual impairment impacted their ability to bond with their child demonstrates that this topic should be addressed when giving a new diagnosis. Medical providers should be aware of the complex psychological implications that a young child's visual impairment can have on a mother and be prepared to address them.

Keywords: visual impairment; maternal identity; bonding; feeding

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## INTRODUCTION

The first two years of life are a remarkable period of human development as the transformation of a newborn into a toddler is largely influenced by their ability to visually perceive their surroundings. Visual development involves the acquisition of both oculomotor skills (accurate fixation and pursuit eye movement) and perceptual skills (visual acuity, color vision and motion perception) (McCulloch, 1998). In general, these abilities are acquired in tandem with the anatomical and physiological maturation necessary to support them (McCulloch, 1998). As infants gain awareness of their environment, their mother's face quickly becomes one of the most common visual images (Graven & Browne, 2008). It is therefore not surprising that one of the most primitive unions is that which develops between an infant and their mother (Loots, Devise, & Sermijn, 2003; Thomas, 2002).

From a biological perspective, there is evidence that neural and hormonal mechanisms underlie the formation of these bonds between mother and child (Broad, Curley, & Keverne, 2006). Research has demonstrated that bonding is initiated shortly after birth, and is essential for the development of a healthy parent-child relationship (Symanski, 1992; Werth, 1984). The theory of maternal-infant bonding was initially developed by Klaus and Kennell and popularized throughout the 1970s (Symanski, 1992). Bonding is defined as "a unique positive relationship between a parent and child that is specific to a particular child and that endures over time" (Symanski, 1992). Bonding is recognized as a gradual process that results in a reciprocal interaction between

a parent and a child that starts shortly after birth (Werth, 1984). There is evidence that the concept of bonding implies a focus on the parent's feelings towards their child (Symanski, 1992). Bonding has also been found to be mediated by other factors including family dynamics, resources, and support. In addition, Wills (1979) discusses how birth order can impact a mother's willingness and ability to form a connection with her child (Wills, 1979). Prior research supports that the initial establishment of a close relationship may be more crucial when infants are premature or suffer from congenital anomalies (Symanski, 1992).

Mutual eye contact plays a primary role during infant social interactions and has been recognized as a vital component in the mother-infant bonding process (Thomas, 2002). Throughout the first two to three months of life, the newborn eye can only perceive low level, non-colored light (O'Connor, Wilson, & Fielder, 2007). Around three months of age the pathway for colors begins to develop (Graven & Browne, 2008; Lewis & Maurer, 2005). By one year of age most of the critical components of the visual system are significantly developed (Graven & Browne, 2008).

Children demonstrate a preference for their mother's face within a few months of life (Carlsson, Lagercrantz, Olson, Printz, & Bartocci, 2008). Studies show that by three months of age infants are sensitive to adult gazes, and that by five months of age a person's eyes are more salient to an infant than other facial features (Jaffe, Stern, & Peery, 1973; Thomas, 2002). A newborn's preference for face-like patterns is believed to be rooted in subcortical mechanisms that are necessary for the development of social functioning in the adult brain (Carlsson, et al., 2008).

Feeding time, where the mother and infant are in close proximity, has been found to be a period of intense bonding (Else-Quest, Hyde, & Clark, 2003). During feeding, mother-infant dyads remain in close contact and engage in extended periods of mutual gaze. Data indicates that in order to enhance and facilitate visual stimulation, infants should remain 8-12 inches from their mother's face (Graven & Browne, 2008). During feeding time, children are typically held around this range. Research specifically exploring feeding practices concluded that breast feeding mother-infant dyads spend significantly more time engaging in mutual gaze than do bottle feeding dyads (Else-Quest, et al., 2003). However, adequate bonding does not require skin contact (via breast feeding) in the early postpartum period (Else-Quest, et al., 2003).

Infants have an innate drive to communicate with their caregivers (Akhtar & Gernsbacher, 2008). As they cannot verbally share their feelings, their "linguistic environment" is intimately entwined with facial expressions and eye contact (Akhtar & Gernsbacher, 2008; Jaffe, et al., 1973). Eye contact, direction of gaze, smiling, and other facial features that elicit a visual response are important in the formation of a relationship between mother and child (Preisler, 1991). However, when a child is born blind or with a severe visual impairment, they are unable to establish mutual eye gaze. A lack of sight does not prevent infants from feeling close with others but rather forces them to establish interpersonal connections through alternative means and takes more time to develop. This is consistent with much of the literature which has demonstrated that children with severe visual impairments tend to achieve developmental milestones at a delayed rate because they must learn to rely on nonvisual modalities to engage with others (Akhtar & Gernsbacher, 2008; Cass, Sonksen, & McConachie, 1994; Moore & McConachie, 1994).

In today's society, mothering has become a topic of social, medical and political interest (Lee, 2008; Murphy, 2003). Constant scrutiny and monitoring has forced mothers to question their identity as adequate caregivers and emotional providers. With the birth of a child with a disability, mothers become subject to new, additional expectations and challenges that may cause them to question their own maternal identity (Wills, 1979). These social pressures can create additional stress and diminish parental resources necessary for nurturance and attachment (Huebner & Thomas, 1995). Not only has previous research demonstrated that the type of disability can influence parental attachment and bonding, but also that this process can be more challenging for a parent when their child has a more noticeable physical disability (Reda & Hartshorne, 2008).

While many studies have explored the complex issues raised by having a child with a visual impairment, no one has specifically asked to hear personal stories surrounding these circumstances nor included firsthand accounts from mothers. Further, current research does not provide data on the comparative personal and emotional experiences of mothers who have both sighted and non-sighted children around the issues of bonding during early feeding and maternal identity. The goal of this study is to use the experiences shared by mothers to examine the broad range of sentiments related to infant bonding and early maternal identity in mothers of both sighted children and children with a visual impairment. This research also sheds light on adaptive responses that mothers have employed to enhance feelings of mutual bonding with their child with a visual impairment, as well as on how healthcare providers can best support mothers with a newborn who cannot see.

## METHODS

The study design described was approved by the Brandeis University Institutional Review Board.

### *Sampling Methods*

We recruited participants for this study through Perkins School for the Blind (Watertown, MA) and through the website wonderbaby.org. We provided a recruitment notice (see Appendix A) to the Educational Director and two preschool teachers at Perkins School for the Blind. The teachers then provided mothers with the study information and all interested mothers were encouraged to contact us directly. We also spoke to a group of parents whose children attend Perkins School for the Blind. We provided them with the recruitment notice and asked them to contact us as well. Additionally, the recruitment notice was posted on the website wonderbaby.org. For each person contacting us, we performed a brief phone questionnaire (see Appendix B) to assess their eligibility. Subject inclusion criteria included the following:

- All participants must be mothers
- All mothers must have at least one biological sighted child and one younger biological child with a diagnosis of blindness or severe visual impairment\* \*

*\*\* A child will be considered blind or severally visually impaired according to the standards developed by the World Health Organization International Statistical Classification of Diseases, Injuries, and Causes of Death.*

- The World Health Organization defines “blindness” as visual acuity of less than 20/400, corresponding to visual field loss to less than 10 degrees in the better eye with best possible correction.
  - The World Health Organization defines “severe visual impairment” as best-corrected central vision of 20/200 or worse in the better eye, or a visual acuity of better than 20/200 but with a visual field no greater than 20°.
- All mothers must be sighted
  - Mothers must have done the majority of the feeding for both children
  - All mothers must be able to speak and understand English fluently
  - The child with a diagnosis of blindness or severe visual impairment should be no older than three years of age and should have no major congenital birth defects other than those that affect vision
  - When there are more than two children in a family, the child closest in age to the individual with the visual impairment will serve as the internal control

Eight respondents who expressed interest were eligible for study participation and interviews were scheduled at their convenience. A copy of the informed consent form (see Appendix C) was e-mailed to each of the participants and collected prior to the interviews. An in-person interview was scheduled for one of the eight respondents and phone interviews were scheduled for the remaining seven respondents. All participants received a \$25.00 gift card for their participation in the study.

### *Interview Design*

We designed a semi-structured interview guide with open-ended interview questions (see Appendix D) to facilitate a conversation about the participants' experience of bonding during feeding. The questions were designed to qualitatively explore how mothers experienced bonding during feeding with their child with a visual impairment as compared to their prior bonding experiences during feeding with their sighted child. The interview guide also explored a mother's response to the diagnosis of a visual impairment in her child and whether having a child with a visual impairment impacted their maternal identity. Question design was based on previous literature regarding visual impairment, bonding, and the author's prior interactions with mothers of children with visual impairments. Though the same interview guide was used for each participant and all questions were asked to all participants, some questions were adapted based on the thoughts and experiences expressed by the participant. Nonetheless, the overall interview content remained the same.

### *Data Collection & Analysis*

Interviews lasted between 45 and 60 minutes and all interviews were audiotaped. The audiotaped interviews were transcribed by a confidential transcriptionist. All documents containing identifying information were kept in either a password-protected database or in a locked filing cabinet in the Genetic Counseling department. All informed consent forms will be kept in this filing cabinet for five years. Any potentially identifying information was removed from the transcript and field notes and was labeled with numbers prior to coding and analysis.

The qualitative analysis software Atlas.ti (Version 6.2) was used to code the transcripts and organize the data into themes that described how having a child with a visual impairment impacted bonding and maternal identity. The transcripts were read through line by line and open coding was used to identify significant topics mentioned by the participants. Codes and key quotations were grouped into themes. These themes consisted of broad topics that were emphasized throughout the interview and highlighted the most commonly expressed experiences and opinions. Participants' responses were then categorized into subthemes (see Figure 1).



## **RESULTS**

### *Demographics*

Eight mothers between the ages of 28 and 46 years (average 36.5 years) participated in this study. Of the eight participants, four live in Massachusetts, one lives in Utah, one lives in Colorado, one lives in California, and one lives in Manitoba, Canada. All mothers have at least two children, one that is under the age of three years and has a visual impairment, and at least one older child that is sighted. Two of the eight mothers have more than two children. See Table 1 and Table 2 for detailed demographic information.

Three participants have a son with a visual impairment and five participants have a daughter with a visual impairment. The ages of the children with a visual impairment range from 9 months to 3 years 4 months (average 1 year 11 months). The ages of the children who are sighted range from 2 years 2 months to 6 years 6 months (average 4 years 1 month). Mothers reported the current diagnosis for their child with a visual impairment and indicated whether it was learned at birth or later in the child's life. See Table 3 for additional information.

All mothers reported doing the majority of the feeding for their children. Individuals were considered to have exclusively breast fed their child if breast feeding was the primary mode of feeding for the child's first three months of life. Three mothers breast fed both children. Three mothers used a mixed method of feeding for both children. One mother switched from mixed feeding to breast feeding with the birth of her child with a visual impairment and one did the opposite. At the time of the study four mothers were

not currently working outside the home. Of those who worked outside the home prior to the birth of their child with a visual impairment, one mother returned to work after six months and two mothers returned to work after more than a year. One participant did not return to work outside the home (see Table 1 and Table 2).

	Numbers	Percent
<b>Age of Mothers</b>		
At interview (yr)		
25-30	3	37.5
31-35	0	0.0
36-40	2	25.0
41-45	2	25.0
46-50	1	12.5
At birth of child w/ VI (yr)		
25-30	3	37.5
31-35	1	12.5
36-40	2	25.0
41-45	2	25.0
At birth of sighted child (yr)		
20-25	3	37.5
25-30	0	0.0
31-35	3	37.5
36-40	2	25.0
<b>Number of Children</b>		
2 children	6	75.0
> 2 children	2	25.0
<b>Feeding- VI</b>		
Breast	4	50.0
Bottle	0	0.0
Mix of breast & bottle	4	50.0
<b>Feeding- Sighted</b>		
Breast	4	50.0
Bottle	1	12.5
Mix of breast & bottle	3	37.5
<b>Employment</b>		
Post birth child w/VI		
Not employed pre or post birth	4	50
Returned after 3 months	0	0
Returned after 6 months	1	12.5
Returned after 1 year	0	0
Returned after > 1 year	2	25
No return to work outside home post birth	1	12.5

**Table 1.** General demographics of the participants ( $N= 8$ )

VI: Visually impaired

Participants	Age at Interview (yr)	Age at Birth of Sighted Child (yr)	Age at Birth of VI'ed Child (yr)	Early Feeding Practice for Sighted Child	Early Feeding Practice for VI'ed Child	>2 children (Y/N)	Return to Employment after Birth of VI: (not employed, 3mo, 6mo, 1 yr, >1 yr, did not return)
01	30	24	27	mix	mix	N	Not employed
02	36	31	34	breast	breast	Y	Not employed
03	39	35	39	breast	breast	N	Not employed
04	41	36	38	bottle	breast	N	Not employed
05	43	34	42	mix	mix	N	Returned after > 1 year
06	28	24	26	mix	mix	N	Returned after >1 year
07	29	25	29	breast	breast	N	Returned after 6 months
08	46	40	44	breast	mix	Y	Did not return

**Table 2.** Detailed demographics of the participants ( $N=8$ )

*Not employed:* Was not employed outside the home prior to the birth of her child with a visual impairment

*Did not return:* Was employed during and prior to the birth of her child but, did not return to work following the birth of her child with a visual impairment

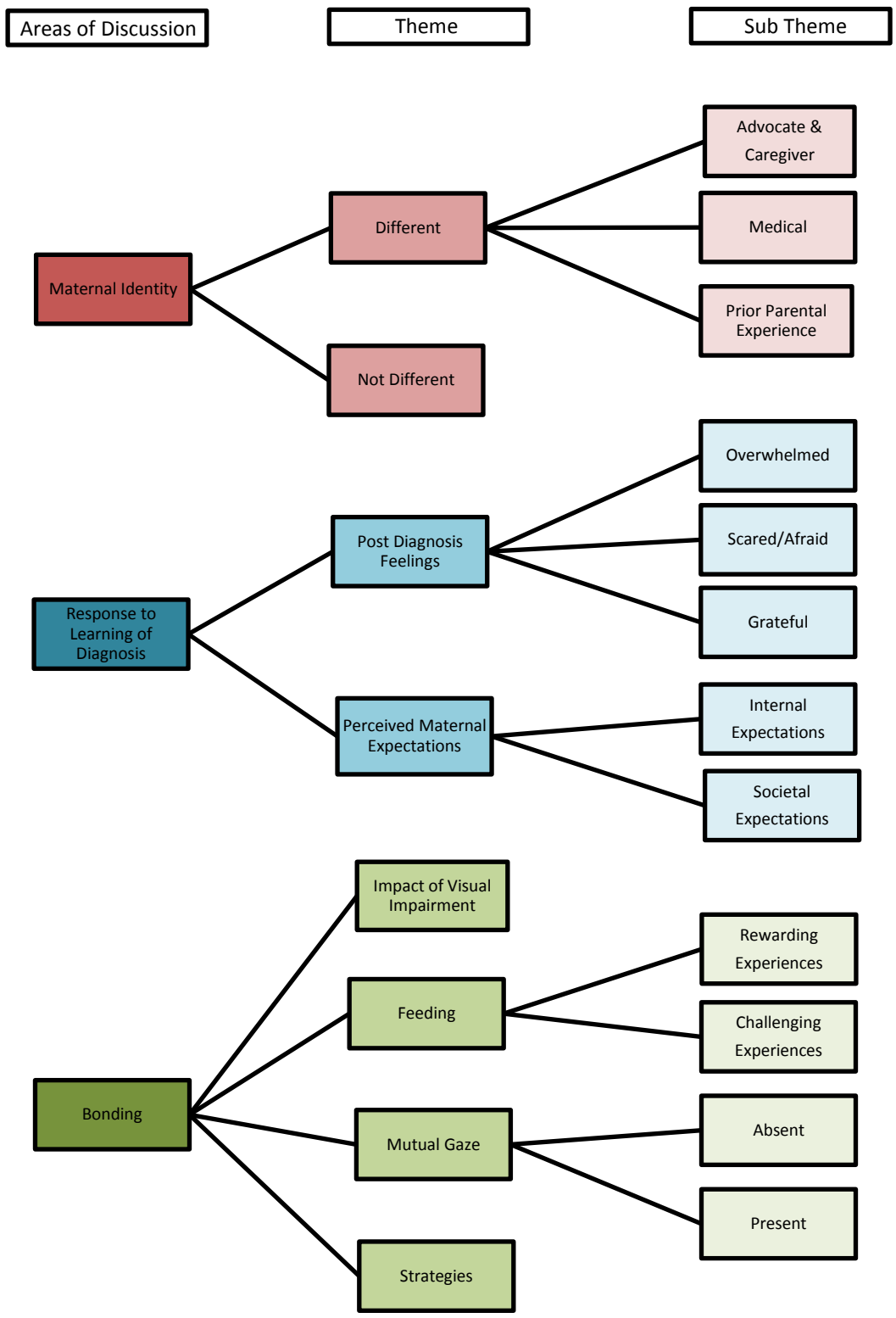
Participants	VI	VI-Gender	Sighted	Sighted-Gender	VI-Condition
01	3yr 4mo *	M	6yr 6mo	M	Sclera cornea
02	1yr 7mo *	F	4yr	M	Bilateral cataracts
03	9mo	M	4yr	M	Cortical visual impairment
04	2yr 8mo	F	4yr 5mo	M	Lebers Congenital Amaurosis
05	9mo	M	9yr 2mo	F	Optic nerve atrophy
06	2yr 2mo *	F	4yr	M	Cortical visual impairment, Myopia, Strabismus
07	1yr 7mo *	F	3yr 6mo	M	Low vision
08	2yr 5mo	F	4yr	M	Lebers Congenital Amaurosis
<b>Average</b>	1yr 11mo	M=5, F=3	4yr 9mo	M=7, F= 1	

**Table 3.** Demographics of children at the time of the interview

\* Visual impairment diagnosed at birth (within one week of delivery)

### *Themes*

The interview questions were designed around three main areas of discussion: (1) Maternal Identity, (2) Response to Diagnosis, and (3) Bonding with regards to the birth of a child with a visual impairment. By categorizing the codes used for analysis under these areas of discussion and examining the frequency of comments, we identified eight primary themes and several sub-themes representing the participants' feelings and experiences. Figure 1 represents the themes and subthemes expressed by participants.



**Figure 1.** Three main areas of discussion, corresponding themes and subthemes

## **Maternal Identity**

### *Theme: Differences in Maternal Identity*

Most (6/8) participants reported that they experienced a change in maternal identity with the birth of their child with a visual impairment. Participant 01 summarized her feelings by stating:

*“I guess I’m a mother of a child with some health problems and that’s something I’ve got to take on as part of my identity now... it makes just kind of a different family... I just feel like we are different and like I have a unique situation with the way I am mothering, with the way I have to do it.”*

Participant 02 commented:

*“It’s always different raising a child with a disability. You think about things that you don’t think about with a perfectly healthy child.”*

This same mother elaborated on her feelings and explained how she had a tendency to want to isolate herself in order to avoid questioning her self-identity:

*“I know people are gawking at us and people are curious, so sometimes people can say it gracefully and sometimes people can be rude and you know all of my emotions are in that too. So those kinds of things make me feel different. I wasn’t used to going out and being stared at. I wasn’t used to wanting to punch people in the face when they asked ‘what’s wrong with your baby’. There is so much of my ‘self’ and my emotion involved in that.”*

Participant 03 explained the difference she felt by explaining:

*“The day to day is just different, I think, you know every child is different, I think the child’s visual impairment is just drastically different in much more large scale ways.”*

More specifically, several of these mothers reported that they became identified by their role as medical and social advocates for their children, and subsequently felt isolated from other mothers who did not have a child with a visual impairment.

Participant 05 commented on this topic by stating:

*“I’m not only his mom, I’m also his advocate, you know. Sometimes he doesn’t know things and I have to speak for him ... maybe I’m a doctor too because I have*

*to learn a lot of things you know, medically, I know a lot of medical terms ... I'm an educator because I have to learn those things too you know, to get him what he needs to get the education part."*

Similarly, participant 06 replied:

*"I mean it [mothering] is hard, and it's a harder job because you know, you have so many medical issues in general."*

During the course of discussing maternal identity, many mothers described feeling extremely protective and more vigilant of their child with a visual impairment.

They not only identified themselves as caregivers but also felt responsible for providing for their child in novel ways. Participant 02 commented:

*"You look at other people who are not going through that, I mean I even looked back on my other kids and you have a baby and you just go on your merry way and everything is fine and they grow and they develop, and when something like this happens you feel really protective and it isolates you to a certain extent because you know that other people don't know how it feels."*

Participant 06 elaborated on this topic by replying:

*"I think for him [sighted child] it's more like a mom, like, I don't know, you get to do the fun stuff, you know that typically developing kids do, but with her [child with VI] it's more like a caretaker, you know, a nurse, and that kind of thing, an appointment scheduler, taxi driver, all that stuff is more obvious in her care [child with VI]."*

As all mothers had at least two children, one of whom was sighted, they were able to compare their experiences of raising their sighted child with those of their child with a visual impairment. The ability to contrast these experiences provided mothers with an opportunity for self-reflection and introspection. Through this process of self-analysis, mothers questioned their maternal identity and sense of self. At the time of the interview, five out of eight mothers stated that parenting their sighted child influenced their feelings surrounding their child with a visual impairment. Participant 02 explained her feelings of inadequacy in taking care of her child with a visual impairment:



*“I guess I was sort of getting cocky after so many kids and feeling like I knew how to do this and you feel very inadequate. It made me feel like, you know, that I had approached everything in one way and could I change my approach and did I need to change my approach. You know, I felt really insecure as a parent.”*

*Theme: No Difference in Maternal Identity*

While the majority of mothers stated that having a child with a visual impairment impacted their maternal identity in some way, two mothers stated that they did not identify themselves differently. These two mothers felt that they were still mothers, just with some additional responsibilities. Participant 07 responded:

*“I mean you think of each child differently, and you take into account the disability, but I don’t think it has really changed how I see myself as her [child with VI] mom.”*

### **Response to Learning of Child’s Visual Impairment**

*Theme: Post-Diagnosis Feelings*

While four mothers recognized that there was something different about their child’s vision almost immediately following their birth (within one week of their child’s birth), the other four mothers in this study bore more of a diagnostic odyssey and did not learn of their child’s visual impairment until they were a few months old. Regardless of when the visual impairment was diagnosed, six participants reported experiencing an inordinate amount of fear and being extremely overwhelmed after the diagnosis.

Participant 02, whose child was diagnosed at birth, replied:

*“It was really overwhelming. When you have a baby, there are all these expectations and such excitement that when this happened, it made you feel like your feet got knocked out from under you, and the vision part was scary to me, but even scarier was not knowing what else.”*

Additionally, this mother remarked:

*“It was fear, I mean, just an overwhelming sense of fear. It was confusing because I felt unprepared ... I am an experienced mom, I have other kids and I knew how to take care of a baby, I knew that I was a good mom in raising my*

*other kids, I felt like I don't know how to do this. This is something new to me and it was so scary and you just worried."*

Participant 01, whose child was also diagnosed at birth, described her sentiments when recalling the following experience:

*"I was sitting in the exam chair and holding him [child with VI] and my husband was sitting on the other side of the room with our older son [sighted] and asking questions and trying to understand what was going on, and my chest was leaking, um, through my shirt because I had, I hadn't been able to nurse right before the appointment like I wanted to and I felt like my heart was literally breaking and opening and I looked down and I thought I was going to be bleeding because it hurt so much. It was like something, something's wrong, "Oh, it's just breast milk, well, it feels like it hurts a lot."*

Participant 04, whose child was not diagnosed at birth, could still vividly recall the internal conversation she had as she rushed between two doctor appointments and shared this memory:

*"What are you going to do? When is she going to get married ... is she going to get married? Will she have babies? Like, you know, as a sighted person [I thought] how the hell is she going to do anything."*

Other mothers reported that their sense of fear came from a lack of understanding and exposure to the world of people with visual impairments. Participant 05, whose child was not diagnosed at birth, stated:

*"I didn't even have any idea what you know, a person with vision twenty over two hundred, for example, will see. I thought that they were completely blind."*

While her child was diagnosed at birth, participant 02 shared the feelings of other mothers when discussing her concern for how to care for a child with a visual impairment:

*"You know, obviously, intellectually you can think through that, you know if she can't see me, then other things are important to her senses and that's an unfamiliar approach to parenting that I just felt overwhelmed and scared and unqualified and nervous that I was going to mess it up."*

Three mothers conveyed sentiments of gratefulness upon learning of their child's diagnosis. Participants explained that this emotion stemmed from a place of relief: relief that their child had no additional major health concerns and that they would be able to adapt and grow without their vision. Participant 03, whose child was not diagnosed with a visual impairment at birth explained:

*"We were really thankful when he was born because he seemed better than we feared he would be ... He breathed on his own, he nursed, he never needed a feeding tube, never needed any sort of respiration ... I don't know what other people say but we feel grateful... I think that's one of my first emotions... We'll just deal with what comes and we have so much to work with really."*

Participant 03 further clarified her feelings of gratefulness by explaining that despite her child's visual impairment, he was still able to show affection:

*"I wouldn't care if one of my kids had to live over the garage until he was 50, but as long as he, he's got to love me, like if we didn't have any kind of connection that would be very hard, so I think that was my biggest fear."*

Participant 02 elaborated on how her child's diagnosis enhanced her feelings of gratefulness:

*"I think for all of us it [the diagnosis] kind of snapped us into what matters in life and in that way, it was a really good thing for our lives and for our parents and all our self-images."*

#### *Theme: Perceived Maternal Expectations*

A common theme that emerged among participants was a change in their expectations for themselves. Seven out of eight mothers reported that they felt a significant difference in how they were expected to care for and provide for their child with a visual impairment. Both perceived internal expectations as well as perceived societal/external expectations influenced how mothers viewed themselves with regards to their child with a visual impairment.

Mothers recognized that their perceived internal expectations often caused them to look back on the birth of their sighted child and feel that they missed out on creating warm memories with their child with a visual impairment because they were so preoccupied with their child's disability. Participant 02 described how her own internal standards of mothering still remain a subject of distress when she looks back on the birth of her child with a visual impairment:

*"I regret now when I look back that I couldn't just set that [the visual impairment] to the side for a little bit because a newborn baby doesn't last for very long and I look back on those days, they were filled with worry and fear and I missed, I feel like I missed the joy and excitement of a brand new baby ... I mean she was still my brand new baby, and now I know this, but looking back, I didn't, and that was so huge that it was overwhelming. It took over the emotions of a newborn and I regret that a lot."*

Participant 07 explained how her internal expectations influenced her interactions with her child with a visual impairment. She recalled an encounter from her daily routine which exemplified this:

*"We were at the store today and I saw her [child with V]) playing with a toy, I saw her paying an interest in it, so she's more likely to have that bought for her than her brother [sighted] is."*

Participant 06 expressed that she also felt internal pressure to provide differently for her child with a visual impairment than she did for her sighted child:

*"You can tell that your role is different, you are much more involved, 24 hours a day in their [children with VI] care, more than the other kids, like, for example, they [sighted children], you put them to bed and they go to bed."*

Mothers also discussed feeling external pressures to care for their child with a visual impairment in a certain, socially acceptable way. For example, participant 02 recalled:

*“I know people are gawking at us and people try to be curious, and sometimes they can say things gracefully, but I am still a bit self-conscious that they are judging me, they are watching me.”*

While most mothers (7 out of 8 participants) felt that having a child with a visual impairment influenced how they should act or feel towards their child with a visual impairment, participant 05 did not feel that she experienced a change with respect to these characteristics:

*“You are still a mother and you still do whatever you should do for a child.”*

### **Bonding**

*Theme: Impact of Visual Impairment*

All mothers had a personal story to share as to how bonding with their child with a visual impairment was different than bonding with their sighted child. When I asked participants how they felt having a child with a visual impairment impacted the ability for them to feel close to their child, and for their child to simultaneously feel close to them, they discussed both physical and emotional differences. Mothers also described a difference in their conscious intent to bond, stating that they experienced a more deliberate effort to connect with their child. Participant 01 described her need to feel connected to with her child with a visual impairment:

*“I have to bond with this baby even though he has health problems... I have to bond with him by any means as soon as possible ... With him [sighted child], I wasn't as anxious about that and I was like, you know, I'm blessed that I have this little boy and we're trying to get to know each other...”*

Participant 02 further elaborated on her intent to bond:

*“I think for her [child with VI] it came naturally, I mean I think from the moment she was born she knew I was her mom and trusted me completely, but I think with me, I was much more deliberate about making sure that there was a bond.”*

On more than one occasion, mothers described feeling less bonded with their child with a visual impairment due to the fact that they did not show typical signs of affection, such as hugging or kissing. Participant 04 detailed the differences in physical closeness she felt with her child with a visual impairment compared to her sighted child:

*“There’s not that rushing to hug like a kid does. They do that at like you know, four or five months, but [with her] there is no turning and big hugs ... She kind of like leans back, she does it in her own way, which it is, but it’s not normal. You have to teach her how to hug; you have to teach her how to kiss. She has once herself leaned forward and given me a kiss ... For other kids you don’t have to show kisses, they just see it and start modeling it.”*

In general, mothers reported that their desire to establish a mutually close relationship with their child with a visual impairment was similar to that for their sighted child, but added to that, was the fear of failure and letdown of not connecting with their child.

#### *Theme: Feeding*

Feeding is a primary concern for all newborns as it is essential for their growth and development. Feeding time is also a period of intense emotional connection between a mother and her child. Seven out of eight participants reported that their child’s lack of sight, i.e. the inability to establish a mutual gaze, altered their early experiences surrounding feeding and subsequently impacted their ability over time to feel bonded to their child.

In comparing feeding time between their children, mothers described having far fewer rewarding experiences with their child with a visual impairment as compared to their older sighted child. Additionally, the rewarding experiences that mothers did have with their child with a visual impairment were different from those of their sighted child, as they primarily occurred during periods of physical contact or alone time with their

baby. In describing a rewarding experience with her child with a visual impairment, participant 01 stated:

*“ When I could have [him] in bed next to me when I was sleeping and just nurse him in the bed and then I felt like, ‘Oh, I can keep my baby close to me and I don’t have to sit up in a rocking chair to nurse him’ ... I can be really close now.”*

In discussing the aspects that she found rewarding during feeding time with her child with a visual impairment, participant 05 explained:

*“That part of you know, holding him, and he was enjoying it so much and he was peaceful and quiet and it’s just a very good feeling. Actually when he stopped breast feeding, I felt kinda uh, lost, you know, I lost some kind of that bonding.”*

Mothers expressed the personal challenges they felt surrounding feeding a child with a visual impairment as compared to their experiences of feeding a sighted child. Many of these challenges were associated with a lack of feeling close to their child during feeding due to an absence of reciprocated emotion (which stemmed from a lack of eye contact). Participant 04 described the impact that her child’s visual impairment had on her feeding experience:

*“You feed, and then you kind of pat on the shoulder, or you put them over your shoulder and do the burping which I always thought was fun, and they snuggle right there. She didn’t snuggle right there. She never really snuggled right there ... I guess she didn’t know how to ... but I wanted her to.”*

Participant 02 also elaborated on the lack of bonding she felt during feeding time with her child with a visual impairment:

*“I think when I breast fed my other kids it was more of a connection time. I always felt like I would be looking at her but she didn’t return my gaze and so a lot of times I would feel really horrible about that, so I would try to distract myself.”*

*Theme: Mutual Gaze*

One of the most prominent findings was the impact that the lack of eye contact had on mothers. All participants reported that the inability to establish a shared gaze with their child was one of the most challenging aspects of having a young child with a visual impairment. Participant 02 detailed the difference in mutual gaze between her sighted children and her child with a visual impairment:

*“When she did open her eyes, she didn’t look at me, she didn’t look at my eyes, and I felt like with my other kids, that right when they opened their eyes, we connected.”*

Participant 08 commented on the significant impact an absence of eye contact can have during the newborn period:

*“You just don’t feel that connection because they can’t look at you and they can’t smile and the whole smiling thing is all you have when they are tiny ... all you have until they can verbalize and play is smiling and eye contact.”*

Specifically, in regards to feeding, mothers discussed that they felt less connected and missed the characteristic smiles and giggles that are essential in helping a mother to know that her child feels attached. Participant 01 stated:

*“He always looked past me and looked past things and didn’t focus on anything.”*

She contrasted this experience to that with her sighted child:

*“He [sighted] would always stare up at me and that was kind of sweet. He’d stare at me and make eye contact and he’d stare at me while he nursed the whole time, which is not something he [child with VI] did.”*

Participant 05 detailed the extent to which she felt eye contact enhanced her ability to bond with her sighted child:

*“I think the moment I enjoyed the most was when I was breast feeding her [sighted] and she was looking at me, you know, she was staring at my face and I was looking at her, that was the best time.”*



The absence of eye contact caused Participant 06 to not only feel less bonded to her child with a visual impairment, but to also question her child's ability to identify her as the mother in the family:

*“There’s no way to tell, her to tell us that she feels close to us. She doesn’t really know the difference I guess, but more sometimes it’s kind of like sad that she’ll go with anyone you know, like I remember one time he [sighted] wanted his mom, but she [child with VI], she’s more likely to go with anyone.”*

*Theme: Strategies*

Four mothers felt that it took more effort to bond with their child with a visual impairment as compared to their sighted child. But, most mothers shared strategies that they developed to increase feelings of bonding between themselves and their child with a visual impairment. Most strategies employed by participants took advantage of the other four senses. Participants 02 and 08, respectively, recalled the strategies they used:

*“I tried to keep blankets around. They gave us good advice about our smells. I tried holding her [child with VI] hands and I talked to my babies a lot ... Those suggestions that people told us about keeping things the same, you know, lighting, she was pretty light sensitive early on, so I would try to sit in a not real bright area ... I was trying the best I could.”*

*“I did also try to sleep or nap with her [child with VI] to feel close to her. She was in a co-sleeper in our room for about a year but I would sleep in the bed with her many times as well. I also put her on my lap-on her back-facing me so I could talk to her while I was pumping.”*

Participant 07 explained that she became much more aware of her surroundings and was much more intentional with her actions to promote bonding:

*“I would try and take her [child with VI] to a place where there were less distractions, especially when she was starting to pay attention to, starting to really hear things around her... I would get used to showing her stuff in a different way and then describing it to her differently.”*

Participant 04 referenced the use of music and sounds to enhance feelings of bonding with her child with a visual impairment:

*“I just used a lot of talking and singing ... a little tickling, giggling, snuggling you know, swinging around and throwing in the air... motions I think, and lots of songs.”*

Participant 06 also found music to be extremely instrumental in the bonding process with her child with a visual impairment:

*“If you sing to her she knows who you are more. She like knows your voice and she loves music. Pretty much to get her to do anything everyone has to sing to her.”*

When asking participants if they had discussed bonding and feeding with other mothers, the majority explained that they had not due to the fact that they were either focused on other aspects related to their child’s care, or that they felt that they did not feel comfortable discussing such topics. Participant 08 summarized why she had not engaged in discussion of these topics:

*“I mean most of the time when I talk to other parents of visually impaired kids we are talking about the practicalities of it. Or about school, play dates... that kind of stuff as opposed to your feelings. It is almost a little bit of a taboo subject, like you say ‘I don’t really feel bonded to my child’ you feel like a bad mother and so it’s almost something you don’t want to talk about.”*

## DISCUSSION

In this exploratory study, we interviewed eight mothers who have a child that is blind or visually impaired and at least one older sighted child and discussed issues of bonding during feeding and maternal identity. The themes and subthemes detailed above highlight key issues and common topics identified in the interviews. We spoke with these individuals who openly shared their stories and granted us insight into their personal lives. Through these interviews, we learned that the bonding process is both physically and emotionally different for mothers of children with visual impairments. Since all mothers expressed that a lack of mutual gaze during feeding impacted their ability to bond with their child with a visual impairment, the bonding process should be discussed when a young child receives a diagnosis of a visual impairment. The diagnosis of a visual impairment in a child further impacts a mother's identity and the expectations she has for herself as a mother. Health professionals and educators who work with new mothers of a child with a visual impairment should therefore be aware of and recognize the psychosocial implications of bonding during feeding.

### *Impact of Visual Impairment on Maternal Identity*

Caring for any young child takes an inordinate amount of time, but these demands escalate even further when a child has a disability. As presented in the study by Helitzer et al. (2002), mothers became "cultural brokers" with the difficult task of bridging the clinic and medical culture with the family world (Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002). Additionally, mothers of children with a disability have

been found to assume responsibilities usually performed by other professionals, such as teachers, therapists and health care specialists (Helitzer, et al., 2002). The findings reported here are consistent with earlier conclusions, but in the specific context of one form of disability, a visual impairment. Further, this study validates prior outcomes as the mothers interviewed here expressed that they felt the need to wear many “professional hats” in order to adequately provide for their child with a visual impairment. In general, mothers felt that they were forced to rapidly acquire many new skill sets to provide the “essentials” to their child.

Our findings are consistent with the study by McGuire et al. (2004) in which researchers described a four step process of mothering a child with a disability. One pivotal part of the process that they describe is “negotiating a new kind of mothering”. This includes redefining the maternal image to reflect the role of a mother of a child with certain special needs and learning how to become an expert caregiver to their child (McGuire, Crowe, Law, & VanLeit, 2004). Our study demonstrates that mothers experienced some difficulty in adapting to the challenges that come with nurturing a child with a visual impairment. Mothers who were comfortable in their role as mothers of children without a disability questioned their ability to successfully care for their child with a visual impairment and struggled with feelings of inadequacy and isolation. Our study also confirms findings of McGuire et al. (2004) who noted that mothers who questioned their self-identity (in the presence of a diagnosis) experienced a loss of self-esteem (McGuire, et al., 2004).

A new theme not previously discussed in the literature was how a mother’s prior bonding experiences with her sighted child (or children without any type of disability)

positively impact a mother's desire to bond with her child with a visual impairment. Many mothers felt compelled to work at bonding with their child with a visual impairment with the goal of developing similar levels of closeness as they had with their sighted child.

### *Response to Diagnosis*

Following the birth of their child with a visual impairment, mothers were less likely to enjoy the overall excitement and enthusiasm associated with a newborn baby. In those where their child was diagnosed at birth, the post-partum period was dominated by questions, concerns, and anxious anticipation. The post diagnosis period for mothers whose children were diagnosed later in infancy (not at birth) was also characterized by these emotions. As demonstrated in the study by Wills (1979), grief, anger, and depression are natural responses when learning that a child has a visual impairment. In addition to these emotions, participants in this study also reported that they felt extremely overwhelmed, scared and unprepared. Mothers felt apprehensive at the prospect of taking care of a child with a condition to which they themselves could not personally relate.

Some participants expressed a sense of relief upon receiving their child's diagnosis. These mothers conveyed that they were grateful that only their child's sense of sight was altered. In most instances, a visual impairment is not as noticeable as other disabilities nor does it prevent an individual from gaining independence or establishing meaningful relationships. Prior research substantiates these findings, as the nature and the extent of a condition have been found to impact parental reactions (Schuengel et al., 2009). In a comparison study, Schuengel et al. (2009) found that parents of toddlers with a neurological disorder were more emotionally distraught than parents of toddlers with a

physical disfigurement such as cleft lip or cleft palette (usually correctable to some extent) (Schuengel, et al., 2009). While the level of disability, physical as compared to neurological, can variably impact parental acceptance of their child, our sample supports that the diagnosis of a visual impairment was somewhat easier for mothers to accept.

When receiving the diagnosis of a visual impairment in their child, mothers felt both internal and external pressures to act in a different way. This was most prominently exemplified by mothers who reported that they felt they had a new and higher standard of care to live up to, and would be judged by friends and family if their child did not grow along the “typical” developmental trajectory. Additionally, mothers alluded to their having an internal barometer which served as a personal measure of acceptable care for their child. Yet mothers often struggled with allowing themselves to have different expectations for their children (visually impaired vs. sighted) and the way they interacted with them.

Lee (2008) explained that mothering has been constructed as “both the private responsibility of individual mothers, and also a matter of public scrutiny and intervention, with mothering practices defined as ‘good’ and ‘bad’ ” (Lee, 2008). In combination with prior literature, this study further elucidates the extent to which maternal expectations undergo change in the context of child with a visual impairment.

### *Bonding*

The importance of early human relationships, especially with primary caregivers, is well established. The process of maternal-infant bonding is considered vital for normal infant development as well as for maternal attachment (Symanski, 1992; Taylor, Atkins, Kumar, Adams, & Glover, 2005). While the relationship between a mother and her child

is initiated before a baby is born, this bond is influenced by external factors, specifically a medical condition (Symanski, 1992). A child's visual impairment prevents the establishment of a mutual gaze between a mother and her child, subsequently decreasing a sense of bonding, and encouraging mothers to develop alternative strategies to increase feelings of connectedness between themselves and their child.

As supported in prior research (Else-Quest, et al., 2003), the practice used for feeding, breast or bottle, did not influence a mothers' feelings of closeness during feeding time with their child with a visual impairment. However, participants did report a profound difference in the emotional experience surrounding feeding time with their child with a visual impairment, regardless of whether mothers breast or bottle fed their infants. They described a lack of eye contact, mutual gaze, and reciprocal emotions. Since preverbal forms of communication are dominated by the visual experience (Moore & McConachie, 1994), the role of gaze direction in monitoring mutual attention to objects and events, and the use of gestures to communicate intentions is critical in the establishment of a mutual bond (Akhtar & Gernsbacher, 2008; Moore & McConachie, 1994; Preisler, 1991). Therefore, mothers in this study commonly employed the use of sound and smell to increase the feelings of bonding.

A new theme found in this study was the difference in satisfaction mothers experienced during feeding time with their child with a visual impairment. During feeding, mothers did not receive the same sense of gratification or enjoyment that they did with their sighted child. Feeding time with their child with a visual impairment was less rewarding due to the lack of reciprocal emotion. Subsequently, many mothers felt

feeding time highlighted the challenges they faced instead of providing a time to feel bonded to their child.

Absence of gaze and responsive emotions (smiling and giggling) has been considered a great disadvantage for parents of children with a visual impairment as it deprives them of essential information about their infant. Mothers in this study overwhelmingly felt that they had to work harder to create a bond with their child due to a lack of eye contact. When describing rewarding experiences with their sighted child, mothers commonly referenced looking into their child's eyes and receiving a smile. In comparison, descriptions of rewarding experiences for their child with a visual impairment consisted of spending time alone and engaging in physical contact such as cuddling or napping, but did not include feeding time. Additionally, mothers found the use of song and singing to increase feelings of bonding with the child with a visual impairment.

The strength of the maternal connection was a primary concern for one participant. She expressed sadness that her child with a visual impairment could not identify her from other women, and thus would willingly go with anyone who was able to meet her needs. This concept has not been explored in the literature but is important to parents when attempting to forge a bond in the absence of vision.

When discussing ways in which to enhance bonding, mothers employed a variety of strategies that took advantage of other senses, specifically the use of sound and tactile techniques such as skin to skin contact. It is known that these strategies can increase the feeling of closeness between a parent and their child (Symanski, 1992). While some mothers received guidance from healthcare providers on how to enhance bonding, the



majority developed techniques on their own through a process of trial and error. Mothers did not feel comfortable talking to other parents about bonding and feeding as they felt that they would be stigmatized.

Mothers felt that they had never been given the permission to discuss their personal feelings or received any validation that bonding can be difficult. Symanski (1992) explains that mothers need to be reassured that bonding is an ongoing process and that lack of early eye contact will not compromise their long term relationship with their child (Symanski, 1992).

#### *Implications for Practice*

The results of this study provide evidence that mothers experience a different and unique bonding process when they have a young child with a visual impairment. As a result of their child's additional needs, mothers experienced a change in their maternal identity and perceived maternal expectations (both internal and societal). Genetic counselors, lactation consultants, intervention specialists as well as other health care providers that interact with a mother in the first few months following a child's diagnosis can aid in the adjustment process by discussing bonding and possible difficulties that they might experience due to a lack of eye contact. Informing mothers that their feelings are not unique, but rather widespread among individuals who have been in a similar situation may initially help mothers to feel less overwhelmed and isolated as well as less likely to question their own competence as a mother.

#### *Limitations and Future Research*

This was a small qualitative study designed to explore the impact of a young child's visual impairment on a mother's bonding and identity. The interviewees

generously shared their experience so as to provide a better understanding of the emotional implications of having a child with a visual impairment. However, the sample size was small, consisting of only eight female participants and we knew nothing about the family structure, resources or supports of the participants.

Further, half of the participants were recruited through Perkins School for the Blind. These individuals not only live in the state of Massachusetts where they have access to a certain level of care, but live in close proximity to the school and were also motivated to obtain services from the school. Additionally, seven out of eight of the interviews were conducted over the telephone. We did not notice a difference in the amount of information shared between the participant that we interviewed face-to-face, but it is not possible to quantitatively verify differences. In the absence of eye contact and other non-verbal communication, it could have been difficult to build a rapport and gain the participant's trust throughout the conversation. In contrast, the extra confidentiality afforded by the telephone may have allowed participants to express feelings they otherwise may not have expressed.

Only two out of eight participants had children with the same diagnosis. Therefore, responses could have been influenced by the heterogeneity of conditions and differences in the timing of the diagnosis. Additionally, only two participants had more than two children, therefore, no data on the number of children and emotional response to a visual impairment could be inferred. As with all qualitative studies, there was the limitation of recall bias. It is possible that interviewees' memories and emotions have changed with time. Also, it is important to note the subjectivity and personal bias of the interviewer when coding the interviews and determining the themes.

This study did not explore the impact of visual impairments on paternal bonding. It would have been useful to have been able to compare experiences between parents. Additionally, we asked no questions about the experiences of siblings and bonding. A few parents referenced that their sighted children were influential in helping them bond with their child with a visual impairment, but no comprehensive data was collected on this topic. Further, it would be interesting to complete a longitudinal study with this cohort examining how a mothers' sense of bonding changes as their child ages and is able to use other senses and speech to convey their emotional wants and needs.

## CONCLUSIONS

Mothers who have a child with a visual impairment were interviewed about their bonding experiences and how these experiences impacted them on a deeper, emotional level. Some of the major themes that emerged included changes in maternal identity, struggles during feeding time and difficulty establishing a bond in the absence of a mutual gaze or reciprocated facial gestures. This study provides the first qualitative analysis of how a mother's bonding experience during feeding time is impacted by her child's visual impairment. Understanding how visual impairments can have psychological implications on maternal bonding will assist providers in offering more attentive and personalized support to mothers. This study demonstrates that mothers may not initially realize the implications of a diagnosis for them, and thus may benefit from additional guidance on topics that are not usually addressed with new mothers, specifically bonding during feeding.

Genetic counselors that see children with a visual impairment may be more adept at recognizing the widespread implications of a diagnosis than other healthcare professionals. Effective counseling may depend on the extent of the visual impairment and the psychological state of the mother. Other medical providers that care for children with visual impairments have a responsibility to be aware of the implications on a mother and to acknowledge her need to bond with her child and somehow provide support.

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## APPENDIX A

### Recruitment notice

# Do you have a young child with a visual impairment?

I am a graduate student in the Genetic Counseling Program at Brandeis University and I am seeking volunteers to participate in a research project. The goal of this study is to explore how a mother feels while bonding with her child with a visual impairment.

### IN ORDER TO PARTICIPATE YOU MUST:

- Be a mother of a child **UNDER the age of 3 years** with a **visual impairment**
- Have at least **one child older than 3 years** with **normal vision**
- Have done the majority of the feeding for both children (bottle or breast)

Participation in this study is voluntary. All participants will be compensated with a \$25.00 gift certificate. Participation will include an eligibility survey (by phone or email) and an audiotaped face-to-face or telephone interview lasting ~1 hour.

If you are interested in participating in this study, please contact Abbe Golding at [agolding@brandeis.edu](mailto:agolding@brandeis.edu)

Please note that all identifying information of the participants will be kept confidential and will be destroyed after the completion of the study. Identifying details will be changed to protect the privacy of the participants.

I appreciate your willingness to participate in this study and look forward to hearing from you.

Sincerely,

Abbe Golding  
Genetic Counseling Student  
Brandeis University  
Waltham MA



## APPENDIX B

### Eligibility Screening Tool

**Name:**

**Location:**

**Phone Number:**

**Email (Work or Personal):**

1. Do you have a child with a visual impairment
  - If yes, how old is he/she?
  - Is this the first child in your family with a visual impairment?
  
2. Do you have any other children?
  - If yes, are they older or younger than your child with the visual impairment?
  - If yes, how old is he/she?
  
3. Are both of your children biologically related to you?
  
4. Did you do the majority of feeding for both your children?
  
5. Would you be willing to meet for an in-person interview lasting about an hour?
  - If unable to meet in person, would you be willing to participate in a telephone interview lasting about an hour?



## APPENDIX C

### Informed consent form

**BRANDEIS UNIVERSITY  
DEPARTMENT OF BIOLOGY  
GENETIC COUNSELING GRADUATE PROGRAM**

### **Informed Consent to Participate in Research**

**Through a New Lens: The Impact of an Infant's Visual Impairments  
on Maternal Bonding and Maternal Identity During Feeding Time**

**Principal Investigator:** Judith Tsipis  
**Student Researcher:** Abbe Golding

#### **INTRODUCTION**

Abbe Golding is a graduate student in the Genetic Counseling Program at Brandeis University. She is conducting a research study to learn more about the bonding experience of mothers when their child has a severe visual impairment or is blind. Judith Tsipis is the Director of the Brandeis University Genetic Counseling Graduate Program and a professor of biology. This research project is being conducted as part of the Master's Thesis requirement for Genetic Counseling.

You are being invited to participate in this study because you have a child with a visual impairment and at least one older child who is sighted.

Taking part in this research study is voluntary. You should not feel any pressure to participate. You can decide to stop taking part in this research study at any time for any reason.

Please read all of the following information carefully. Ask any questions that you have about this research study. Do not sign this consent form unless you understand the information in it and have had your questions answered to your satisfaction.

If you decide to take part in this research study, you will be asked to sign this form. You will be given a copy of the signed form. You should keep your copy for your records. It has information, including important names and telephone numbers, to which you may wish to refer in the future.

#### **PURPOSE OF STUDY**

The purpose of this study is to obtain an in-depth understanding of the experiences and emotions of mothers who (1) have a child (under the age of 3) with a visual impairment and (2) have at least one older sighted child. We hope to better understand how maternal bonding is impacted by

a lack of mutual eye contact during a critical period of development. It is our hope that the experiences shared by participants in this study will be useful in helping health professionals understand the impact of an infant's visual impairments on maternal bonding and maternal identity during feeding time.

### **PROCEDURES TO BE FOLLOWED**

You will be asked to participate in an audiotaped face-to-face interview or telephone interview lasting approximately one hour. During this interview you will be asked questions regarding your experiences as a mother of a young child with impaired vision and also asked to reflect on how they differ, if at all, from your earlier experiences with your sighted child.

### **RISKS**

Participation in this study presents no more than minimal risk. However, it is possible that by taking part in this interview, you may experience thoughts or feelings that are upsetting to you. Should that occur, Dr. David Rintell, a licensed psychologist is available to speak to you. He can be contacted by phone at 617-734-6778 or via pager 617-732-5700 (extension #34587).

### **BENEFITS**

There will be no direct benefit to you for your participation in this study. We hope that in the future, information obtained from this study will help to gain a better understanding of the emotional experiences of mothers and their feelings surrounding infant feeding.

### **ALTERNATIVES**

An alternative is to not participate in this research study.

### **PRIVACY AND CONFIDENTIALITY**

During this study all records containing identifying information, such as names, email addresses, telephone numbers, and home or work addresses will be kept strictly confidential. All study related materials (including consent forms, interview transcripts, and audiotapes) will be kept in a secure location accessible to only the student researcher. Any databases containing identifiers will be password protected using a password known only by the student researcher. Upon enrollment in the study you will receive an ID number which will be used to code transcripts, interview notes, and audiotapes. If you are quoted or referred to in a written or oral report you will receive an alternate name. You will never be referred to by your real name or any other identifying information obtained from this interview.

### **PAYMENT**

You will receive a \$25 gift certificate to Amazon.com for participation in the research study as a gesture of appreciation for your time and feedback.

**COST**

There will be no cost to you to participate in the study, other than the time it takes to be interviewed.

**WHOM TO CONTACT**

If you encounter any problems related to study participation or have questions about the study, you may contact the Student Researcher, Abbe Golding, at [agolding@brandeis.edu](mailto:agolding@brandeis.edu) or (561) 436-5740

You may also contact the Principal Investigator for this project, Judith Tsipis, at [tsipis@brandeis.edu](mailto:tsipis@brandeis.edu).

If you have questions about your rights as a research study subject, contact the Brandeis Committee for Protection of Human Subjects by email at [irb@brandeis.edu](mailto:irb@brandeis.edu), or by phone at 781-736-8133.

## PARTICIPANT'S STATEMENT

I have read this consent form and have discussed with Abbe Golding the procedures described above. I understand that any questions that I might have will be answered verbally or, if I prefer, with a written statement. I have been given the opportunity to ask questions and all questions have been answered to my satisfaction.

I understand that my participation is voluntary and that I may discontinue participation in this study at any time, or for any reason.

If I have any questions concerning my rights as a research subject in this study, I may contact the Brandeis Committee for Protection of Human Subjects by email at [irb@brandeis.edu](mailto:irb@brandeis.edu), or by phone at 781-736-8133.

I have been fully informed of the above-described study with its risks and benefits, and I hereby consent to the procedures set forth above. I agree to have my interview audio taped and understand that it will only be used for research purposes.

I understand that as a participant in this study my identity and data relating to this research study will be kept confidential.

Consent for audio recording     YES     NO

\_\_\_\_\_  
Date

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Student Researcher Signature

## APPENDIX D

### Interview Guide

**Date:**

**Time:**

**Location:**

Background Information from Eligibility Screening:

First child in the family to be diagnosed with a VI: No Yes Diagnosis: \_\_\_\_\_

Age: \_\_\_\_\_ Name: \_\_\_\_\_

Age of sighted sibling (s): \_\_\_\_\_ M F

Name/age of one closest in age to child with VI: \_\_\_\_\_

#### I. Introduction and Background

- a. Conduct informed consent process and discuss confidentiality
- b. Let the participant know that she can take a break or terminate the interview at any time for any reason
- c. Explain the presence and purpose of recording equipment and note-taking
  - i. *With your consent, I will be audiotaping our interview so that I don't miss anything. I many also take a few notes during the interview. Afterward, the interview will be transcribed by a confidential transcription service and your name will not be associated with it. Any potentially identifying information that might come up as we talk will be deleted from the transcript before data entry.*
- d. Briefly describe the research aims and purpose of interviews
  - i. *The aim of this study is to explore the impact of visual impairments on maternal bonding. You are the expert on this subject and I want to learn about this experience from you. Also, I want to stress that the bonding process can vary among mothers and babies due to a number of factors including visual impairment. As there is no one way or right way to bond, I merely want to learn about differences .The way this is going to work is that I am going to ask you a series of questions about your children. Again, if at any time you don't want to answer or I don't ask something that you feel you want to share please let me know. Any experiences you can share will be valuable.*

e. Do you have any question before we begin?

## II. Questions

**a. Today we will be talking about your family. I know that is personal and unique to each individual so I appreciate your willingness to share your experiences with me. I know we spoke a little about this on the phone, but could you tell me a bit more about your immediate family?**

i. How many people are in your immediate family?

**b. Could you tell me a little bit about yourself?**

i. Need to know:

- Age:
- Race:
- Marital Status:
- What is your current employment status?
  - PT or FT?

**c. Following the birth of \_\_\_\_\_ (name of child with a visual impairment), did you stay at home or did you return to work?**

i. Did you do the same when your other child/children were born?

**d. How old was \_\_\_\_\_ when you recognized that there might be something wrong with his/her vision?**

i. What made you first recognize that \_\_\_\_\_ had a visual impairment?

ii. How old was s/he when diagnosed with \_\_\_\_\_?

- **Probe:** Tell me a little about the process

iii. How did you first react/initially feel when you learned that \_\_\_\_\_ would always have trouble seeing/would not see?

- **Probe:** When you heard this did you feel sadness? Confusion? Scared? Angry?

- **Probe:** What about that experience was \_\_\_\_\_?

**e. Did learning about \_\_\_\_\_'s condition alter your view of yourself as a mother?**

- i. How do you define yourself as the parent of \_\_\_\_\_? Does it vary from the way you define yourself in terms of your other child (ren) who are not visually impaired?
  - **Probe:** Daily activities? Cuddle? Recognition?
- ii. Do you believe this characterization varies from mothers who do not have a child/children with a visual impairment?

*Now I am going to switch gears and talk about feeding:*

**f. Did you breast or bottle feed \_\_\_\_\_ (child with VI), or did you use a mix of the two?**

- i. *IF breast fed*, for how long?
- ii. *IF a mix or bottle*, did you still do the bulk of the feeding or did you share with your partner?

**g. Tell me about some of the memories you have about feeding/feeding time?**

- i. Was there a specific time that was hard? If so, what was it? Were they related to \_\_\_\_\_'s vision or some other factor?
- ii. Was there a specific time you felt especially close to \_\_\_\_\_ during feeding?

*Now I would like to discuss your experiences with your first child, \_\_\_\_\_.*

**h. When \_\_\_\_\_ (sighted child) was born, did you breast feed, bottle feed or use a mix of the two?**

- i. *If different feeding method from VI baby → What caused you to switch?*
- ii. *IF breast fed*, for how long?
- iii. *IF a mix or bottle*, did you still do the bulk of the feeding or did you share with your partner?

**i. Tell me about some of the memories you have about feeding/feeding time**

- i. Was there a specific time that was hard? If so, what was it? Do you think anything specific was a contributing factor?
- ii. Was there a specific time you felt especially close to \_\_\_\_\_ during feeding?

- j. **When you think back to your other child/children (sighted), can you recall any major difference between the two (sighted as compared to visually impaired) regarding feeding?**
- k. **What, if any, special strategies did you developed to enhance your ability to help you and your VI son/daughter connect to one another?**
  - i. What type of strategies?
  - ii. For what?
- l. **As you know, this whole research study is about how parents establish bonding with their children (*In this study bonding can be thought of as the close, emotional relationship between a mother and her baby*)**
  - i. Have your expectations of a mother's role changed based on your child's condition?
  - ii. How has your child's visual impairment impacted the establishment of a mutual bond between yourself and your child? (ability for you to feel close to them and them to feel close to you)? How so?
  - iii. Can you describe any difference/s between the closeness you feel with this child (**name of VI child**) and the closeness you feel/felt with your other child/children?
- m. **Have you talked about bonding or feeding with other parents of children with visual impairments?**
  - **Probe:** Were there other resources you connected with? (Books, websites, pamphlets)
  - ii. Are you part of a support group for feeding and bonding?
  - iii. Do you think that would be helpful

### III. Closing comments

- a. Thank the participant and ask them about the interview experience
- b. Remind them that David Rintell is available as a resource if the experience any emotional distress following the interview
- c. Reassure participant of confidentiality of responses
- d. Offer to send a copy of the abstract to the participant when the study is complete