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Making Space for Positive Constructions of the Mother-Child Relationship

*The Voices of Mothers of Children with
Autism Spectrum Disorder*

Unlike most research that employs attachment theory and ideologies of good mothering, this study takes a feminist theoretical perspective in order to explore positive aspects of the mother-child relationship, as described by mothers of children on the autism spectrum. Qualitative oral history interviews were conducted with five mothers of children diagnosed with ASD (autism spectrum disorder) in Toronto and the York Region of Ontario. Three themes emerged from the data analysis: building a bond through learning and growth of the self; “you will grow with them and your love will grow”; and “find support where you can from people who will understand.” The findings from this study indicate that mothers of children on the autism spectrum can experience their mother-child relationship as a positive bond, one that develops as result of the mothers’ self reflection and growth, which they in turn attribute to the influence of their children, and give this bond back to their children through their mothering practices. These findings make the case that the scope of intervention services must be broadened to focus on facilitating, and acknowledging the positive side of the mother-child relationship amongst families of children on the autism spectrum.

The experience of the mother-child relationship amongst mothers of children with Autism Spectrum Disorder (ASD)¹ has not readily been explored through maternal narratives. Within the scholarly literature, the relationship and interactions between a mother and a child on the autism spectrum is generally presented as non-existent and disorganized (Naber et al., 2007: 1131 and 1134; van Ijzendoorn et al., 2007: 604; Watson, 1998: 55, 56), stressful (Olsson and Hwang, 2001: 540-41; Sen and Yurtsever, 2007: 240-42), or studied from a deficit perspective, with the perspective of mothers with typically developing children presented as normal and then compared to mothers of children with exceptionalities, whose relationships are seen to come up short (Beck, Daley,

Hastings, and Stevenson, 2004: 633–634; Naber et al., 2007: 1131; Wimpory, Hobson, Williams, and Nash, 2000: 529).

Attachment theory and (implicit) ideologies of motherhood are often the basis for such comparisons, both of which establish interaction expectations for mothers and their children. As a result, when a woman has a child with a disability, ideological values of motherhood no longer apply: “...mothers of children with disabilities make their way within a society that devalues their children and in which their motherhood has ‘failed’ to follow the culturally appropriate trajectory” (Landsman, 1998: 77).

This article argues that Attachment Theory and ideologies of motherhood can no longer be a foundation towards understanding the mother-child relationship, as both perspectives exclude the experiences of mothers who have children with ASD. This research study suggests that a child’s diagnosis of ASD will not eliminate the experience of a mother-child relationship; the experience of the mother-child relationship is simply unique to each and every mother.

Through a feminist perspective and an oral history approach the present study explores the mother-child relationship as experienced by mothers of children with ASD, by asking how mothers of children on the autism spectrum describe their mother-child relationship. Hearing maternal narratives, amongst mothers of children on the autism spectrum, are an important source of empowerment for other mothers in the early stages of the diagnosis to know that there is hope, and that in spite of the challenges they may be faced with, their mothering experiences can include the experience of joy, love, and pride in raising a child with ASD.

Theoretical perspective adopted for this study

Feminist scholars have been critical as to what and whom defines women’s experiences, and how such perspectives can undermine women’s confidence as mothers (O’Reilly, 2006: 34–44, 46– 47; Rich, 1976: 13, 42, 68). According to Adrienne Rich (1976), women’s experiences as mothers have often been understood within the scope of an institution, rather than as an experience (13, 42). Motherhood as an institution has developed circumstances for women that do not reflect their reality, but are so influential they end up shaping women’s experiences as mothers (42). Thus, motherhood is said to lack authenticity and agency, as women mother their children based on ideological values found within the institution of motherhood (O’Reilly, 2006: 44; Rich, 1976: 42).

In order to move away from motherhood as an institution, and value the individual experiences of being a mother, feminist scholar, Adrienne Rich (1976), suggests talking about women’s experiences as mothering, rather than as motherhood (13, 208). In doing so, this feminist perspective acknowledges women’s experiences as a facilitative factor toward their sense of empowerment (O’Reilly, 2006: 45–50). Although the notion of empowered mothering is not clearly defined within the feminist literature, according to Andrea O’Reilly

(2006) challenging ideologies of motherhood has “...destabilized the hold this discourse has on the meaning and practice of mothering and have cleared the space for the articulation of counter narratives of mothering” (45). By not having a specific definition of mothering, more space is created for diversity in the experience of being a mother, and as a result, empowered mothering has at its foundation mothers validating their experiences, exercising their sense of agency and individuality, and realizing there is no right way to mother (Horwitz, 2004: 43-57; O’Reilly, 2006: 45, 47). Thus, in keeping with this approach, this study seeks to challenge dominant ideologies and narratives of motherhood, specifically as they relate to mothers of children with ASD, and to extend the knowledge base of qualities that are apart of the mother-child relationship.

Attachment theory and motherhood

The applicability of attachment theory to children whose developmental trajectory are not based on normative development calls into question the validity of attachment theory as a means to understand the nature of the mother-child relationship. Due to the challenges children with ASD demonstrate in social interactions (Bowler, 2007: 1-25), an unfair assumption has been made that the mother-child relationship, as defined by Attachment Theory, cannot be experienced by mothers of children with ASD (see Naber et al., 2007: 1131). Attachment Theory is based on four different types of attachment categorizations (Howe, 1995: 78-95), which are not enough to understand the dynamics of a relationship, especially amongst mothers of children on the autism spectrum. For example, a mother’s attachment may be seen through her advocacy work in establishing services for her child. I would argue that Attachment Theory does not clearly demonstrate how an attachment style emerges into the specific qualities of a mother-child relationship among mothers of children with ASD. Relationships are complex, intertwined, and continuously evolving (Howe, 1995: 9-14, 22-24) to be captured or explained by a single theory. For mothers such categorization will further perpetuate the assumption that mothers of children on the autism spectrum cannot develop a mother-child relationship. Each individual mother develops a relationship with her child, the quality and pattern of interaction will be different, irrespective of whether or not the child has an exceptionality.

Ideologies of motherhood with an exceptional child

Attachment Theory limits the understanding of how the mother-child relationship develops among mothers of children with ASD, along with associated characteristics of that relationship. Ideologies associated with motherhood, in western society, establish standards that dictate expectations of what it is to be a “good mother” (Rich, 1976: 43, 46), and expectations of how mothers should interact with their children in developing a “good” mother-child relationship (Landsman, 1998: 77, 79; O’Reilly, 2006: 43). Mothers of children

with exceptionalities often feel pressure to conform to a traditional view of motherhood (McKeever and Miller, 2004: 1181), and are directly impacted by such expectations. For example, in Antonia Nelson's (2002) research study that looked at the impact of a child's exceptionality on the mother, she found that when mothers were given the diagnosis of their child's exceptionality they felt they had to "negotiate a new kind of mothering," which included their mother-child relationship (520). More importantly the question remains as to why their experiences of mothering are called into question when their child has an exceptionality?

The idea of maternal sensitivity, found within Attachment Theory, holds mothers of children on the autism spectrum accountable for their children's attachment style development (Howe, 1995: 63) in the "good versus bad" mother ideology. The "good mother" ideology classifies maternal sensitivity as sacrificing the self for the child in order to meet the child's every need (Green, 2004: 32-33; McKeever and Miller, 2004: 1181; O'Reilly, 2006: 46). Therefore, a mother who demonstrates a secure attachment style with her child can be automatically categorized as the "good mother."

The "bad mother" discourse has been perpetuated for mothers of children on the autism spectrum, with such terms as the "refrigerator mom" developed by Bruno Bettelheim during the 1960s, which has pathologized their sense of motherhood (Kingston, 2007: 29; McKeever and Miller, 2004). The "refrigerator mom" terminology accused mothers of lacking maternal sensitivity (e.g., being unresponsive, lacking warmth and caring toward their children), as a result causing the development of autism in their children (Bettelheim, 1967: 125-26, 390, 398-99). Although the term no longer has merit, undoubtedly, remnants of such an ideology has caused "...silence, guilt, and pain among mothers of children with autism" (Kingston, 2007: 29).

O'Reilly (2006) asserts that such ideologies dis-empower mothers when they do not follow the predetermined trajectory of being the "good or ideal" mother (43, 46). This experience of disempowerment is further compounded for mothers of children with ASD, as their experiences of being a mother and developing a relationship with their children are further scrutinized due to the nature of the child's exceptionality.

Given the predominance of the good mother ideology and the stronghold attachment theory has in psychological research on mother-child relationships, not surprisingly, mothers of children with ASD have been silenced within much of the scholarly literature, specifically in regard to discussing their mother-child relationship positively or otherwise. The silence of these mothers is further perpetuated by the fact that research that has been done on the mother-child relationship, amongst mothers of children with exceptionalities, much of it has quantified their experiences through the use of self-report measures, rather than through interviews to garner an in-depth understanding (Beck et al., 2004; Hastings et al., 2005: 630-634; Gray, 2006: 971-72; see Greenberg, Seltzer, Krauss, Chou, and Hong, 2004: 17-18; Montes and

Halterman, 2007: 1041-44; see Orsomond, Seltzer, Greenberg, Krauss, 2006: 124-29). As a result expert knowledge and quantitative data are presented as the only valid reflection of their mother-child relationship in the literature (Kingston, 2007: 46).

The mother-child relationship and the child's diagnosis of ASD as reflected in the literature

Within the literature the quantitative data specifically presents a strong emphasis on the stress and emotional factors related to raising a child with ASD (Herring, Gray, Taffe, Tonge, Sweeney, and Einfeld, 2006: 879-80; Olsson and Hwang, 2001: 540-41; Sen and Yurtsever, 2007: 240-42; see Hastings et al., 2005: 639-41), positive attributes of the mother-child relationship or the child with an exceptionality and their contribution to the family is readily ignored in the literature (Green, 2007: 151; King et al., 2006: 354). Specific topics on ASD that dominate the literature (e.g., depression, high stress levels amongst mothers) are portrayed as the only and standard experiences of parenting a child with ASD. For example research findings indicate that feelings of sadness, loss, and guilt are predominant amongst mothers of children diagnosed on the autism spectrum (O'Brien, 2007: 135-46; Olsson and Hwang, 2001: 535, 538-42; Sen and Yurtsever, 2007: 238-39). Also, in addition to sadness, parents may also feel a sense of "ambiguous loss" related to no longer having the "perfect" child and the expected parental role (King et al., 2006: 362-63; Landsman, 1998: 73; O'Brien, 2007: 137, 140-41).

Although families of a child on the autism spectrum are raising their child under challenging circumstances, which may impact the nature of the mother-child relationship, how and in what ways are not explicitly explored in the literature. Sadness and guilt impact parenting competency where parents may question their ability to handle challenging behaviors demonstrated by the child (Kuhn and Carter, 2006: 564-75). In Jennifer Kuhn's and Alice Carter's (2006) study, amongst 171 mothers of children diagnosed on the autism spectrum, 21 percent of mothers felt their guilt impacted their abilities in parenting, and 80 percent said they did feel guilt when first informed about their child's diagnosis (565-66). However, the study did not indicate what aspects of their parenting abilities were impacted by their feelings of guilt, and what impact, if any, this had on the mother-child relationship.

Although findings from these research studies do not explicitly conclude that mothers of children with ASD never develop a positive mother-child relationship, there still exists an implicit assumption that mothers of children with ASD will continue to question their role as mothers, feel discouraged in finding positives within their mother-child relationship, and have a different (i.e., worse) mothering experience that is not consistent with the "norms" of attachment between mother and child. Furthermore, Kuhn and Carter (2006) assert that "Little is known about how cognitions among parents of children

with an ASD may affect their parenting experience, and few assessment measures exist to investigate this area” (565). In addition, within this body of literature on ASD, no connection is made between the emotional and social demands of raising a child on the autism spectrum in regard to how such feelings impact mother’s perceptions of developing a relationship with their child.

Method

Selection of participants

Participants were selected based on research findings which lend support to the emotional readiness of mothers in discussing the nature of their mother-child relationship. The literature has demonstrated that over time parents are better able to deal with the diagnosis through coping strategies (Gray, 2002: 215-22, 2006: 972-76; Tzoy, Connolly, and Novak, 2007: 255-57), readjustment of their beliefs about the child and their parenting role, and recognition of the positive aspects of the child (King et al., 2006: 358-63). Based on these findings, which were done over a one- and ten-year period, mothers who were in the five to ten years post-diagnosis period were sought for this research study.

Participants

Three of the five women were single mothers, and two were married. The mothers ranged in age from early 40s to early 50s. All the mothers were Caucasian (although from diverse backgrounds). Four out of the five mothers had sons (one of whom was a step-mother), and one mother had a daughter. Except for one mother, all the other mothers had additional children. The age of the children (with ASD) ranged in age from fifteen to twenty years of age. The age range of diagnosis was between three to five years of age for four mothers, and twelve years of age for one mother. Within the autism spectrum, two children were diagnosed with PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified), one with autism, and two children with Asperger’s Syndrome. Four out of the five mothers described their children as having moderate to high language skills.

Procedure

Recruitment occurred in Ontario, at twelve agencies that specifically provide services for families and children with developmental exceptionalities (e.g., ASD), four community centres, and one childcare centre. Permission was granted to advertise the research study via a flyer on their information boards. Research participants made contact with the researcher either through telephone or e-mail.

All procedures were approved by the Ethics Board at the affiliated university of the researcher. The mothers were interviewed over a three-week period at an Ontario university or at a private space within a community agency. The

interviews were recorded, and lasted between forty-five minutes to one hour.

The current research study uses a qualitative approach to data collection and analysis. The particular strategy used in the current qualitative study is oral history interviewing. Oral history interviewing generally involves a 'natural flowing' conversation, which gives participants the room to tell stories, reflective and current, about their mother-child relationship without a predetermined chronological approach to asking questions (Babbie and Benaquisto, 2002: 330-345). However, a list of general questions was developed to serve as a general guideline for conducting the interview, in order to demonstrate the goal and direction of the interview (see Appendix I).

Member checking interpretations of research findings with participants have been described as increasing validity in qualitative research designs (Dockett and Perry, 2007: 51-52 ; Morrow, 2005: 250-60). In this study three mothers agreed to review their transcribed interview and direct quotes, and agreed for them to appear in this research paper.

Data analysis

The data were analyzed using thematic analysis (Cresswell, 2005: 230-56) via NVivo, a qualitative software program that allows the researcher to organize and categorize the data based on developing themes and concepts.

Results

The findings presented in this study seek to represent the mother-child relationship as it has been experienced, including up to the point of the research study. In this study no operational definition of a "mother-child relationship" is offered. Rather, it is constructed by the mothers in their narratives of their lived experiences of mothering a child on the autism spectrum.

Building a bond through learning and growth of the self

Within the narrative accounts, self-growth and learning was expressed as a positive aspect of the mother-child relationship. The mothers described growth and learning as enabling them to discover aspects of the self they never knew they had, which in turn contributes positively to their role as mothers and to the relationship they have with their children. The mothers narrated about the growth and learning of the self they experienced as a result of having a child with ASD. The mothers described self-growth and learning as a positive journey of self-discovery that may not have happened if it was not for their children. Some mothers specifically discussed their growth as positively contributing to their mother-child relationship, because they now had the skills needed to support their children's development.

I think she's [daughter Crystal] just taught me how to love, really like a deep kind of love that is very different than a man and woman love, ... and its made me appreciate my own mother a lot more just being a mother,

and taught me, you know our relationship is good, we work at it, we think about it, and [I] try to do the best for her.... So basically in terms of positives for me and Crystal, well certainly for me, I have grown to be a better mother with her, I have found things in me that I didn't know were there. [Researcher: like what?] How can I describe it, well I learned to be assertive. (Amy, mother of Crystal)

Parenting Sean has built compassion within me and helped me to realize that all is not what it appears to be. Being a parent of a child with autism has stopped me from being so judgemental. I am learning to recognize that everyone has something to contribute, and I am really grateful that Sean has so many wonderful qualities. (Laura, mother of Sean)

And just grow with your child because I think that's what it is, you're growing into being a mother with a special needs child while they're growing, and so it's not everything at once. (Amy, mother of Crystal)

Part of the growth for some of these mothers was finding a voice they never knew they had, feeling a sense of empowerment, and being grateful that their children had brought this into their lives. The learning and growth that took place for these mothers made them feel more connected to their children, because their children were able to allow them to grow into the mothers they are today who can support and be proud of their children.

Having a child with autism has given me a voice, it has given me courage, and I have learned that things I would not necessarily fight for myself, I will fight for my child. It is like being a mother bear ... as an individual you might put up with a whole lot, but when it comes to your child and what they need and are entitled to ... I think it is really important to give support to those parents who don't know their child's rights and how to advocate for them. We have to learn if we are going to help our child, we need to speak with our own voice, to passionately advocate the needs of our child. This is a gift I could not have acquired any other way. I think it is a positive aspect of having a child with autism; it transforms many mothers from timidity to empowerment.... (Laura, mother of Sean)

“You will grow with them and your love will grow”

All the mothers in the research study talked about the love that exists in their mother-child relationship, and as being a positive quality of their mother-child relationship. Through their narratives they demonstrate the transformation of their love in specific areas that has positively benefited the child, and their experience of mothering. The growth of their love is a continuous process and is at the foundation of their mother-child relationship as

they appreciate moments of joy, value the lives of their children, and maintain a positive outlook.

And I just loved this baby before she was even born, like most mothers ... I just loved her to bits you know, she was the light of my life ... I really believe she's the best thing that has ever happened to me.... I always said I fell in love with her, and I continue to fall in love with her ... there was protection there instantly and instinct, but everyday more love. (Amy, mother of Crystal)

...there is love, I love him very [much]. You know, with all and all I am proud of him that he is doing well, that he has been able to achieve what he's achieved (Irene, mother of Joseph)

You can lose focus on the child because it is very frustrating at times, but you just give them so much love and you get it back, you get all that love back.... (Sheila, mother of Jonathan)

There is no doubt that the mothers of children with ASD experience challenges in raising their children; however, this does not diminish the positive emotions they have and continue to develop for their children. Within their descriptions the mothers demonstrate that they maintain their positive emotions they have about their children:

I think the stress is really ever present. So what I try to do now is see the humour more, and laugh more with my son. He says some really funny things, and I just try to enjoy him more. (Laura, mother of Sean)

And, you know my patience wore thin sometimes, but I've always been positive, and very positive with her ... we are very connected, because there is just her and I, we're very bonded. (Amy, mother of Crystal)

Mothers discussed explicitly and implicitly the importance of maintaining a positive outlook, and the role it plays in their mother-child relationship:

I never looked, I don't look at it as a negative [ASD] because I don't want her to look at it as a negative, and I don't want other people to look at it as a negative. (Amy, mother of Crystal)

When asked what advice she would give a mother who has just found out about their child's diagnosis of ASD, in regard to the mother child relationship, one mother said the following:

I'd tell them to remember who their child was before they ever heard the

word autism, and to celebrate who their child was before they ever got the diagnosis. (Laura, mother of Sean)

“Find support where you can from people who will understand”

The mothers discussed the importance of receiving support from various sources throughout the years. They felt the nature of the support they received gave them the skills and an outlook needed in facilitating their mother-child relationship. The support was a source of, and facilitated confidence in being a mother of a child with ASD. The diversity of support ranged from words of encouragement, mothers feeling their children are accepted and understood, and parenting strategies.

I go to a support group ... it's [a] parenting support group, I have been going for a year and a half. That support group has really helped me a lot, the tools I have learned, I have used on Jonathan ... for me it is to just continue to get as much support as I can for myself, to be a better parent. (Sheila, mother of Jonathan)

... I was searching for other mothers to talk to when I was first with Crystal, and it was such a wonderful thing when I did connect with someone on the phone who totally understood me, who I could even go visit and not worry if Crystal did weird things, people wouldn't look at me like you know “what's the matter with her child?, why is she doing this or that?” yeah, that's really helpful.... (Amy, mother of Crystal)

... find support where you can from people who will understand. Build that support at an early age and keep it going.... And so the more people who know your kid and are used to your kid, those family supports, you know the larger family groups, friends, parent relief workers, whoever you can get who can build in that kind of support for you and the your child, that's going to support you and your child's relationship, you know. (Lisa, mother of Matthew)

Discussion

As described by the mothers, the mother-child relationship is experienced as learning and growth of the self, love for the child, in addition to being positively impacted by supports. The mothers attribute positive growth and learning of the self to their children, and impart that learning and growth of the self back to their children in the way they mother.

Building a bond through learning and growth

The findings demonstrate these mothers do acknowledge a relationship between themselves and their children, and demonstrate to us what that relationship is about and how it is experienced. Assertiveness, compassion, advocacy,

understanding, and how to love are some of the qualities reflected in mothers' growth and learning; qualities they feel their children have brought to their mother-child relationship. The growth and learning the mothers experience brings them full circle, it is as if their children bring into their lives the skills they would need in order to support the child, and positively discover and experience the mother-child relationship.

A unique finding of this research study was the mothers' discovery of their inner voice as being a positive aspect of their mother-child relationship (e.g., advocate). The ability to find their inner voice and, therefore, become an advocate meant their children's rights would always have a voice within society. Becoming an advocate is as much a transformation for these mothers as it is for their children, because through a mother's advocacy work she is paving the way for her child to be respected and included within the society they live.

The notion of growth has been found in other research studies amongst parents of children diagnosed on the autism spectrum (Bayat, 2007: 709-711; Hare, Pratt, Burton, Bromley, and Emerson, 2004: 433; Pakenham, Sofronoff, and Samios, 2004: 253-256). Kenneth Pakenham and colleagues (2004) found that 73 percent of parents in their research study experienced a positive personality change as a result of raising a child with Asperger Syndrome (254). In addition, Dougal Hare and colleagues (2004) have found positive advantages amongst mothers caring for a child on the autism spectrum (e.g., mothers "...reported that they had become more patient and tolerant and could appreciate other people's good qualities more...") (433). The current research study has extended their findings by demonstrating how positive changes within the mother lend themselves to positive interpretations of and practices in the mother-child relationship.

Guillermo Montes and Jill Halterman (2007) found, on self-reported measures of the parent-child relationship, a close mother-child relationship was reported amongst families that had a child with autism (1043-1044). However, within their discussion Montes and Halterman did not explore specific qualities of the mother-child relationship that lead mothers to report having a sense of closeness to their children (1044-1045), which this research study was able to accomplish.

Mojdeh Bayat (2007) explored the positive and negative impact of autism on family functioning. His findings demonstrate that positive transformations of the family (e.g., family relationships became more connected and strengthened over time, parents had more compassion, etc.) are an indicator of family resilience (e.g., strength in the face challenges, being able to overcome challenges) (702-714). His findings support this research study by suggesting resilience may be an outcome of self-growth and learning. Such that self-growth and learning establish resilience in mothers as they continue to support their children, and see the positives in their mother-child relationship in the face of challenges.

“You know you will grow with them and your love will grow”

The mothers of this research study candidly discuss the love they have for their children. They argued that the transformation of their love into these different areas positively benefited the child, and their experience of mothering. In a recent research study that explored expressed emotion (e.g., feelings and attitudes about the child) amongst mothers of children with intellectual disabilities, through the use of self-report measures, researchers concluded mothers had more negative expressed emotion (e.g., more critical) towards the child with an intellectual disability compared to their other children that did not have an intellectual disability (Beck et al., 2004: 633–634).

The findings of this research study challenge Beck's and colleague's research study by demonstrating that mothers do express love for their children with no indication that it is dependent on their child's diagnosis of ASD. In addition, mothers were specifically asked about the process of getting to know the child in light of the diagnostic characteristics, the general consensus was the diagnostic characteristics are an outline of the child in order to support the needs of the child, but that there is more to the child than those characteristics alone.

King and colleagues (2006) assert that the literature has portrayed children on the autism spectrum as having a negative impact on the well-being of families by being a factor of stress (355; see McKeever and Miller, 2004: 1177). Not only are children blamed, but the literature has also implicitly perpetuated the “refrigerator mother” discourse by not acknowledging the emotional attachment mothers feel towards their children, and the different ways mothers express such emotions. The findings of this research study have substantially challenged this implicit, and sometimes explicit, perspective in the literature, as the mothers clearly express the love they have for their children in many ways (e.g., positive outlook, valuing their children's lives).

The mothers' maintenance of a positive outlook about their children also demonstrates the love they have for their children. Such finding is consistent with David Gray's (2006) research findings which suggest that with time, parents of children with ASD, often use emotion focussed coping strategies, as a result focussing more on “...an appreciation of their child's good qualities...” (975). This is an important point to emphasize, because mothers in this research study valued the qualities they saw within the individuality of their children, which were not demonstrated to be governed by the diagnostic characteristics associated with ASD.

“Find support where you can from people who will understand”

For the mothers in this study support was and continues to be an important aspect of the mother-child relationship. Overall, the mothers feel the dynamic nature of the support (e.g., parenting strategies, support network of family and friends, acceptance and understanding) they received was beneficial to the relationship they have with their children because it allows them to be better mothers. This research finding is similar with the current

literature that demonstrates the importance of support for families of children with exceptionalities (McWilliam, Tocci, and Harbin, 1998: 1-16). However, unique to this research study are that the findings suggest specific supports (e.g., mother-child parenting strategies) mothers of children diagnosed on the autism spectrum may require in order to support the development of their mother-child relationship in positive ways.

The quality of formal support systems created acceptance and understanding which made mothers of children on the autism spectrum not feel alone. The acceptance and understanding mothers received through a close network of friends, families, and service providers, may be a factor in making mothers more comfortable and confident in their abilities as mothers, because such support is not dictated by expert knowledge of how to mother their children.

Limitations

Although this research study has made an important contribution to the literature on ASD and the mother-child relationship, the study is not without its limitations. Firstly, the research study was limited in regard to diversity; as all the mothers in the research study were Caucasian (although from diverse backgrounds). Therefore, the findings cannot be extended to mothers from different racial groups whose mother-child relationship may be influenced by cultural understandings of exceptionalities.

Secondly, the descriptions of the mother-child relationship only represent the mother's perspectives and not those of their children. Our understanding of the mother-child relationship can be further extended by looking at the perspectives of the mother-child relationship as experienced amongst children with ASD. Our knowledge of the diagnostic characteristic associated with ASD (e.g., limited social skills) (Bowler, 2007: 1-25), through their descriptions, can be extended in regard to how those characteristics manifest within the mother-child relationship.

Lastly, the research study was not a longitudinal research study design; as a result no conclusions can be made about how the mother-child relationship develops over time. The research study captured retrospective and current descriptions of the mother-child relationship during one interview session, which as time passes mothers may have come to understand past experiences differently than at the time of the experience.

Implications of research findings

The mothers of this research study have demonstrated that they do experience a mother-child relationship, supporting the implication that family centered practices should include methods which focus on strategies and programming geared towards supporting and strengthening the mother-child relationship (among families of children with ASD).

Mothers of children with ASD are often at the forefront in supporting their children's development (Norton and Drew, 1994: 71), as much of the

research is conducted from their perspective, it is important their voices are listened to in order to develop effective services that can enhance and support the relationship development with their children. For example, during the initial stages of establishing a family service plan, service providers need to ask questions (e.g., how do you feel about being an advocate for your child?, how do you feel about the relationship that you have with your child?, how do you spend quality time with your child and family?, etc.) that explore a mother's thoughts and feelings surrounding her relationship with her child (with ASD), but most importantly they must listen to the responses which will demonstrate specific experiences, memories, and bonds a mother may want to share with her child (e.g., going to the movies, playing sports, etc.), therefore guiding strategies towards such outcomes.

Intervention services are often based on working collaboratively with families, an outcome of these research findings is that service providers develop an awareness and understanding that their collaborative efforts, with families of children with ASD, is to instill empowerment. Collaboration needs to go further than giving mothers a voice in decision making, but to validate the contributions and efforts mothers are making in regard to supporting their children (e.g., advocacy), no matter how small or large, will only empower mothers to continue their efforts, and feel good about their role as mothers.

Three mothers in the research study acknowledged the impact the child's diagnosis of ASD had on their marriages in which both parents could not deal with the diagnosis as a couple, because each was dealing with the diagnosis independently. Therefore, support services need to be developed that focus on the impact a child's diagnosis has on the relationship of a two parent family, in order to give parents the strategies they need to communicate honestly, openly, and effectively about their feelings of being a parent of, and raising a child with ASD. Facilitating such an open dialogue can create awareness and understanding among each parent about the other person's feelings, which encourages couples to support each other.

Future research initiatives need to focus on the experiences of raising a child on the spectrum among single parent families, and fathers. Single parents may face unique challenges as they absorb 100 percent of the responsibility in raising a child on the autism spectrum without the extra support to balance those responsibilities. In order to address these challenges among single parent families more funding for respite care, ODSP, home care, etc, are needed.

Unfortunately, most of the research on ASD is presented from the perspective of mothers, which neglects the opinions and experiences of fathers. Fathers of children on the autism spectrum may face similar, as well as a different set of challenges in dealing with their child's diagnosis. The impact of the diagnosis may affect fathers differently than mothers which warrant research in order to develop services that specifically meet their needs.

Conclusion

The purpose of this research study was to explore the mother-child relationship as experienced by mothers of children with ASD, in order to give a voice to their experiences. Through the mothers' narratives we have learned that these mothers do experience their mother-child relationship in positive ways. Mother's self discovery continues to contribute positively to the way in which they mother their children (e.g., as an advocate), and in their experience of the mother-child relationship as a bond through self-growth. Although the mothers are faced with challenges in raising their children, they continue to experience love, and demonstrate a deep sense of commitment in doing the best for their children.

This research study has begun to pave the way for mother-centered research initiatives which listen to the voices of mothers as a valid way to understand their experiences, and facilitate social change. The findings of this research study are very informative, it is hoped that they are able to inform future developments of intervention services with a focus on supporting women of children with ASD in building, discovering, and strengthening their mother-child relationship.

Through their narratives these mothers have demonstrated that attachment theory is no longer enough to understand the depth and dynamic nature of the mother-child relationship. The narratives presented in this paper challenges all of us to broaden our understanding of mothering, as an experience that is unique to each and every mother, and to understand the mother-child relationship void of preconceived notions of what it means to be a mother and the experience of a mother-child relationship.

Appendix I Interview Protocol

Introduction

Narrative interview (Script);

Introduction to topic: "I am interested in looking at the development of the mother-child relationship of mothers with children diagnosed with Autism. I am interested in getting stories about the experiences up to today that have shaped / influenced your mother-child attachment."

Length: Approximately 45 minutes to one hour.

Questions: The list of questions has been devised to demonstrate the goal and direction of the study, which will be a guideline for conducting the interview in order to build or explore on what the participant have said.

- 1) Tell me your story, keeping in mind the mother-child attachment and its development between you and your child who has autism.
- 2) What have been the joys?

- 3) What have been the challenges?
- 4) How do you feel your attachment to the child who has autism is different from other children?
- 5) How do you feel your attachment to your child is different from that of other mothers with children who do not have autism?
- 6) Tell me about what aspects of your relationship with your child you find meaningful/enjoy the most?
- 7) What words of encouragement would you give to mothers of children newly diagnosed with autism about their mother-child relationship?

¹ASDs are said to be a range of neuro-developmental disorders (e.g., autism, Asperger syndrome, pervasive developmental disorder-not otherwise specified), which impact the cognitive, linguistic (e.g., limited language development), behavioral patterns (e.g., repetitive behavior patterns with objects or mannerisms and minimal eye-to-eye gaze), and social development of the child (e.g., minimal social reciprocity). ASD runs along on a continuum in which specific behaviors appear more or less pronounced (Bowler, 2007: 1-25).

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