

1-1-2007

Stress Factors and Child-rearing Practices in Somali-Canadian Mothers of Young Children Diagnosed with Autism Spectrum Disorder

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**STRESS FACTORS AND CHILD-REARING PRACTICES IN SOMALI-CANADIAN
MOTHERS OF YOUNG CHILDREN DIAGNOSED WITH AUTISM SPECTRUM
DISORDER**

by

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A Major Research Paper
Presented to Ryerson University

in partial fulfillment of the requirements for the degree of

Master of Arts
in the Program of
Early Childhood Studies

Toronto, Ontario, Canada, 2007

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STRESS FACTORS AND CHILD-REARING PRACTICES IN SOMALI-CANADIAN MOTHERS OF YOUNG CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

This study investigated stress factors and child-rearing practices in Somali-Canadian mothers of young children (between 6 to 12 years of age) diagnosed with autism spectrum disorder.

A grounded theory methodology was used for this study. Focus group discussions were held with 10 mothers residing in Toronto. Nine categories arose which were compiled into four themes 1) concerns and uncertainty over the child's development, 2) language and cultural barriers, 3) lack of resources and 4) financial burden. It was discovered that major stressors included lack of informal support, negative experiences from professionals, and financial challenges. The participants indicated that their major coping system was acceptance of their child's condition.

Keywords: autism, early childhood, coping, stress, Somali parents

Acknowledgements

I wish to thank the members of the Somali Parent Support Group and other parents who contributed to this project. This study would not have been accomplished without their support.

I am grateful to my supervisor, Dr. Angela Valeo for her encouragement and positive attitude. Her constructive feedback and generosity of time helped me throughout the research process. I wish to thank my second reader Dr. Rachel Berman for her patience and constructive comments and the Chair, Dr. Judith Bernhard for her guidance and assistance.

I would like to acknowledge Dr. Mehrunnisa Ali, who instructed me and shared her expertise in qualitative research. I am grateful to Instructor Martha Lee-Blickstead and Dr. Michael Mueller, who initially encouraged me to research this topic which has been my passion. Last but not least, I would like to thank my family, friends and colleagues for their support, guidance and encouragements.

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Introduction and Literature Review

According to the United States Centers for Disease Control and Prevention, Autism Spectrum Disorders are developmental disabilities that cause significant impairments in many areas of children's development especially aspects of social interaction and communication. Also present are repetitive behaviors and interests as well as sensory issues. These deficits affect children's ability to communicate ideas and feelings, interact with others to gain relationships and to take care of themselves (National Research Council, 2001). Autism Society Canada also points out that the current prevalence in children with Autism Spectrum Disorders in Canada is estimated at one in 165 children, with many Canadian families, especially immigrant families, being affected by this disorder.

As Canada's population becomes increasingly ethnically diverse, the need for research addressing ethnic issues in those communities also increases. A review of the literatures suggests that, while researchers have largely focused on the stress experienced by mainstream families with a child with Autism Spectrum Disorder little or no work has been conducted looking at the particular impact on immigrant families. This study of stress factors in child-rearing in Somali-Canadian families of children with autism spectrum disorder will attempt to reduce the knowledge gap in the literature by finding particular stressors and coping strategies of this group.

Parents of children with Autism Spectrum Disorder tend to report more parenting stress than parents of children with other developmental delays or parents of typical developing children (Bromley, Hare, Davison & Emerson, 2004; Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005; Sivberg, 2002). Recently there has been a rise

in the number of published research reports regarding stress and coping, however there is rather little research that focuses clearly on parenting stress and coping in families of children with autism, and there is little or no research that focuses on parenting stress and coping in immigrant families of children with autism spectrum disorder (McGrath, 2006).

The purpose of the current research was to identify factors related to child-rearing stressors and coping styles in 10 Somali-Canadian mothers of children aged 6 to 12, diagnosed with Autism Spectrum Disorders.

The study of stress factors in child-rearing in Somali-Canadian families with children who have developmental disabilities is a very important topic of investigation as it may provide additional knowledge of maternal experiences, ideas and beliefs. Being a new immigrant and a member of visible minority group can increase the number of stressors with which a family must cope. Families may have to deal with racial discrimination, language and cultural barriers due to their particular ethnic background. It is vital to establish and learn factors that contribute their stressors in order to reduce or help them to develop strategies to better cope those stressors (McCreary, Cunningham, Ingram & Fife, 2006).

The key terms of the study are stress and coping. Stress is defined as a real or interpreted threat or concern from the outside world affecting the parent when demands tax or exceed the mother's resources. The individual responds to stress in ways that affect the individual as well as their environment (Knussen & Sloper, 1992; Levine, 2005; Pensarino, 2006; Russell, 2007). Based on Lazarus and Folkman's model of stress and coping, coping refers to a person's skills, experiences and resources to manage the internal and external demands of the stressful situations (Knussen & Sloper, 1992).

A child diagnosed with Autism Spectrum Disorder represents a regular source of stress on the family unit with not only parents being affected, but also siblings and relationships among family members (Higgins, Bailey & Pearce, 2005).

According to Waite & Lee (1996) children hold a unique position in the marital relationship in that the children belong to the partnership rather than to either of the individuals and they increase the stability of the marriage. However, parenting children with special needs has been reported to produce stress from variety of sources, such as the child with disability, sibling(s), lack of skill acquisition, socio economic status of the family, and the environment (Akkor, Askar & Karance 1996; Duarte, Bordin, Yazigi & Mooney 2005; Tarakeshwar & Pargament, 2001). The stress can also arise from the prolonged dependency and demands for the special care of the child, disappointments with delayed skill developments, particularly in the area of speech and language, and the worry in regards to future self sufficiency.

Havens (2005) indicated that families of students with disability had higher rates of divorce and separation when compared to families of non-disabled children. Stress in families of children with disability is most often a factor that leads in divorce or the breakdown of the family.

Researchers report that parents of children with autistic spectrum disorders are more likely to experience extreme stress than parents of children with other developmental delays and more so for minority families (Bromley et al. 2004; Hastings et al. 2005; Sivberg, 2002). Parents with children with autism have to deal with stress resulting from the particular physical and emotional demands of caring for a child with autism spectrum disorder. Disruptive behaviours associated with the disorder, such as

tantrums and obsessive compulsive behaviours (Higgins, Bailey & Pearce, 2005). Furthermore, immigrant families may have to deal with professionals' bias toward children of particular ethnicity, religion, appearance, or national origin. Some teachers could also be prejudiced against minority students with autism because they come from a group that they dislike or misunderstand (Wilder, Dyches, Obiakor & Algozzine, 2004).

As Lai & Ishiyama (2004) indicated, minority parents can contribute to an understanding of a child's behaviour and cultural views to the classroom teachers. However, there is far less school participation of minority parents than their "Caucasian" counterparts. Also Lai & Ishiyama (2004) had identified eight reasons in educational establishment for the low rates of minority parent participation these are: limited proficiency in English, lack of familiarity with the school system, discomfort in interacting with teachers, implicit trust of teachers, respect for the teachers as the experts, unfamiliarity with concepts of parental participation expected in schools, insufficient numbers of teachers from ethnic minority backgrounds and finally different ethnic belief systems. If these issues are not addressed it could continue to contribute to the parents' daily stressors. In addition, Higgins et al. (2005) stated that a high level of stress experienced by the mothers of children with autism spectrum disorder has a reverse relationship with the child's educational progress.

In their combined sample of parents of children with Down Syndrome, Autism and Developmental Delays, Hall and Marteau (2003) discovered that acknowledgement of fate or God's will were linked with better parental adjustment while acknowledgement of the environment and heredity were linked with poorer adjustment.

In addition, Bjorck & Klewicki (1997) and Tarakeshwar & Pargament (2001) found an association between the use of positive religious coping methods and lower level of depression and anxiety.

History of Somalis in Canada

All the participants in the study are originally from Somalia and it is useful to provide a basic historical and cultural overview of Somalis for the reader.

Somalis first started migrating soon after the dictator Mohamed Siad Barre's regime took over the rule of the country on October, 1969. In the 1970s the first Somali refugees started settling in Canada. Due to the political and civil turmoil in Somalia, more continued to leave the country and in the 1980's the Somali community in Canada grew. Though, at the beginning most of the refugees and immigrants were single males and females, in the early 1990's a large number of families started arriving and settled in Toronto. The 2001 census showed 33,725 Somalis living in Canada, and about half, 17,380, lived in Toronto (Diversity Watch).

Child rearing practices

In Somali culture, childbearing usually starts soon after marriage. Expectant and newly-delivered mothers rely on a strong network of the women in the community. Before a birth, the female relatives, neighbors and friends hold a party for the expectant mother where she receives emotional support and at times monetary support.

It is a tradition that when a child is born, the new mother and baby stay indoors at home for 40 days, a time period known as afartanbah. This is done to reduce postpartum stress for the mother and to enhance mother and child bonding. Female relatives and friends visit the family and one or two women may stay with the family to help take care

of them. The women contribute to house hold chores, grocery shopping and preparing special foods for the mother to help her body recuperate the physical demand of the pregnancy. New foods are withheld to avoid food allergies for the mother and the new born as the mother is breastfeeding. Usually an elderly or an experienced woman, e.g. her mother, grandmother, sister or a neighbour, takes the initiative to assist and give childrearing advice to the new mother. Within the first 8 weeks of the baby's life, a naming ceremony is held for the child. Sometimes, the naming ceremony is held at the same time as the celebration at the end of (afartanbah) the 40 days. These ceremonies are big family gatherings with lots of food, accompanied by the ritual killing of a goat and prayers. In the rural areas, a woman's status is enhanced with the more children she bears. As a result it is not unusual for a Somali family to have seven or eight children (Lewis, 1996; & Children's of Minnesota, 2003). Somalis believe that children are "Sebi" which means that they are innocent and are not capable of being responsible for their actions so each and every adult in the community is responsible for the care and well being of all children.

Methodology

Qualitative methodology has been cited as suitable for studying little-understood phenomena (Cutcliffe, 2000; Eaves, 2001; Patton, 2002). Since stress factors and child-rearing practices in Somali-Canadian families of children with autism spectrum disorder have not, to date been researched, a grounded theory research design was applied.

Grounded theory design was chosen as it is an interpretative research methodology which is based on the belief that as individuals within groups describe situations, experiences, beliefs with the self and others, common patterns of behaviour emerge. Most of all, grounded theory provides a theory that is induced from the data rather than hypothesized beforehand (Creswell, 2005; McCallin, 2003; Patton, 2002).

Participants

The participants were 10 Somali-Canadian mothers of children with Autism Spectrum Disorder (varying severity). The children's ages ranged from six to twelve years of age. Appendix V reports the children's descriptive data including ages, gender, age of diagnosis and birth order. The age of diagnosis ranged (from two to seven years), but most (60%) had been diagnosed between two and three years of age. Most of the children (80%) were male and a small number (20%) were female. All the children had siblings. Birth order of the children varied; two of the females and one of the males were first born, the rest were one male 2nd born, one male 3rd born, three males were 4th born and one male was 5th born. The average children per family was 4.2 (see Appendix V).

The participants of the focus groups were a homogeneous group. All the parents self-identified as Somali-Canadian and were immigrants from the same ethnic, cultural and religious group. They spoke the same language and had a child who had been

diagnosed with Autism Spectrum Disorder. All the participants were citizens of Canada and live in Toronto where the study was conducted. The average age of the participants was 38.3 years. Their ages ranged from 32 to 42 years. Seven were married and three were divorced. Five had a high school diploma, four had a degree or a college diploma, and one was enrolled in college at the time of the study. All the participants had children that were diagnosed with Autism Spectrum Disorder, 8 of the children were boys and 2 were girls. One of the children (boy) had a twin girl who was typically developing. Nine of the children were born in Canada and one was born in Middle East. The average income of the participants was \$31,000 per year. Three participants had relatives living with them and seven did not have any extended family living in Toronto. Seven were fluent in English and Somali and three indicated they could manage but needed an interpreter when dealing with schools and/or service related issues. Of the 10 participants, seven were stay-at-home mothers, two were employed, (one full time and the other part time) and the third mother was a part time student. The participants received no compensation for their participation in this study.

The researcher is a founding partner of the Somali Parent Support Group (which provides a forum for Somali parents who have children with special needs), to avoid researcher bias, two parents of the Somali Parent Support Group volunteered to do the recruiting. Parents were recruited through word of mouth by those two parents who courteously agreed to assist the researcher. Parents had an opportunity to discuss among themselves if they wanted to participate or not. The study was carried out through English and Somali language focus groups, as all the parents were fluent in English and Somali. Seven of the participants of the focus groups were members of the Somali Parent

Support Group in Toronto and three were parents who were planning to join this group. The first group session took place in a meeting room at Northwood Neighbourhood Services (a community organization that provides settlement support service), where this parent support group met once every month. The place was chosen because the parents were most likely to feel comfortable in that setting since they had been using this facility for the past two years. The first focus group session took place on June 22, 2007 and six mothers participated in. The second session took place on June 30, 2007 in one of the participant's home and four mothers participated. The participants were informed of the purpose and procedures of the research during the initial recruitment by the two parent volunteers. The purpose and procedure were also reviewed at the beginning of each focus group session by the researcher. The participants signed consent forms to share information and were reassured of their anonymity. However, anonymity among group participants could not have been guaranteed as the focus group members already knew each other. Since anonymity was not possible within the group, confidentiality among the participants was attempted to be assured through consent form (see Appendix I).

Prior to the focus group sessions, open-ended questions were developed that would invite the mothers to discuss their stress factors and coping strategies. The questions originated from a review of relevant literature focused on parent stress and their coping mechanisms. The questions were posed in a way that allowed the parents to narrate their experiences and beliefs. Appendix (III) provides a list of the questions and probes that were used during the focus groups. Probes were designed to clearly understand what the participants were intended to portray or to clarify their responses.

Focus Groups

Focus groups were the choice of data gathering because it often uncovers issues, opinions, beliefs, and values of the participants (Fern, 2001; Puchta & Potter, 2004). In addition, Slaughter, Pinfold, Flintoft, Gort, Thiel, Blackstien-Hirsch, Axcell, Paterson, Cameron, Estabrooks, Mercer, Goel & Williams, (1999) pointed out several of advantages of focus groups. First, focus group formats do not discriminate against people who cannot read or write and they encourage participation from those who feel they may have nothing of importance to share or are hesitant to be interviewed on their own. This inclusiveness is important when seeking opinion. In addition, focus groups provide a way for data collection that takes advantage of group interaction and usually produces abundant experiential data. Participants can choose issues that are important to them within the framework of the research questions that are posed to them, and consequently provide valuable information (Cutcliffe, 2000; Fern, 2001; Puchta & Potter, 2004; Slaughter et al.1999).

Procedures

The participants were divided into two groups (one of six participants and a second of four participants) so all parents had opportunities to share their experiences, thoughts, ideas and opinions and the researcher would be able to make notes of body language, (e.g. if a participant nodded her head with agreement to what it had been said then nodded head was written down along with the main point that the speaker had made). If a participant made a comment with tears, “tears on eyes were written down”. The duration of each focus group session was between one hour to one hour and a half. At the end of each focus group, the participants were asked if they had anything else to

add and they indicated that was all they could think of. The researcher then went through briefly the issues they brought up and parents confirmed what were their main stressors and coping strategies, then the parents were thanked and the meeting was concluded.

At the beginning of each group session the purpose of the research was reviewed with the participants. They were also informed of the goals of the research and the importance of their input and ideas into the project. The researcher made it possible for the participants to discuss and share any aspect of the issues they felt were important by encouraging them to share their experiences as parents of children with special needs since they came to Canada, and discuss strategies they have been using to cope with the stresses of daily living. Other questions and probes were also used during the discussion (see Appendix III).

The information was collected through parent discussions aided with open-ended questions. The group discussions were audio-taped with the participants' permissions. Brief notes were also taken during the sessions. The parents were asked to complete demographic information (see Appendix II), and help was offered to those who required assistance to complete the form.

The researcher refrained from drawing any conclusions while listening to the discussion. The researcher re-wrote all field notes and recorded overall impressions as soon as possible after the end of each focus group. For example, as some of the literature suggested, verbal and non-verbal cues, how the individuals participated and with whom, and whether or not the verbal statements matched the non-verbal behaviors were noted (Cutcliffe, 2000; Denzin & Yvonne, 2003; Slaughter et al. 1999).

The researcher transcribed word for word and transliterated the audio recordings of both focus group sessions. This process was labelled “conversations” and used individual participants’ real names in order to be able to assign comments and/or questions made by the participants. Participants were later given pseudonyms to protect their identity.

The transcripts were read as many times as possible before open coding started.

Coding

After becoming familiar with the transcript, a copy of the original transcript was used to categorize the statements. Statements which were similar, or which stated similar ideas (concepts) were highlighted with the same color and given a category name. Every line, paragraph, on every section of transcript was coded for related concepts. The categories that showed similarities were combined to eliminate redundancy. The constant comparison method (Slaughter et al.1999) was used as the researcher continuously compared the categories and codes of the new transcripts. The process of coding was continued until the entire transcript was covered and then the concepts were sorted into categories.

The researcher assigned a label to each concept and from these the following categories emerged: a) child development (issues related to child’s learning and skill acquisition); b) worries (concerns about child’s present condition and future progress); c) school problems (difficulties and disagreements encountered from school personnel); d) public attitude (negative experiences from people toward child or parents’ personal characteristics); e) isolation (issues related to child’s behaviour or language and cultural barriers); f) inadequate support system (lack or limited informal or formal support);

g) lack of knowledge (limited knowledge and understanding of the disorder by the parents and professionals); h) health (inability to meet medical and dietary needs of the child); and i) economic difficulties (constant struggle to meet the need of the whole family). Definitions of these are illustrated in appendix IV. Finally four thematic areas were developed.

To increase the study's reliability and validity, the researcher confirmed the results by showing them to some of the participants and asking them if the researcher had correctly recorded what they meant.

Rose (2000) stated that a researcher's identity could appear multidimensional to those who are being studied. The researcher in this study was, in some circumstances, seen as the expert as some of the participants indicated that they were glad that the researcher had the knowledge and now how to do the study. In another circumstance the researcher was seen as an agent with the mothers viewing her as providing a platform for them to voice their circumstances as immigrants of different cultural background. On the other hand, during the focus group discussions the researcher was seen as part of the group as the participants shared personal experiences, fears, beliefs and hopes without worrying the researcher's perception about them as she shares same values and customs.

As an insider the researcher benefited from knowing the language, values and customs of the participants as they discussed their stressors and coping strategies. However, there was a drawback to being an insider and having to adhere to the institution's (University's) rules for ethical conduct, for example, In Somali culture there is reciprocal respect between individuals and before the formal recruitment started some mothers heard about the upcoming research. They approached the researcher indicating

that the research was an interesting one and beneficial to them but they would not be able to participate. However, these parents indicated that if the researcher really needed them to be there they would be there. A culturally appropriate response would have been to have the researcher to say “the study cannot be done without you being there” and those parents would have participated in the study. But because of the rules of ethical conduct, the researcher felt that this could be interpreted as coercion. As a novice researcher, the researcher chose to clear any ethical mishaps and chose two parents from the Somali Parent Support Group to do the initial recruiting. The researcher believes that if she has done the recruiting herself or in conjunction with the two parents, the number of the participants would have been to some extent greater than the current number (N=10) of participants. In this circumstance, the researcher felt that there was no clear cut approach as an insider between rules of ethical conduct in regards to human subjects and culturally appropriate practices. After the focus groups were concluded the researcher had contacted those parents to tell them that they were needed to be there but it was not appropriate approach in regards to ethical guidelines that the researcher had to follow.

Findings

All together, nine categories were identified as stress factors for the mothers. The categories and definitions are illustrated in appendix III. These categories are combined in four thematic areas as follows: a) concern and uncertainty over the child's development, b) language and cultural barriers, c) lack of resources, and d) financial burden. Some categories fall under two themes. For example, the category of isolation is included in two different themes. The following is the first theme that was mentioned by both groups as questions were discussed.

Concerns and Uncertainty over the Child's Development

All the parents stated one of their stressors to be the lack of their child's skill development especially as the child grew older and his/her delay became more noticeable. Some of the skill concerns they reported included, concerns about delays in the development of speech and the ability to communicate with others, concerns over self help skills such as, toileting and eating different types of foods, the social skills such as inter acting with family members, and limited development of cognitive skills. The participants felt that some of the above concerns played a major role in allowing the child to become aware of his/her surrounding or following directions. As a result, the majority of mother expressed strong concerns over safety issues.

Safety

Safety of their child was an important concern for nine of the participants. These mothers emphasized that their main concerns about their children was their safety. Shukri and Warda, the mothers of two boys ages 7 and 9 respectively, indicated that their

children were able to leave the house during the night no matter what precautions were taken. The mothers shared their experiences and daily worries:

...There is no night that my husband and I spend the night in our own bedroom together...one of us has to sleep in the living room to keep eye on him [middle son with autism]. In order to do that...you have to be half sleep, no one understands what we go through (Shukri).

...all of us worry about the safety of our children, because they do not understand things that are danger to them, if it is cars or persons who could kidnap them...(Jamila).

These statements express feelings of constant worry that the mothers have about the safety of their children. The mothers seem to recognize that as their children get older the situation will become far more challenging if the children do not acquire some skills.

The following comment affirms this:

... There is growing [developmental] issues...at the present time I am not asking my child to be good academics but to develop skills that will make him free [independent] (pause) so he could live on his own when he grows up...(Ruun).

Other mothers nodded in agreement as Ruun spoke.

Lack of language skills, sleep and eating issues were also some of the concerns of the participants.

...I am worried of his growth and intellectual development and how to improve his language skills (Khadra).

Though Anab's 6 year old son does not have sleep problems she appears to speak for other parents who have children with sleep issues.

...Some children don't sleep, they don't eat and can't tell you "here is where I am hurting". Sometimes you feel or become hopeless (Anab).

Anab's comment about the lack of language seemed an issue that all the participants identified with as some nodded and others verbalized their agreement.

Services

The mothers consider that insufficient services contributed their children's lack of skill development. The parents shared that they feel hopeless and depressed when the services that they fought so hard for are not what they hoped for. One mother said that they are allowing people in their homes and taking their children into programs but the results are all the same. These professionals will tell you here are some things that you need to do and will help him to develop some skills. One mother shared the following statement:

...Is frustrating not knowing how to teach him, things he needs to [learn] know. I am not a teacher, and people [who supposed] to teach him say [to me] I will show you, but how can I become experts like them like that...(Amran).

Parents were especially concerned about how the children will be able to look after themselves as adults. In Somali culture children are seen as financial security and they are expected to take care their parents but these parents are not only worried that they will not be able financially to rely on their children with special need but they worry about who will take care of them if they out live them. One of the parents brought up this concern and stated:

...The most difficult one is their future, children supposed to take care of their parents; it is not that the parents have to take care of them for the rest of their life (Anab).

Language and Cultural Barriers

Language barrier refers to lack of English proficiency (mothers' understanding and being understood by English speakers is limited) and Cultural barrier refers to people's reaction to the beliefs, customs and everyday behaviour of the mothers which erect barriers of social inclusion and, according to the participants, is the cause of their worries and stresses.

Barriers such as the language and cultural difference of the family and a lack of understanding of linguistic and cultural diversity by professionals are some of the key influences that guide a family's level of participation in community program (Bennett, Zhang, & Hojnar, 1998; Zhang, & Bennett, 2003).

The participants indicated that because of limited language they were missing opportunities to develop relationships with the professionals with whom they worked in the community and schools.

One parent recalled challenges she encountered the first time she tried enrolling her son into her neighborhood school.

...after I shared with them that my son was Autistic, the vice principal with no consideration or attempt to welcome my child, told me that my son did not belong in their school. He said to me that there are special schools for children like him. My son then was transferred in a school in different neighborhood. And before the end of the school year, I took out my other children from that school and moved out the area because I felt they didn't want my son or my family as they said my son didn't belong that school. It is frustrating not being sure year after year what is going to happen (Amran).

For me what depresses me is, the teachers always tell[ing] me bad things that my child did. I respect them, they are the teacher of my child, how can I say to them tell me what he learned. I am afraid they may take in wrong way, so I don't do anything. And everyday I am worried what else they say to me, it is not good feeling but there is not much I can do. Sometimes

I want to go somewhere else but that's what the teachers want and I am not going to do it (Ruun).

These descriptions illustrate feelings of frustration, helplessness and worries experienced by the mothers due to language difficulties and school personnel's cultural lack of sensitivity. These parents felt that they were harassed and under pressure because they are different. They speak a different language and practice different customs. The following comments by couple of parents demonstrate this:

My son has eating and sensory problems. He doesn't like to touch or eat at all, so anything that he could eat for me I give it to him, but I have to feed him. Some people don't understand how important it is that a child has to eat. I am a mother, how can I just sit and starve my child. It is my responsibility to take care of my child even if I feed him at age 5 or 6 (Anab).

Some of the parents feel that they have to be on their guard all the time as everything they do or say is interpreted as child abuse. One of the mothers seems to blame their diverse background and lack of awareness of different cultures by the part of the teachers or professionals as the main contributor of their difficult circumstances as she states the following comment:

One time the day care teachers called children's aid because Leyla's [a mother who was not part of the focus group but all the participants knew] kid had a rash on his back but they assumed he was abused. The sad thing is that Leyla liked and trusted those teachers... because we look different and do things little different they think we are abusers. They don't even give us chance to explain or know us better. (Shukri)

When they were asked by the researcher what could be done to prevent these from happening, they all felt that no one cared to know or have a respect of Somali culture, values and traditions.

In addition, the lack or limited social support, formal and informal, and limited knowledge of Autism by the professionals involved with the families are seen as some of the contributors of their stress.

The participants also indicated that they also are frustrated by the way that the doctors treated them.

I swear, there is no doctor that I trust. They treat you like you are a child because you come from different part of the world and don't speak English they way English speakers do, they think that we are not worthy to be informed what they are giving to our children...(Amran).

Another mother feels that she is not treated the same way as the persons from the dominant culture:

At age three, I knew something was wrong with my son, like he wasn't developing like my other children. But his pediatrician continued saying he will be alright, some children develop differently or give him time... Now I really blame myself listening him. My son was diagnosed when he was 6 years old; imagine what a waste of precious time. I get knots in my stomach when I hear doctors...I am sure if I was normal [typical] Canadian he would have done something the first time I told him about my suspicion (Faisa).

An undergraduate mother also indicated her frustration about the schools and community organizations and how she feels isolated and insignificant.

... The most challenging are the schools and agencies (that offer programs) they tend to destroy all the hope you have. They drain you emotionally. The schools suppose to be where the children get the help they need and it is the challenging part not for the child but for the whole family... Truthfully, we are still fighting. When they refuse to help your child they also reject you. Teachers and doctors supposed to be the most trusted people but here is the opposite (Jamila).

The participants also felt that the professionals that are working with them have limited understanding and knowledge of Autism and this makes them unsure about the future in regards to their children becoming self sufficient.

In reality the doctors don't know the situation that the children are in or what to do with them. So, instead of admitting or making proper referral they would say Oh...he is autistic there is nothing that can be done. So the doctors are the ones who tend to destroy your hope...the lack of knowledge on autism is not only exclusive for doctors but some teachers don't know autism nor how to deal children with autism. I worry the future, if my son doesn't get help, what will be his future then (Ruun).

Communication gap between the professionals also seems to contribute the parents' frustrations and despair, as this mother shares her feelings:

... Many things bring us stress, for example, teachers, doctors and other professionals don't know much about Autism. It is hard when there is no one that you can trust with your child, one person will tell you something and another one will tell you something else... There is also a long waiting list, everything you will be placed in a waiting list. So even though you know your child needs help there is nothing you can do to help. That is really heart breaking. I want to do everything for him but there is nothing I can do. It is frustrating and I feel useless. A parent should not feel this way at all (Jamila).

In Somali culture, teachers and doctors are some of the most trusted and respected people in the society. The participants feel that they are in unfamiliar territory. If they cannot trust these professionals what is next. It is as if they are in seclusion and anxious to trust another professional or authority figure.

Here are some statements of the participants that show why they prefer to seclude themselves and stay home all the time with their child with special needs.

When we are outside and my child screams and other people stare at us is the biggest thing that worries me. The worst thing is when we are in the mall and my child starts picking up things such as potatoes chips. People just look at you and they don't understand. The only thing they see is an older child that looks healthy that has behavior problems... people don't have knowledge about autism... Going outside is what worries me the most and because of it I don't go out (Shukri).

The mothers indicated that they are very proud of their parenting skills. However, they are frustrated when strangers confront them or start sharing unsolicited behaviour

strategies with them and conclude their statements “this is how we do it here in Canada” without even asking why the child is acting the way he is acting.

The other things that stress me are the [child’s] behavior and people blaming me or all the mothers [of children with autism] in general. The child’s behavior is what people notice first. So they interpret that the child has bad behavior and the mother doesn’t care. So the mother is responsible whatever behavior the child exhibits (Faisa).

The mothers felt that this constant public humiliation forced them to isolate themselves from the outside world and the children ended up missing precious outdoor activities such as, knowing their environment and interaction with other people.

That is one of the reasons why some of the parents don’t leave the house with their children (with autism). When all the people are staring at you like you are a bad (incompetent) mother you are not going to enjoy to go out with your child (Nasro).

Treatment from professionals, teachers and doctors alike, and bad experiences from the general public when the participants are in family outings was interpreted as having direct relation with their linguistic and cultural background.

Lack of Resources

The Somali culture emphasizes kinship from birth to death and family is a major source in providing financial and emotional stability. The participants in the study shared their feelings regarding a lack of support, isolation and inadequacy to meet the needs of their children. As Boyd indicated social support may be defined as a “multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support” (p.208).

Some of the parents made these statements in regards to limited resources:

There is no time that I could spend with my other children. If I could find a person who could stay with other children I could take him to the park, or if the person stays with him, I could have time with my other children.

It would have been something for me. But we are stuck to each other. In Somalia this wouldn't have happened, there is always a relative, neighbour or friend willing to help out (Shukri).

Difficulties that they are encountering from some immigration policies were mentioned by both groups as questions on how to gain family support were discussed. The participants indicated that they would like to bring a family member especially a female relative, as Somalis are accustomed getting help from female relatives, but they stated that the immigration will not allow them unless the person is a minor (under 18 years of age) and an immediate family member. However there are cousins who do not meet those criteria but are more experienced which could help the family in the long run, as Somalis treat their nephews and nieces as their own children. They also indicated that there is also another barrier; since they are low income families they are not able to apply a visa for a short term visit.

My younger daughter, said... (pause) she said "you and abo [dad] give all the attention to Aden. When you come from work you say (where is Aden?). When abo [dad] wakes up "Aden". Everything is Aden" I told her, but he is sick. You know what she said... "He is not sick, he is only silent, he is eats, drinks, and runs like everybody else". I told her many times that he is sick; she will say "you love him more than me"... I feel we are favouring one from the others and is overwhelming to see my children think we are neglecting them. I have relatives who could help me but they are not here [Canada] and there is no way I could bring one of them (Warda)

Yet as in the previous quote, another mother who feels that she could benefit from physical as well as emotional help from a relative.

I also worry, God forbid, if something happen to me or my husband, I really don't know where my children will end up and this worries me a lot. If we were in Somalia, we would have had parents and relatives who would take care of them, so I wouldn't have worried as much as I worry now (Shukri).

Some of the mothers indicated that it is hard for them to trust non family member to look after their children as a participant expressed her feelings by making the following statement:

Sometimes my neighbor asks me if she could look after him but it is so challenging for her. (pause) I am afraid he may do something because he is so active that he may even run away. I don't feel comfortable leaving him with other people, I don't know them very well and they don't know who he is, what he likes or what ...no it is too difficult (Saida).

In those circumstances family members and relatives are needed to be physically present in order to support each other as a unit. When the family members and relatives are absent so the resources such as emotional, financial and physical unity and this challenges the family's strength of dealing with crisis.

Financial burden

Lack of extended family has significant implications for these Somali Canadian families with children with special needs, in that not only do they face limited physical and emotional support, but they also face tremendous decrease in economic resources.

The parents shared that they were already struggling economically as they were all low income families and not able to meet or obtain goods and services they consider essential for their children with special needs. This not only made them feel hopeless but also contributed to marital stress.

Some of the parents had these to say:

There is no enough money to support our children, some parents even they can't pay one lab test [test that the healthcare system does not cover]. They can't afford, eventually the child will grow up without improvement... This is what we are against of and it frustrates us. This is the biggest obstacle that we are facing (Ruun).

The participants indicated that some of the children have food allergies or sensitivity and were not able to eat what the rest of the family consumed. Due to their

financial situation, the parents felt that these foods were contributing their children's behaviour and gut problems.

Financial help is also needed for the children who have feeding problems, which are actually majority of these children [with autism] which do not eat what the rest of their family members eat. They need special diet plan. Financially we can't afford to pay what we already know our children need and that is crazy (Faisa).

Even though, Faisa's child does not have food allergies but has a strong food preference, she was advocating for other families who struggle and constantly worry about their children's physical development.

This mother shows concerns about her child's nutritional intake and the effect that it may have. As she states:

Imagine, my child only drinks milk or juice and sometimes eats biscuits. There is nothing else he puts in his mouth. So you can see he needs to see a specialist and start a special diet, however, so far, I don't have anything. I am worried of his growth and intellectual development and how to improve his language skills (Khadra).

The parents had emphasized that their children's nutritional conception was a very important issue, and was stretching the family's financial means and at times doubted their parenting abilities.

The participants not only talked about the needs of the children, they also shared their own needs and what they thought could alleviate their circumstances. The following comments illustrate their feelings:

It is not only the children. Sometimes I need some rest, or spend sometime with other people [adults]. Staying in-side twenty four hours per day really will change you. You will forget yourself and you will forget what life is all about (Zamzam).

The participants also felt that there is correlation between knowledge on Autism and financial aid. They indicated that since people were not aware that children could gain some skills if provided with the necessary interventions and in turn the society will benefit in the future as these children will require less financial assistance as they grow older.

Realistically, there is no one family who can afford that expense, so the government should support us. However, the situation is that no one believes that children with this disorder could improve, so the government and politicians won't provide the necessary funds; and it is not fair (Jamila).

One parent believed that if she could bring a relative who could look after her children, she would have been able to work like her husband and would have been able to pay the majority of the cost that could have improved her child and families' way of life and she stated:

... What the parents and the family could help is getting additional support [extra hand] (Warda).

Several parents with obvious frustrations stated:

Housing is another one that I worry constantly, the quality of the materials that are built in these houses are not good. Almost all of our children have some sort of allergies and we think this is making worse the condition of our children and we can't afford to move in better houses (Ruun)

There is no help, the parent has to do everything if it is financial issues...and for our children we hope for the best (Amran).

According to parents the financial issues also causes friction among family members especially between the parents. Seven out of the ten participants indicated that financial issues were one of the things that they argue with their spouses. The other three who were separated shared that though financial issues were some of the reasons they were separated, it was not the main contributor.

Coping strategies

The parents indicated that they use various types of coping strategies. A common one that the parents shared was religious in nature. This was one of their statements:

First of all God brings [brought] this disorder and only God can take care of it. Secondly, to have friends, not just friends per say, but ones that you can trust, that is how you cope (Shukri).

Some of the parents shared that seeing other families in the same circumstances helped to ease their disappointment in life and helped alleviate doubts about their parenting skills. In addition, since some Somalis believe that disability is caused because of what they have knowingly or unknowingly done. Some participants felt that the disability was not something that was exclusive to them as they met many parents in the support group they attended.

...friends who are in similar situation and support groups where you can see people who are in the same situation that you are in or even more challenging ones. [support group] you can get help and you can help the others. The worst thing is when you are in your own to face personal crisis (Amran)

Several participants indicated that everything happens for a reason and having a child with special needs should not be seen as a burden but as a blessing.

For me I put trust in God. We shouldn't kill ourselves things that we don't have control over it (Anab).

Though all the participants expressed that their main coping strategy is religion, they also indicated that there are other ways they try to cope, some of them involving connecting with other parents through focus groups, sharing their skills and experiences with other parents and getting support from relatives.

When you are down the only person who can understand you is a person who is in the same situation. I call some parents who have children like my son and I talk to them. Knowing that there are other Somali families

who are going through same thing that I'm going through helps. I know I am not alone (Ruun).

Furthermore, some of the parents felt that helping other families and sharing their expertise helped them to cope as they felt good about themselves.

What helps the most is when I help another parent. It really makes me feel good and I know I can change the way that person feels in their situation in that particular time because I was [have been] there. Helping other people helps (Amran).

One of the mothers indicated that having an elderly female relative in her disposition helped her immensely as she confides in her and receives emotional, as well as physical support from her.

We have couple of family members who live with us. And that helps a lot. I talk to them and share what I worry about and they give me a lot of support. I know we should have trust in God and I do. (pause) but without the help of my relatives I don't know if I could have stayed here. We are struggling as it is with a new country, new ways of doing things, new language. I think I would have moved with my relatives where ever most of them are, even if it could have been leaving Canada. People don't understand it is hard having a child with difficulties [special needs] without the help of the whole community (Jamila).

Even with the support from family members still this mother indicated that she still struggles and worries about her child and the future.

Discussion

This study set out to identify factors related to child-rearing stressors and coping styles in ten Somali-Canadian mothers of children with autism spectrum disorder.

Four major themes emerged from focus groups discussions.

The findings suggest that the parents see lack of developmental gains of the children as one of their stressors because the majority of the children did not acquire skills to interact or communicate with significant others. In addition, the children did not appear to improve in their cognitive skills. Due to those limited skill improvements, the parents put more importance on safety of the children as the children do not have the concept of danger. Mothers who had children with eating disorders also expressed greater stress. However, the findings suggest that the mothers placed more emphasis the children's limited cognitive ability over other concerns. In Somali culture children are expected to care for their parents and relatives, due to these expectations the mothers worry about the future. In addition, Somalis do not believe in placing one of their own in an institution so families care for their disabled family member within the family. If the children outlive their parents, other family members are expected to continue the care of that individual so usually parents worry about the burden that they will place other individuals within the family.

Somali parents are proud of their culture and of providing the optimal condition for their children to live and grow up regardless of whether or not a child has a special need. The added challenges of language and cultural difficulties puts limits parents' ability to meet their parenting obligations and caused stress because many blamed

themselves as being the only responsible for the situation they were in because they chose to live overseas.

Bynner (2001) stated, that one of the most significant factors contributing to participants' stress is social exclusion and a lack of access to resources (material, cultural, emotional) which would allow them to develop competency. These reinforces the way parents felt. Because of their limited language competency and formal or informal support system the participants felt they were socially isolated.

The participants also felt that the professionals that were working with them had limited understanding and knowledge of Autism and this gave them uncertainty about the future in regards to their children becoming self sufficient.

Furthermore, some of the mothers showed great concern over the loss of trust for teachers and doctors. Wilder et al. (2004) reported that families of diverse cultural backgrounds often deal with professional bias, dislike or misunderstanding and the participants of this study pointed out that they felt that their own identity (as Somali and Muslim women) was under attack as people discriminated against them and this caused some of them to live in isolation.

It was evident that the mothers felt lack of support from immediate and extended families and that the community they lived in had direct impact on their daily struggles. In turn, the mothers also believed that lack of support contributed other challenges with their typical developing children and spouses. The majority of the mothers felt that they were neglecting their other children and some indicated that because of the lack or limited social support they had marital problems as their capability were stretched.

Even though, some of the literature indicated that families of students with disabilities had higher rates of divorce and separation compared to families of typical developing children (Havens, 2005), the result of this study indicate that 70% of the participants were still married and 30% were separated. This may indicate that majority of the parents chose to stay together even with the challenging and stressful situation they have to cope with.

Some of the mothers stated the need for support groups for Somali-Canadian women which could allow them chance to develop networks, volunteering opportunities by helping other families and overall creating a community so they can help one other with any issue in regards to child rearing and forge the missing support from the extended family.

The lack of extended family has significant implications for these Somali Canadian families with children with special needs. Not only do they face limited physical and emotional support but they face tremendous decrease in economic resources.

The parents shared that they were already struggling economically as they all were low income families and not being able to meet or obtain goods and services they consider to be essential for their children with special needs made them feel hopeless but and constantly contributed to disagreements between the parents.

The Somali culture emphasizes that all the family members contribute to the family unit, thus the family is a major source in providing financial and emotional stability. The participants in the study shared their feelings of lack of support, isolation and inadequacy to meet the needs of their children to be very stressful.

The result of the study supports the finding of other researchers such as Higgins et al. (2005) that a child with Autism Spectrum disorder represents a constant source of stress on the family unit and more so for immigrant families who have additional stressors due to their ethnic, culture, language, religion and nationality backgrounds.

Though all the participants expressed that their main coping strategy involves faith and religion, they also indicated that there are other ways they try to cope, such as connecting with other parents through focus groups, sharing their skills and experiences with other parents, and getting support from relatives. Several mothers indicated that everything (e.g. the disability of their child) happened because it was God's will and because of this one of their coping strategy was, not blaming themselves as the cause of the disorder because it was something out of their hand. Bjorck & Klewicki (1997) and Tarakeshwar & Pargament (2001) found that parents who used positive religious coping methods showed lower levels of depression. The Somali-Canadian mothers in this study used religious coping as a culturally appropriate strategies which led them to accept the child's delay. According to Master, Best & Garmezy (1991) resilience refers to the process of adaptation in the presence of challenging circumstances. These Somali-Canadian mothers showed resilience by overcoming many challenges from fleeing conflict country to caring for a child with special needs in their adopted country. Weiss (2002) argued that a sense of difference and isolation could have major problems; these parents are culturally different from the dominant group and, in addition, they have children with special needs that some of them exhibit hard to control behaviours in public. This study found that what was unique about these participants was that they were proud of their parenting skills and had difficulty dealing the outsiders' interpretation of

their parenting abilities. As a result many of the mothers reacted by secluding themselves and living in isolation. Half of the parents (50%) indicated that most of the time they cope with stressful incidents by avoiding those situations and staying home or moving from the neighborhood.

Conclusion

Somali-Canadian parents of children with autism spectrum disorder in Toronto narrated that there are various factors that contribute to their stressors. Though they share similar stressors with other parents of children with special needs such as dependency and demands of the special care of the child, demands of other children, and lack of developmental progress, the participants of this study indicated that due to their linguistic and cultural difference from the mainstream population they were experiencing particular difficulties related to language and cultural barriers. In addition, because they were immigrants, many were experiencing additional financial stressors. Moreover, since Somalis greatly rely on the resource and support of family members and extended families, a lack of this support system contributed to the mothers' daily stressors.

The statements of the participants were considered valid and credible. Since this research was based on focus groups, the participants' statements are considered credible because the members of the group corroborated each others' experiences throughout the discussion. A reliability and validity check was used to confirm accuracy with respect to transcripts, translations and interpretations of the data with two of the participants.

Limitations

There are some limitations to this study. The study only included a small number of Somali-Canadian parents (N=10) who have been in Canada for 9 years. It is likely that stress would be higher in recently arrived families and in families where the parents or caregivers may have psychological issues. Although the researcher is fluent in both languages, some of the powerful emotion may have been lost in the translation.

It must be noted that initially there were 23 potential participants, but because of issues unique to this community, that number was reduced. Although all the participants were willing to orally discuss their experiences, many did not feel comfortable having their statements appear in print and declined to participate. This limited the study to 10 mothers.

Future studies of this nature would also benefit from the presence of a note-taker to assist the moderator of the focus group. Although all sessions were taped, the researcher felt that many significant experiences and opportunities were not captured during discussions because the moderator was also the note-taker. These examples would have strengthened the results.

For future research it is recommended that recruiting be started months before the planned date of the interviews or focus groups to gain the trust of the possible participants. Recruiting should also be done by the Somalis especially parents or people who can relate with the population that is going to be studied. Word of mouth rather than letters seem also the best way to recruit. It appears that some of the potential participants may not participate if the recruiting is done mainly on letters. Letters seem to make the research more government related venture. However, a contact from a person seems to be

considered trust-worthy and has a more personal and human touch to it. Somalis value face-to-face contact as it shows that the researcher respects them.

Implications

In spite of the limitations noted above, the present study has important implications. It demonstrates that there is the need for assessing cultural and ethnic differences in future parenting stress research. In addition, it highlights that the stress factors for mainstream Canadian families cannot be generalized to other ethnic and culturally diverse groups living in Canada. Caution should also be used to generalize cultural orientations as people even from the same general cultural background may show wide variations in stress and coping strategies, based on their level of socioeconomic status and education, among other things.

Practice

Development of family resource programs in home languages is beneficial. In addition, printing pamphlets for professionals to allow them to become familiar with cultural practices and beliefs is needed, and professionals should be encouraged to know the family and take advantage families knowledge and strengths. In addition, bringing knowledge of diverse cultures into teacher education is essential.

Recommendations

This study highlights the need for an expansion of community based parent groups that are culturally specific. Other recommendations include the need for increased education and awareness of differences in beliefs between ethnic groups. For example, it may be that judgments are often based solely on the colour and physical appearance of a group without appreciating subtle differences in beliefs and attitudes between cultural

groups who may share the same colour skin and dress patterns. It is also recommended that members of the cultural group are represented in the professional bodies working with these groups.

Future research

This study was preliminary and only included a small number of Somali-Canadian mothers (N=10) additional research with a larger sample is needed to gain more understanding on issues of stress and coping strategies of Somali-Canadian mothers living in Canada.

Mothers' perceptions and the effect of blame of having a child with special needs by family, community members or the general public should be explored.

Only mothers participated in this study, thus future research should explore Somali-fathers' perception of disability and their stress and coping strategies.

In addition, more advanced planning and involvement of Somali members is needed for recruitment.

In future research rules of ethical conduct of research with human subjects and culturally appropriate approach in regards to recruitment should be reviewed.

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Ryerson University

Consent Agreement

Stress Factors and Child-rearing practices in Somali-Canadian Mothers of Young Children Diagnosed with Autism Spectrum Disorder.

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigator:

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Purpose of the Study:

The purpose of the study is to identify and evaluate issues related to child-rearing stressors and coping styles in twelve Somali-Canadian mothers of children (between 3 to 8 years of age) with Autism Spectrum Disorder. The main focus of the study is to examine parents' perception with regards to child-rearing stressors (i.e. what are their worries, and what triggers those worries and anxieties) and to find out what tactics they use to manage (which strategies have worked and which ones have not worked for them and why).

All the participants are members of the Somali Parent Support Group in Toronto and the group sessions will take place at Northwood Neighbourhood Services' boardroom where the members of the parent support group meets once every month.

Description of the Study:

You will be asked to attend a focus group session. The group will be composed of six mothers including you so all the participants will have opportunities to share their experiences, thoughts, ideas and opinions. The session is expected to take from 90 to 120 minutes; approximately four main questions will be asked, but you will also be given a chance to add additional information you might find of significance to the topic, or to ask questions. The interview questions are mostly related to child-rearing stressors and strategies that are used to cope and what you think will alleviate those stressors.

What is Experimental in this Study:

None of the procedures used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information for the purpose of analysis.

Risks or Discomforts:

I realize that you might find some of the questions personal in nature and that you might feel uncomfortable answering them. If you should feel uncomfortable at any point during the discussion you may choose not to answer the question without providing reasons for your decision, or you may discontinue participation, either temporarily or permanently. You may also choose to withdraw specific comments you make, which will then be excluded from your interviewer's records.

Participation or non participation will not have an effect on your relationships with the Somali Parent Support Group (Northwood Neighborhood Services).

Benefits of the Study:

The study of stress factors in child-rearing in Somali-Canadian families with children who have developmental disabilities is a very important topic of investigation, will provide additional knowledge of maternal experiences, opinions and ideas for professionals who will be working with these families and also the development of necessary resources and policies to help these families.

Immigrant families go through challenging periods of adjustment that most often lead them to re-assess their values, beliefs and child-rearing practices. When obtained a description of child-rearing stressors that show life experiences of Somali mothers offer a structure to support other parents and to enhance or develop better child-rearing practices. The results could help professionals create better strategies that will allow mothers to manage their identified stressors and share coping strategies with others.

Confidentiality:

I assure that your name will not be used in the report, or anywhere else in the research project except for this form which is used for the purpose of ethical accountability. The form with your name on it will only be kept until the completion of the study (September 2007), and confidentiality will be maintained to the extent allowed by law.

The interviews will be audio-taped and then transcripts of the discussions will be made. Only the primary researcher will have access to the tapes and transcripts. You will be able to review and edit the tape(s) with your responses prior to completion of the study. Upon the completion of this research project (September 2007), the tapes will be erased and the forms destroyed. Some individual answers might be recognizable throughout the report; however, no names will be given to protect the participants' identity.

You are asked to keep any information or comments shared during the group discussion confidential.

Although confidentiality will be promised by the researcher, it cannot be guaranteed from other participants in the focus group.

Incentives to Participate:

You will not receive payment or any other material benefit for your participation in this study. However, your contribution is very valuable, and will be greatly appreciated by the researcher.

Snacks and drinks will be provided during the focus group session.

Costs and/or Compensation for Participation:

There are no costs associated with your participation in the study.

Voluntary Nature of Participation:

Participation in this study is voluntary. Your choice of whether or not to participate will not influence your future relations with Ryerson University. If you decide to participate, you are free to withdraw your consent up until the final draft of the research paper (August 10, 2007) and to stop your participation at any time without penalty.

At any particular point in the study, you may refuse to answer any particular question or stop participation altogether.

Questions about the Study:

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact the research supervisor:

Dr. Angela Valeo
(416) 979-5000 ext. 7696

If you have questions regarding your rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.

Research Ethics Board
c/o Office of the Associate Vice President, Academic
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to be in the study and have been told that you can change your mind and withdraw your consent to participate up until the final draft of the research paper (August 10, 2007). You also agree to keep any information or comments shared during the group discussion confidential. You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print)

Signature of Participant

Date

Note: By signing below, you agree to allow the researcher to audio-tape the interview/group discussion.

Signature of Participant

Signature of Investigator

Date

Focus Group Discussion Questions

- Please share with us your experience as a parent since you came in Canada
- What are the biggest challenges that you have encountered so far?
- When you feel sad, depressed, angry, anxious or worried who do you talk to about those feelings?
- What you think triggers those feelings?
- What coping strategies have you used so far?

Probes

- Can you tell us more about that?
- You mentioned...Could you be more specific?
- Who else had the same or similar experience?

Categories of Stress Factors

Categories	Definition	Themes
1. Child's development	It refers to issues and experiences related to the child's learning and skill acquisition	1. Concerns and Uncertainty of the Child's Development
2. Worries	It refers to the mother's concerns and feelings of the child's present condition and what future holds	
3. School Problems	It refers to difficulties and disagreements that the mothers encountered from school, daycare and program personnel	2. Language and Cultural Barriers
4. Public attitude	It refers to mothers' feelings and experiences on how relatives, friends, neighbors, teachers and general public reacted / behaved toward their child and their personal characteristics (language, customs, beliefs & etc.)	
5. Isolation	It refers to mothers' reaction to the treatments, pressures and demands from people, child's behaviour when in public and lack or limited relatives & friends	

Categories of Stress Factors – Cont'd

Categories	Definition	Themes
6. Inadequate support system	It refers to lack or limited informal or formal support for the family and in particular for the mothers	3. Lack of Resources
7. Lack of knowledge	It refers to mothers' feelings of their limited knowledge and understanding on Autism as well as the limited knowledge of the professionals that work with them (inadequate research and limited treatments)	
8. Health	It refers to mothers worries of feeding and allergies that the children struggle with (not being able to meet medication and dietary needs of their children)	4. Financial Burden
9. Economic difficulties	It refers to parents' constant struggle to meet the needs of the family members	

Appendix V

Age of the children	Gender	Birth order	Age of diagnosis	Number of children in the family
9	Male	4 th	2 ½	4
6	Male	3 rd	4	3
7	Male	2 nd	2 ½	4
9	Male	1 st	3	4
8	Female	1 st	4	4
9	Male	(twin) / 3 rd	2	4
7	Female	1 st	7	2
6	Male	5 th	3	6
6	Male	4 th	2 ½	5
12	Male	4 th	6	6

Age of children (Mean = 7.9)

Age of mothers (Mean = 38.3)

Income (Mean = \$ 31,000)

Children per family (Mean = 4.2)

Year of entry in Canada from 1989 to 1998