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This quantitative study proposed to answer the following question: What are the similarities and differences in maternal experiences and perceptions in regard to their children with Autism Spectrum Disorders (ASD) between the United States and Japan? A total of 96 mothers of children with ASD participated in this study. In all, 47 were recruited from North Carolina in the US and 49 were from Osaka, Japan. Surveys with 5-likert-scale questions were used to collect quantitative data. Survey responses were analyzed by using two-sample independent t-tests to compare the difference between the means of two independent groups (American and Japanese mothers). The results indicated that overall both Japanese and American mothers experienced stress and physical and emotional fatigue while little support was available from people outside of the family. It is also shown that more Japanese mothers experience a caregiving burden related to social stigma or rejection than do US mothers, experience more difficulties in their social relationships, and feel more socially isolated than American mothers.

PERCEPTIONS AND EXPERIENCES OF MOTHERS WHO HAVE

CHILDREN WITH AUTISM SPECTRUM DISORDERS:

CROSS-CULTURAL STUDIES FROM

THE US AND JAPAN

by

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CHAPTER I

INTRODUCTION

Rationale

The purpose of this study is to explore and understand the differences or similarities in maternal experiences and perceptions in regard to their children with Autism Spectrum Disorders (ASD) between the United States and Japan. A significant area of the study is that it focuses on mothers of children with ASD in cross-national settings. Autism Spectrum Disorders are currently hot topics in the field of special education due to the high prevalence ratio of ASD (Matson & Kozlowski, 2011). Because cross-national comparison studies are underrepresented in research for families of children with ASD (Neely-Barnes & Dia, 2008; Medan, Halle, & Ebata, 2010), this study aims to contribute to this area of research by comparing the experiences and perceptions of mothers in two different cultures.

Autism Spectrum Disorders (ASD) refers to a wide variety of complex developmental disorders including Asperger's syndrome, Rett's syndrome, and pervasive developmental disorder-not otherwise specified (DSM-IV-TR; American Psychiatric Association, 2000). The number of school children who have ASD increased approximately seven times compared with a decade ago (IDEA Part B Child Count, 2010). In 2012, the Center for Disease Control and Prevention (CDC) reported that ASD affects approximately 1 in 88 children of age 8 in the United States. Most recently, the

National Survey of Children's Health (NSCH) conducted by CDC's National Center for Health Statistics estimated that 1 in 50 school-age children (6 to 17 years) have ASD (Blumberg, Matthew, Kogan, Schieve, Jones, & Lu, March, 2013). This indicates that professionals and educators who work for children have a higher possibility of working with children who have ASD and their families than ever before (Medan et al., 2010). This rapid increase in the prevalence of ASD has resulted a growing body of research on the experiences of families of children with ASD (Meadan et al., 2010).

The most consistent theme discussed in this area of literature is the need for interventions and supports for mothers, who are often primary care givers (Meadan et al., 2010). Mothers of children with ASD experience significantly higher levels of stress and lower level of well-being than mothers of children without disabilities and/or with other disabilities (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Pisula, 2007; Seltzer et al., 2010; Smith et al., 2010; Weiss, 2002). A series of longitudinal studies that measured cortisol levels in mothers' saliva samples reported that their stress levels were, indeed, comparable to that of combat soldiers or Holocaust survivors (Seltzer et al., 2009; Seltzer et al., 2010; Smith et al., 2010). These high levels of stress are strongly related to the ASD-specific characteristics of their children, such as challenges in communication, social skills, and behavior (Baker-Ericzén et al., 2005; Davis & Carter, 2008; Hoffman et al., 2009; Smith et al., 2010). Professionals and service providers need to understand the challenges mothers experience and consider appropriate services, supports, or interventions

benefitting them, because family functions is an important key to the quality of the child's life (Meadan et al., 2010; Neely-Barnes & Dia, 2008).

Collaboration between families and professionals is one of the key principles of the Individual with Disabilities Education Improvement Act of 2004 (IDEA). The IDEA mandated that any decisions concerning education or services for a student with a disability must include family input. In addition to the legal mandates, research has also suggested that education or services would be most effective when families and professionals worked collaboratively (Hill & Craft, 2003; Izzo, Weissberg, Kaspro, & Frendrich, 1999). Yet, it has been challenging to develop true collaborative relationships between professionals and families, especially with families from culturally and linguistically diverse (CLD) background (Coots, 2007; Harry, 2008). Harry (2008) indicated that cross-cultural differences in understanding the definitions of disabilities, the role of caregivers' in school education systems, or transitional goals for adulthood could be barriers to the development of collaborative partnerships. In order to break these barriers, professionals need to learn to be culturally competent. It is necessary for professionals who work with families to understand and respect the diversity of reactions and decisions that individuals make in different situations and cultural contexts (Harry, 2008; Lynch & Hanson, 2011; Muscott, 2002; Seligman & Darling, 2007).

However, most research on mothers who have children with ASD has focused on White European or North American populations. More research is needed on the experiences of mothers of children with ASD from different cultural groups in order to develop culturally competent supports or services for all families (Meadan et al., 2010;

Neely-Barnes & Dia, 2008). Studying the cultural and social factors that negatively or positively affect maternal experiences from different cultures can also help to shed light on the experiences of mothers in the majority. Indeed, cross-cultural comparison studies make it possible to illustrate cultural and social influences on family experiences that might not be seen from within one culture alone (Holt, 2011; Schaffer & Riordan, 2003). Understanding various factors in maternal experiences in cross cultural settings contributes valuable knowledge to service providers, educators, and researchers on the critical needs of families with children with ASD.

Theoretical Frameworks

The design of this study is framed by the ABCX model within Bronfenbrenner's human ecology theory (see Figure 1; Bronfenbrenner, 1979; Hill, 1949). The original ABCX model was developed to explain how interactions between family members are affected by resources and perceptions when confronted with a stressor event (Hill, 1949). The stressor event (A) does not necessarily result in crisis (X) when the family has access to necessary resources (B) and appropriate perceptions (C) and uses them effectively (McKenry & Price, 2005; Xu, 2007). For the present study, the ABCX model provided a helpful framework for understanding how the experiences of mothers were influenced by their resources (e.g., supports from other family members) and perceptions (e.g., how they think and feel about their situations or experiences), which also reflected cultural contexts. Although this study did not particularly focus on coping strategies for mothers in response to stressor events, it discussed how mothers' perceptions (C) and resources

(B) were different between American and Japanese mothers who have children with ASD

(A) and how these factors illustrated their experiences (X).
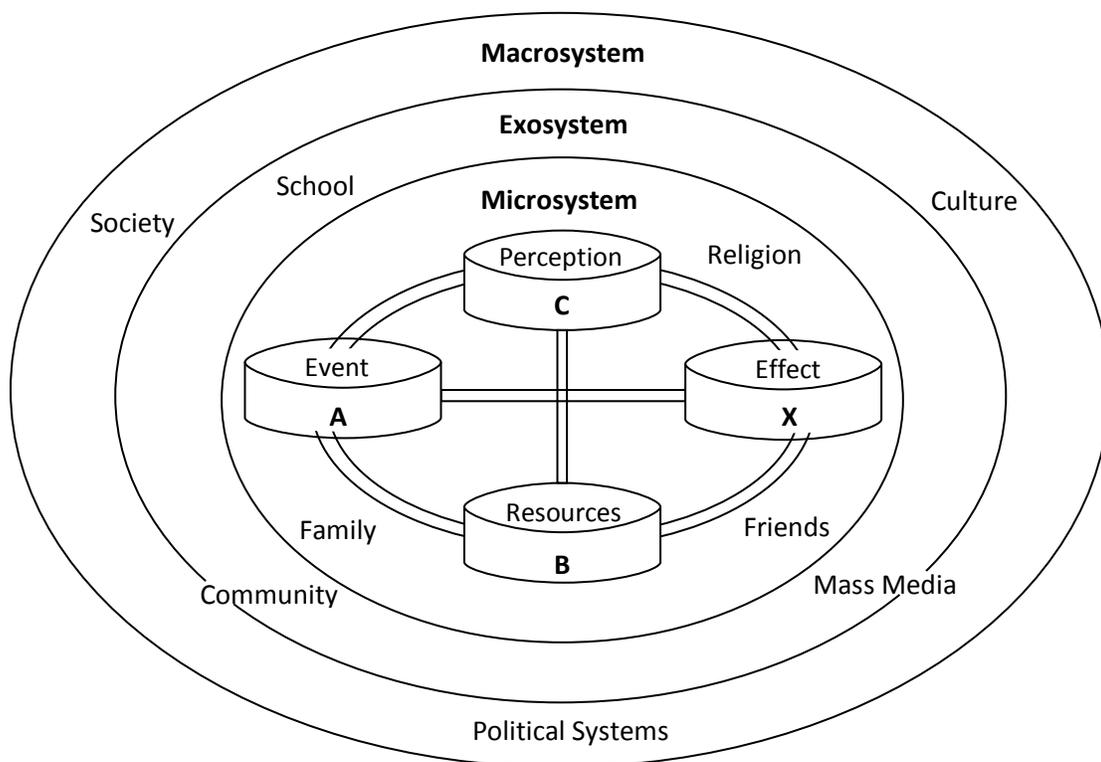
Figure 1. The ABCX Model Within Bronfenbrenner's Human Ecology Theory

Each factor of the ABCX model is influenced by external factors such as

community, culture, and the society (Xu, 2007). Service availabilities, school education,

family responsibilities, or even concepts of disabilities and child development are all

present in social and cultural contexts. For example, each culture has its own

explanations about why children are born with disabilities, how they should be treated,

and the roles of family members (Lamorey, 2002; Xu, 2007). All human activities

including childrearing, social relationships, and what we see and think, always occurs in relation with a broader social network (Bronfenbrenner, 2005; Rogoff, 2003). Therefore situating the ABCX model within Bronfenbrenner's human ecology theory provides a helpful framework for understanding how the same phenomena, such as living with a child who has ASD, appears in different cultural contexts.

Bronfenbrenner (1979) developed the human ecology theory to explain how childhood development is affected comprehensively by the environment around them. These environments, labeled in order of increasing distance from the individual, are the micro-, meso-, exoso-, and macro-systems (Bronfenbrenner, 1979). For the present study, the microsystem indicated the immediate setting that mothers of children with ASD lived in. The mesosystem described linkages between microsystems. The exosystem included external settings that mothers of children with ASD might not interact with directly. For example, the spouse's workplace could be an exosystem for the participant of this study. The macrosystem is a comprehensive system that surroundings all other systems. It included the politics, policies, social values, and culture that the individual was situated in.

Although the human ecology theory was originally developed to explain child development, it has been repeatedly adopted to understand experiences of adults, especially families who have children with disabilities (Bernier & Siegel, 1994; Berry, 1995; Berry & Hardman, 1998; Kazak, 1986; Swick & Williams, 2006). The process of learning the new reality (living with a child with ASD) and developing new behaviors and perceptions in order to cope with it can be understood through a mother's relation

with their broader social environment by using Bronfenbrenner's theory. Through this theoretical point of view, the present research is designed to compare how cultural, social, and family settings influence the experiences of mothers of children with ASD.

Methods

Using a quantitative research design, this study was intended to answer the following question: What are the similarities and differences in the experiences and perceptions of Japanese and American mothers of children with ASD? Quantitative method research is suited to examining differences and similarities across two different groups (Howell, 2007). Participants of this study were 47 American and 49 Japanese mothers of children with ASD at an elementary school age living in North Carolina and Osaka. American mothers and Japanese mothers who lived in these two regions were sampled randomly regardless of their residence areas, community types, or socioeconomic status.

The quantitative study used a survey with a 5-likert-scale ranging from 1 (strongly disagree) to 5 (strongly agree). The survey were analyzed by using t-tests and the Mann-Whitney U test to compare the difference between the means of two independent groups (American and Japanese mothers). Survey were conducted in the participants' native languages: English and Japanese. The researcher used an adaptive translation approach that allowed the translator to adjust wording or context to maintain semantic equivalence in both languages (Harkness et al., 2010).

CHAPTER II

REVIEW OF THE LITERATURE

This literature review provides a comprehensive overview of past research to verify what has been going on in the research community regarding experiences of mothers who have children with Autism Spectrum Disorders (ASD). The first section is an introduction to the following main discussions, and it comprises a brief review of the research on parents of children with disabilities and how their experiences are culturally constructed. The main body of this chapter consists of four key sections: (a) definition for and research trends in ASD, (b) parents of children with ASD in Western countries, (c) definition of culture and human ecology theory, and (d) Asian mothers of children with disabilities. It includes Asian countries rather than Japan alone because there is very little research on the experiences of Japanese mothers who have children with ASD, and Asian countries share the similar cultural background (Braun & Browne, 1998; McLaughlin & Braun, 1998). Research from other Asian countries helps to illustrate the experiences of Japanese mothers of children with ASD.

What Does It Mean to Be a Parent of a Child with a Disability?

Raising a child with a disability has a strong impact on the lives of parents. Having a child with a disability is, in most cases, an unexpected event for the parents (Leerkes & Burney, 2007). During pregnancy, parents build up optimistic expectations about how their life will become with their idealized child (Leerkes & Burney, 2007).

Therefore, discovering that their child has a disability causes parents significant emotional reactions, which are often expressed through negative and complicated feelings of shock, anxiety, and sorrow (Banach, Iudice, Conway, & Couse, 2010; Graungaard & Skov, 2006; Schuengel et al., 2009). The emotional experiences of parents following a disability diagnosis have been repeatedly explained by referencing Kubler-Ross's classic work on the five stages of grief: shock and denial, anger, bargaining, depression, and acceptance (Ferguson, 2002; Hutton & Caron, 2005; Kubler-Ross, 1969; Singer & Powers, 1993). These stages of the emotional cycle do not have to appear in order; rather, these stages can coexist and be repeated by parents of children with a disability (Trute & Hiebert-Murphy, 2002; Trute, Hiebert-Murphy, & Levine, 2007).

However, it is important to remember that recent perspectives on parents of children with a disability have shifted from that of strongly emphasized on pathology to more diverse and strength based viewpoints (Green, 2007; Hastings, Beck, & Hill, 2005; Helff & Glidden, 1998; Trivette, Dunst, & Hamby, 2010; Trute, Benzies, Worthington, Reddon, & Moore, 2010; Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2010). A strengths-based philosophy focuses on family strengths, rather than weaknesses or deficits, as well as the positive impacts that a child with a disability has on the family (Trivette et al., 2010; Trute et al., 2010; Turnbull et al., 2010). Indeed, a child with a disability can be a source of joy or happiness, family closeness, and personal growth (Turnbull et al., 2010). Positive impact of a child with a disability on parents will be discussed more in detail later in this chapter.

While experiencing complicated emotional reactions, parents try to adapt to their new reality of life with a child who has a disability (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Schuengel et al., 2009). The process of adaptation can be explained through three themes of adjustment theory: (a) searching for the meaning of the experiences; (b) gaining a sense of control over the event; and (c) rebuilding self-esteem (Taylor, 1983). These processes of adaptation require significant internal and external supports from family members, professionals, their community, and society (Banach et al., 2010; Davis & Gavidia-Payne, 2009; Guralnick, Hammond, Neville, & Connor, 2008; Hastings, Allen, McDermott, & Still, 2002). Adaptation is a life-long process that occurs within the context of the family's life cycle: early childhood, childhood, adolescence, and adulthood (Seligman & Darling, 2007; Turnbull et al., 2010). Experiences and perceptions of parents toward their children with disabilities are changing along with the life cycle (Turnbull et al., 2010).

Also, experiences and perceptions of parents concerning their children with disabilities are considerably influenced by social and cultural factors (Bishop, Richler, Cain, & Lord, 2007; Blacher & Baker, 2007; Blacher & McIntyre, 2006; Jegatheesan, 2010). The meaning of disability in the cultural context has an especially strong influence on how parents perceive their child. As Lamorey (2002) discussed, "each culture has its own explanations for why some babies are born with disabilities, how these children are to be treated, and what responsibilities and roles are expected of family members, helpers, and other members of the society" (p. 67). It is important for professionals who work

with parents of children with disabilities to understand how cultural context influences parents' experiences.

However, there is limited research on the experiences of parents who have children with disabilities from non-Western countries (Neely-Barnes & Dia, 2008). Most research on the perceptions of parents toward their children with a disability, including autism, has focused on white European or North American mothers (Chang & McConkey, 2008; Dyches et al., 2004). There are few studies that have explored experiences of mothers who have children with disabilities in Asian populations, except those that study immigrant populations in Western countries. Moreover, very few studies examined inter-culture comparisons between Asian and North American mothers (McConkey, Truesdale-Kennedy, Chang, Jerrah, & Shukri, 2008). This research will investigate how cultural and social contexts influence experiences and perceptions of mothers who have children with Autism Spectrum Disorders (ASD) by comparing parents of children with ASD in Japan and the United States.

Autism Spectrum Disorders (ASD)

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000) defined autism as being "characterized by severe and pervasive impairment in several areas of development; reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities" (p. 69). In the DSM-IV-TR criteria, autism is a type of Pervasive Developmental Disorder (PDD), which includes developmental disorders such as autistic disorder, Asperger's syndrome, and pervasive developmental disorder-not otherwise

specified (PDD-NOS). The focus of the present study includes all forms of Autism

Spectrum Disorders (ASD).

More children than ever before are classified as having ASD. Autism and

Developmental Disabilities Monitoring (ADDM) Network in the Center for Disease

Control and Prevention (CDC) reported in 2012 that approximately 1 in 88 children of

age 8 were diagnosed as ASD in the United States (CDC, 2012). Most recently, the

National Survey of Children's Health (NSCH) conducted by CDC's National Center for

Health Statistics estimated that 1 in 50 school-age children (6 to 17 years) have ASD

(Blumberg et al., March, 2013).

From 1998 to 2010, the number of 6- to 21-year-old children receiving special

education services under the category of ASD in public education programs increased

from 54,064 to 370,011 (IDEA Part B Child Count, 2010). This number does not include

all children with ASD, because there are children who receive special education services

for particular needs such as speech therapy and not for a category of ASD (AADM, 2009).

The actual numbers must be higher than the report indicates. Although there is

considerable controversy over what is contributing to this trend in prevalence of ASD,

such as better awareness of the disorder, changes in diagnostic criteria over time, and

diagnosis at earlier ages (Coleman & Gilberg, 2012), there is no doubt in an increase in

the prevalence of ASD (Matson & Kozlowski, 2011). This trend can be seen in many

countries, as well as in Japan (Matson & Kozlowski, 2011; Sun & Allison, 2010). From

1971 to 2008, the prevalence rates of ASD children increased from 1 to 2 in 10,000 to 13

in 10,000 in Japan (Sun & Allison, 2010).

ASD is typically evident before a child is three years of age and lasts throughout his/her life (ADDM, 2009). The intelligence levels of individuals with ASD range from above average, average, and mild to more severe intellectual disabilities (Frith, 2008). Although each individual with ASD has different characteristics or challenges, ASD commonly affects the individual's verbal and nonverbal communication as well as social interaction skills (Baron-Cohen & Bolton, 1993). Most individuals with ASD have difficulty in social interactions with others both physically and verbally (e.g., hugging or having a conversation; Baron-Cohen & Bolton, 1993). Other characteristics generally associated with ASDs are (a) engagement in repetitive activities and stereotyped movements, (b) resistance to environmental change or change in daily routines, and (c) unusual responses to sensory experiences (IDEA, 2004). These characteristics of ASD often make life hard for individuals with ASD as well as their families (NICHD, 2001).

Parents of Children with ASD in Research Conducted in Western Countries

Raising a child with ASD can be highly challenging and stressful for many parents (Benson, 2006; Duarte, Bordin, Yazigi, & Mooney, 2005; Hutton & Caron, 2005; Phelps, Hodgson, McCammon, & Lamson, 2009). Parents, primarily mothers of children with ASD, experience significantly higher levels of stress and lower levels of well-being when compared to parents of children without disabilities and/or with other disabilities (Baker-Ericzén et al., 2005; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Pisula, 2007; Sivberg, 2002; Weiss, 2002). Numerous research has indicated that stress has a negative impact on parents and can cause depression, anger, anxiety, and challenges in marital and family relationships (Bailey, 2008; Benson, 2006; Hastings & Brown, 2002; Hastings et

al., 2005; Higgins, Bailey, & Pearce, 2005; Mugno et al., 2007; Perry, Harris, & Minnes, 2004; Phelps et al., 2009; Risdal & Singer, 2004; Seltzer et al., 2010; Singer, Ethridge, & Aldana, 2007; Smith et al., 2010).

In addition, parents of children with ASD were reported as showing significantly lower levels of quality of life than parents of children with other disabilities (Mugno et al., 2007). More specifically, Mugno and his colleagues (2007) pointed out that mothers of children with ASD showed lower physical health, difficulties in social relationships, and lower psychological well-being than mothers of children with other disabilities (Mugno, 2007). Indeed, a series of longitudinal studies reported that stress levels of mothers who have children with ASD are comparable to that of combat soldiers or Holocaust survivors (Seltzer et al., 2009; Seltzer et al., 2010; Smith et al., 2010). Mothers reported that intense parenting responsibilities made them exhausted and stressed (Phelps et al., 2009). Also, the time commitments placed on their child with ASD strained their relationships with their spouse and/or siblings of children with ASD (Phelps et al., 2009).

Stress factors. McHugh (1999) discussed that autism was one of the most challenging disabilities for the family because of the behavioral characteristics. Major factors that distinguish the experiences of parents with children who have ASD from those who have children with other disabilities include: (a) duration of condition and the chronicity of care, (b) challenging behavior, (c) social interaction skills, and (d) the lack of acceptance or understanding of behavior associated with ASD by the community (Baker-Ericzén et al., 2005; Meadan et al., 2010; Pisula, 2007). Parents often referred to their daily life as relentless and intensely demanding in regard to taking care of their

children (Bourke-Taylor, Howie, & Law, 2010; Phelps et al., 2009; Tomanik et al., 2004).

Children with ASD often require close supervision at all times because of the

unpredictability of their ASD-specific behavior characteristics, such as chronic sleep

deprivation, aggressive behavior toward themselves and/or others, and destructive

behaviors (Baker-Ericzén et al., 2005; Bourke-Taylor et al., 2010; Davis & Carter, 2008;

Pisula, 2007; Gray, 1998). One of the parents interviewed in McHugh's (1999) book

expressed her experience as following:

> It's like a three-ring circus day-to-day. There is no way you can ignore somebody
> who has motor oil for blood, doesn't sleep so nobody sleeps. There's constant
> turmoil in the house. You either accept it or you flail against it your whole life. (p.
> 73)

Their unique social interaction tendencies such as expressing little affection or

showing low interest in people can contribute to the experience of stress in mothers of

children with ASD (Duarte et al., 2005). Children with ASD may look past a person, or

only very briefly at him/her, and that makes him/her feel as if he/she is not an important

part of their world (Baron-Cohen & Bolton, 1993). Children with limited communication

skills (e.g., non-verbal, a small vocabulary, or reliant on limited, highly idiosyncratic

language) can cause both family members and the child with ASD frustration. When

parents fail to understand the child, it may frustrate the child, and as a result they may

display challenging behavior (Gray, 1998). Gray (1998) introduced one case, in which

parents endured several hours of their son's whining until they found that he was upset

because they were driving a rental car since the family car was being repaired. When

such misunderstanding happens in public, the experience of parents can be very difficult.

The burden of care giving is also related to social stigma or social rejection (Bourke-Taylor et al., 2010; Gray, 2002; Green, 2007; Phelps et al., 2009). Parents of children with ASD experience difficulty in coping with their children in public where behaviors of their children are perceived as socially inappropriate (Gray, 2002). Parents of children with ASD who show aggressive or disruptive behaviors are more likely to experience social stigma and rejection than parents of those without behavioral problems (Gray, 2002). Parents reported their feelings of being criticized by others regarding their parenting abilities (Gray, 2002; Hasting & Brown, 2002; Phelps et al., 2009). As one mother described her experience:

> I have always taken my boys shopping . . . Oh it's a disaster initially. [My son] threw a jar of vegemite at an elderly old lady who smiled at him, you know . . . they look at me as though I'm a mother who obviously isn't very good at being a mother. (Gray, 2002, p. 741)

Parents feel embarrassed, and the negative reactions of others hurt their self-confidence (Gray, 2002; Green, 2007; Phelps et al., 2009). A unique aspect of the stigma that parents of children with ASD experience is the fact that the disability is not visible to the public (Gray, 2002). As a result, when children with ASD misbehave in public or act in a socially inappropriate manner, others would react in negative ways and blame the parents (Gray, 2002). One mother commented, "[W]hen they see, see a completely normal looking child who looks to have nothing wrong with him, just being disobedient, and they think, 'Can't you control your child?'" (Gray, 1998, p. 106) In order to avoid public encounters, parents isolate themselves and their families from situations where they might receive bad reactions (Gray, 1998, 2002; Higgins et al., 2005; Phelps et al.,

2009). Parents of children with ASD perceive these restrictions on their social activities as a considerable personal loss (Gray, 2002). Parents also frequently experience avoidance by others, such as not getting invited to their friend's home for social occasions. Green (2007) indicated that parental emotional distress is not correlated with the severity of the child's disability, but rather with the intensity of the stigma toward individuals with disabilities in the community.

Positive impact. It is important to cover positive aspects of parental experiences with having children with ASD. In fact, a growing body of research suggests that the presence of a family member with a disability has a positive contribution to the entire family as well as the quality of life of individual members of the family (Hastings et al., 2005; Hastings & Taunt, 2002; Phelps et al., 2009; Seligman & Darling, 2007). Studies in parents of children with various disabilities reported that the care giving demands of their children provided them opportunities to grow personally, develop a mature perspective on the world, increase sensitivity to others, and highlight spirituality (Hastings et al., 2002; Hastings & Taunt, 2002; Trute et al., 2010).

Phelps and his colleagues (2009) reported a similar finding in their study with 80 parents of children with autism. Parents described their care giving role as beneficial for their emotional and cognitive conditions by providing opportunities to gain psychological strength, such as higher levels of selflessness, compassion for others, and a stronger sense of peace. One parent commented, "We are better, more patient, and understanding towards life in general. It has changed the big picture and put life into perspective" (Phelps et al., 2009, p. 29). Moreover, having children with ASD helps families to build

stronger and closer connections among family members (Bourke-Taylor et al., 2010; Maul & Singer, 2009; Phelps et al., 2009). Families also described that their children with ASD enhanced their social life by bringing them new friends who shared the same experiences and new opportunities for doing new activities that were pleasurable and satisfying (Maul & Singer, 2009; Phelps et al., 2009).

The higher level of parental positive perceptions is related to the higher level of overall family adjustment (Bailey, 2008; Banachet al., 2010; Hastings et al., 2002; Trute et al., 2010; Twoy, Connolly, & Novak, 2007). In order to gain positive perceptions and successful coping skills, however, significant internal and external supports from family members, professionals, their community, and society are required (Banach et al., 2010; Davis & Gavidia-Payne, 2009; Guralnick et al., 2008; Hastings et al., 2002). Using support or having access to necessary support helps parents to gain a sense of hope in their views of the future (Banach et al., 2010; King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009; Schuengel et al., 2009). Future-oriented hope allows parents to regain a sense of control, which supports self-efficacy (Banach et al., 2010).

Only a few studies have investigated cultural differences in regard to the positive experiences of families of children with disabilities. Blacher and McIntyre (2006) and Blacher and Baker (2007) reported that Latino mothers and fathers of children with developmental disabilities reported a much higher positive impact on their families than did Caucasian mothers and fathers. Interestingly, their perceptions toward their children were not different when their children did not have disabilities (Blacher & Baker, 2007). Blacher and Baker (2007) discussed that Latino mothers and Anglo mothers might hold

different beliefs over what should be considered as acceptable child-rearing practices. For

instance, Latino mothers may perceive it as acceptable when their child who attends

preschool drinks from a baby bottle or when their preteen child sits in her lap. Also,

Latino families may not push children for independence so strongly comparison with

Anglo ones (Rueda, Monzo, Shapiro, Gomez, & Blacher, 2005).

Parents and Culture in Human Ecology Theory

There are many definitions of culture in different fields. The encyclopedia of

social psychology (Manstead & Hewstone, 1999), for instance, defines culture as

following:

> Culture is what people learn and use by virtue of participating in a social system
> and what links people together so as to constitute that social system. This means
> that culture includes the patterns of action, ideation, and things with which a
> group of people collectively generate, coordinate, understand, and evaluate their
> worlds. (p. 162)

More helpful in order to understand cultural context of the family, Chang and Hsu

(2007) defined culture in their study about Taiwanese families of children with disability

as the "widely shared ideals, values, formation and uses of categories, assumptions about

life and goal-directed activities that become unconsciously or subconsciously accepted as

'right' and 'correct' by people who identify themselves as members of a society" (p.

2350).

The cultural system determines the setting of daily life for individuals, and its

morals and beliefs provide meaning for daily activities and routines of individuals, as

well as how they understand the world around them (Harkness & Super, 2002; Rogoff,

2003). The cultural system influences a parent through interaction with other parents or adults as well as societal factors, such as ethnic group or social class (Collins, Maccoby, Steinberg, Hetherington, & Bornstein, 2000; Harris, 1995). Culture also has an influence on adults' beliefs about how children should learn and develop (Lee & Johnson, 2007; Rogoff, 2003), and it shapes parenting, teaching, learning, and schooling approaches (Rogoff, 2003).

When we think about mothers' experiences in rearing children with ASD, we cannot ignore the fact that their experiences are situated in many different contexts simultaneously. For example, the family they belong to is a part of a larger system including the neighborhood community, the society, and the culture. To understand the perceptions and experience mechanisms of mothers who have a child with ASD, it is crucial to consider multiple settings comprehensively rather than focusing on an immediate single setting. Therefore, it is helpful to apply Bronfenbrenner's human ecology theory in order to understand the experience of mothers because it reflects the whole of the systems in which they are situated.

Bronfenbrenner's human ecology theory proposes that how individuals perceive and cope with events is affected by comprehensive contexts, including multiple settings ranging from micro-, meso-, exoso-, and macro-systems (Bronfenbrenner, 1979). The microsystem is the immediate setting, within which the individual exists (e.g., family, friends, or neighbors). The mesosystem indicates linkages or relationships between microsystems. The individual does not participate in the exosystem directly, but the settings have significant influence on his/her life. For example, the spouse's workplace or

friends, is a microsystem for the spouse, but is an exosystem for the target individual. The macrosystem is a comprehensive system that is surrounding all other systems. It includes the politics, policies, social values, and culture that individual is situated in. Bronfenbrenner (1979) compares ecological environment to Russian dolls that are structured as a set of nested boxes with each box representing a person's setting. In this human ecological theory, settings within a culture tend to be alike, while settings between cultures have a tendency to be different like the design of the Russian dolls differs from each other (Bronfenbrenner, 1979).

Through this theoretical point of review, the present study examines how cultural, social, and family settings influence the experiences of mothers of children with ASD. Studying the same phenomena such as child-rearing across different cultures will enrich our understanding and expand greater insights into the diversity of reactions or decisions that we make in different situations in different cultural contexts.

Asian Parents of Children with Disabilities

Although the focus of this study is on Japanese and American parents, there are not many studies that have interpreted the experiences of Japanese parents who have children with ASD. Therefore, studies from other Asian countries and Asian American populations will be included in this literature review, in regard to both ASD and other disabilities, to help illustrate the experiences of Japanese mothers of children with ASD. A well-known concept of Asian culture is collectivism. Collectivist culture is "that individuals may be induced to subordinate their personal goals to the goals of some collective, which is usually a stable in-group (e.g., family, band, tribe), and much of the

behavior of individuals may concern goals that are consistent with the goals of this in-group" (Triandis, Bontempo, Villareal, Asai, & Lucca, 1988, p. 324). From studies of Asian American families (Braun & Browne, 1998; McLaughlin & Braun, 1998), common characteristics of collectivistic culture in Asian families can be depicted: (a) family, rather than individual orientation; (b) the obligation of family members to care for each other; (c) the preservation of harmony; (d) expecting children to be obedient and to respect the family; and (d) relationships based on obligation and shame.

In the traditional Asian culture, family is more important than the individual (Triandis et al., 1988). Family members are viewed as part of the family rather than as individuals. Therefore, when any family members have any problems, they are considered as family problems (Braun et al., 1998). In addition, family problems should be kept private, and bringing them into public view is believed to be shameful (McLaughlin et al., 1998; Shon & Ja, 1982). This is linked to preservation of harmony. Keeping problems private, in fact, is to avoid disrupting the harmony of a group (Braun et al., 1998; McLaughlin et al., 1998). Tachibana and Watanabe (2003) reported that Japanese parents hide a family member with a disability from their neighbors because they preferred to avoid situations that disclose family problems. These cultural characteristics can undermine parents' ability to ask for help, especially from an outside service provider (Tachibana et al., 2003).

Hierarchy exists within family systems, and each family member has expected roles according to gender, age, and birth-order (Braun et al., 1998). Traditional gender roles and obligation to the family are still common in Asian families. This strong sense of

obligation to meet the expected roles influences the experiences of mothers of children with disabilities. Chinese mothers of children with ASD reported an overwhelming sense of responsibility toward their children and a willingness to sacrifice their own lives for their children (McCabe, 2010). One of the mothers who quit her job responded to a question, which asked about her satisfaction about her employment status saying, "There's really no satisfied or not satisfied, because caring for a child is a respected mother's responsibility you know" (McCabe, 2010, p. 127). Moreover, in their study on Vietnamese mothers, Park et al., (2010) reported that house-keeping support provided by others made mothers feel less competent because care taking and house work were viewed as mother's responsibilities. Receiving support for the task meant that mothers were not fulfilling their roles (Park, Glidden, & Shin, 2010).

Confucianism is strongly related to ideas about the preservation of harmony and the obligation to fulfill role expectations (Chang et al., 2007; Li, Wang, & Fischer, 2004). In Confucian-based society, being a 'right and proper' person in a relationship with others is the most important social role (Chen, 2001; Law, 2005). Children are expected to be respectful and obedient to their parents and to have high degree of self-control. When a child is born with disabilities, the first thing Asian mothers are forced to face is the idea that their child does not have abilities to meet their assigned obligations, including taking care of their parents, carrying the family name, and inheriting family property (Chou & Palley, 1998). Failing to meet the expectations means 'loosing face' for the individual as well as for entire families, including ancestors (Li et al., 2004). Therefore, having a child with a disability is not only perceived as a burden for the family,

but a social burden as well because of their inability to meet role expectations (McCabe, 2010), so the family of a child with a disability feels shame and loss of face (Jegatheesan et al., 2009). As a result, children born with disabilities are often seen as a dishonor to the family (Law, 2005). Negative images of disability in Asian families also have been reported through the religious beliefs of Buddhism. Buddhism teaches that the cause of disability is a punishment for what one did in a former life, or bad karma (Ratanakul, 2004). Therefore it often results in blame toward individuals who have a disability and/or on their families (Gaventa, 2008).

Religion and Families of Children with Disabilities: Christianity and Buddhism

One important aspect of culture that shapes the values and experiences of mothers is spirituality and religion. Religious beliefs play an important role in shaping cultural attitudes toward disabilities, individuals with disabilities, and how individuals perceive the world around themselves (Miles, 2002a, 2002b; Selway & Ashman, 1998). These cultural attitudes have a strong impact on how families perceive their child with a disability (Bennett, Deluca, & Allen, 1995; Poston & Turnbull, 2004). Although Japanese individuals usually perceive themselves as non-religious, their culture is strongly shaped by a Buddhism doctrine (Roemer, 2009). On the other hand, the dominant religion in the US, particularly in North Carolina where this study was conducted was Christianity (United States Census Bureau, 2012). Both Christianity and Buddhism provide both positive and negative influences on family perceptions.

An example of negative perceptions toward disabilities in Christian beliefs is the idea that people with disabilities cannot connect or have a relationship with God. These

individuals have historically been alienated from religious practices or the Christian community (Bishop, 1995). Also, the connections between sin and suffering are pervasive themes in Christian texts, and illness or disability is depicted as sin and portrayed as something to be healed, not accepted (Miles, 2002b; Schumm & Stoltzfus, 2007). These perceptions can contribute negatively to attitudes of people. For example, Poston and Turnbull (2004) reported that families of children with disabilities expressed their feelings that attending church was difficult. Some families felt that their child with disabilities was not accepted and welcomed, and no support was available at the Church. The Church community can be a source of stress for families when other members of the community do not show their support and acceptance of children with disabilities (Bennett et al., 1995). The social stigma as the result of these negative perceptions to disability can cause isolation of the families.

Similar experiences were reported from studies in Asian families (Chang & Hsu, 2007; Chang & McConkey, 2008; Huang, Fried, & Hsu, 2009). A mother from Taiwan explained her experience as follows:

> I don't attend temple, I don't feel there is a place for us. They told me about the 'karma.' They said you and your son suffer from disability because you have sinned. These kinds of things occurred. It was a direct statement that we must have sinned to have something like this happen. Thus, you carry that pain with you, and it never goes away (Chang & McConkey, 2008, p. 36).

Buddhism teaches that the cause of disability is a punishment for what one did in a former life, or bad karma as discussed earlier (Ratanakul, 2004). This belief in Karma deeply influences the attitudes toward individuals with disabilities in Asia. In their

qualitative study on ten Taiwanese mothers of children with disabilities, Huang, Fried, and Hsu (2009) found that eight out of ten interviewees expressed their belief in the relationship between Karma and disability. All these mothers' educational level or socio economic status did not affect their responses about their beliefs regarding karma.

It is important to remember that religious beliefs have positive influences on family perceptions in both Christian and Buddhist beliefs. Pearce (2005) reported in her comprehensive literature review that family care giving experiences could be positively associated with religious beliefs and practices (e.g., feeling good as a result of care giving). Indeed, past studies repeatedly reported that spiritual and religious beliefs have contributed to parents' ability to gain positive perceptions toward their child with disabilities (Bennett et al., 1995; Blacher & Baker, 2007; Gaventa, 2001; Pearce, 2005; Poston & Turnbull, 2004; Schumm & Stoltzfus, 2007; Selway & Ashman, 1998). Christianity contributed to guiding parents to gain a positive perception toward their child with disabilities by providing views about how their child with a disability is a gift from God or a test of their faith (Bennett et al., 1995; Poston & Turnbull, 2004). In addition, Faith itself can be a strong source of support for families. Faith in a relationship with God brought families strength, patience, and inner peace (Poston & Turnbull, 2004). One main premise of many Christians is that God intends for this world to be good (Schumm & Stoltzfus, 2007) and everything will be all right if you have faith (Bennett et al., 1995). The sense of spirituality and a secure relationship with God enhances positive perceptions of families in areas such as higher self-esteem, more care giving satisfaction, perceived rewards, feeling well, and spiritual growth (Pearce, 2005).

The worldview of Buddhism, in different ways, helps families to similarly accept the disability of their child and their fate, and this acceptance brings a feeling of peace, which helps to relive their stress (Chang & Hsu, 2007; Mak & Ho, 2007; Twoy et al., 2007). Compared to studies concerning Christianity and its influence on family experiences with their child with a disability, however, few studies are available regarding Buddhism. In those few reports, the coping style called "shikataganai" in Japanese, which means that the situation cannot be helped and control of the situation is out of one's hands, was reported as a common coping strategy (Braun & Browne, 1998; Chang & Hsu, 2007; Twoy et al., 2007). In Buddhism, pain and sorrow are perceived as a part of our existence since impermanence and the inevitability of change are basic principles of human beings (Schumm & Stoltzfus, 2007). Therefore instead of getting rid of it, it should be accepted as a part of our life. This attitude of accepting fate as the way it has brought families of children with disabilities a peaceful feeling (Chang & Hsu, 2007; Twoy et al., 2007).

In their study, Twoy and his colleagues (2007) found that Asian Americans showed more resilience in coping to the stressors of caring for their child with autism than European Americans. These Asian American parents were reported to perceive the stressor as a fact of life, in correspondence to Buddhist doctrine. Therefore, they could perceive the stressor in a more positive way based on their values of harmony with nature (Twoy et al., 2007). The world view of Buddhism, the interdependence of all phenomena, influenced the family resiliency through interpersonal relationships and family unity (Mak & Ho, 2007; Twoy et al., 2007).

Why Mothers in Japan and the US?

Accompanying the increase in the number of students with autism, new policies, theories, and practices developed in the United States (e.g., Individualized Education Program [IEP], Treatment and Education of Autistic and related Communication-Handicapped CHildren [TEACCH], or Inclusion movement) were introduced into the Japanese special education system (Ministry of Education, Culture, Sports, Science and Technology, 2003, 2007a; Narita, 1992; Ohtake & Wehmeyer, 2004). Historically, the Japanese educational system has been developed through policies, theories, and practices developed in the U.S. (Narita, 1992; Ohtake & Wehmeyer, 2004; Yamaguchi, 2005). However, introducing practices from the U.S. has repeatedly produced conflict in Japanese educational settings (Kawano-Jones & Jones, 1986; Ohtake et al., 2004).

For instance, when the TEACCH program was introduced, the conflict became obvious. The TEACCH program is a training, clinical service, and research program to support individuals with autism spectrum disorders and their families (Division TEACCH, n. d.). The way the TEACCH program was introduced emphasized the individual's benefit more than the group or community benefit (Ohtake, Uchida, Nakayama, & Satoh, 2003). Ohtake and his colleagues (2003) claimed differences between cultural values, specifically individualism and collectivism, as one of the reasons behind the conflicts. This conflict or confusion experienced in Japan might be in part because the systems introduced from the U.S. were developed based on American cultural norms and were therefore biased toward American culture and didn't necessarily match Japanese settings. Ohtake and his colleague (2004) suggested the importance of exploring and

understanding hidden cultural values in both countries regarding the new theories to support the transition from existent interventions to the new interventions.

One of the cultural values we must understand when introducing new practices is parental perceptions, because it is essential for school educators to work with parents. Research has suggested that education or services would be most effective when families and professionals worked collaboratively (Hill & Craft, 2003; Izzo et al., 1999). Especially when the child has ASD, collaborating with the family is necessary for providing an effective education because of the unique characteristics of ASD, such as difficulty in generalization (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Iovannone, Dunlap, Huber, & Kincaid, 2003; Wilder, Dyches, Obiakor, & Algozzine, 2004).

The family environment is usually the preliminary educational environment for children with ASD from the time they enter this world. Also, the way that families perceive their child with a disability influences the child's life directly through factors such as stress or decision-making processes (Dyches et al., 2004). Yet, no study has investigated the perceptions of Japanese parents toward their child with ASD. Although there is one literature review titled, parental experiences of children's disabilities and special education in the United and Japan (Kayama, 2010), it mostly discussed broad cultural beliefs about disability and the experiences of parents with service professionals in both countries.

As discussed in this literature review, there are some studies that have explored experiences of mothers who have children with various disabilities in other Asian and

Asian American populations. However, Asia has ethnic diversities between subgroups and each region has its own culture, history, and language. Although the findings from studies conducted with other Asian populations may provide insights to help grasp an understanding of the experiences of Japanese mothers of children with ASD, these studies are not enough to understand them fully. In addition, very few studies have examined inter-country comparisons. In a comparison study of mothers of children with a disability in the United States and Korea, Shin (2003) reported that cultural values had a strong impact on the cause of stress for mothers and mothers' attitudes toward their children. Further research that examines various factors in maternal experiences with a child who has ASD in cross cultural settings would provide valuable information for service providers, educators, and researchers who work with diverse populations. The purpose of this study is to explore and understand the differences or similarities in maternal experiences and perceptions with their children with ASD between the US and Japan.

Research Question

What are the similarities and differences in maternal experiences and perceptions in regard to their children with Autism Spectrum Disorders (ASD) between the United States and Japan?

CHAPTER III

METHODS

Research Design

The paradigm of this study is a postpositivism. Differing from positivism, postpositivism does not view the world with only one reality; rather it understands the world with a reality within a certain realm of probability (Mertens, 1998). By using a quantitative method, this study will attempt to discover "realities" of mothers' experiences through the relationship between independent variables (being American vs. Japanese) and dependent variables (experiences and perceptions).

This study utilized both emic and etic approaches to make cross-cultural comparisons while understanding the context in which participants' experiences occurred. Emic approaches capture particular aspects of the specific culture from within the culture by insiders who live in the culture (Holt, 2011). Etic approaches, on the other hand, capture objective aspects of cultures from the outside of the cultures by explicitly comparing their differences and similarities across cultures (Lett, 1996; Schaffer & Riordan, 2003). As a native member of Japanese culture and as a resident in the U.S. for about five years, the researcher had experience as both an insider and outsider in each culture. This made the research standpoint both emic and etic. Use of a combined emic-etic approach is best suited when conducting cultural-comparison research because it ensures an understanding of participants' experiences objectively from outside of the

cultures by comparing their differences and similarities without losing the true meanings of their experiences (Schaffer & Riordan, 2003).

Participants

Participants in this study were 47 American and 49 Japanese mothers of elementary school age children with Autism Spectrum Disorders (ASD). The inclusion criteria for being American or Japanese was set as being non-immigrant. The elementary school age was defined to be between the ages of 5 to 12, which covered elementary school years in both countries (K to 5th grade in the US and 1st to 6th grade in Japan).

This study intentionally focused on mothers of children with ASD at elementary school age, because this age is a relatively stable phase in their life cycles (Seligman & Darling, 2007). By the time the child with a disability reaches elementary school age, most parents have obtained an accurate diagnosis and found supportive resources and services available to them and their children including a preferred pediatrician and an appropriate educational program (Seligman & Darling, 2007). Many parents establish a nearly steady life style during their children's childhood years (Seligman & Darling, 2007). When the child with a disability reaches adolescence, parents and their children will go through a time of transition to adulthood. Many parents experience unaccustomed stress by facing new kinds of realities such as puberty, the child's continuing dependence, and making decisions about the child's future (Seligman & Darling, 2007). As the first cross-cultural comparison study between American and Japanese mothers of children with ASD, this study chose mothers of children in their elementary school ages in order to depict cultural differences and similarities in a stable phase of the life cycle.

Children of the research participants had different forms of Autism Spectrum Disorder (ASD) including Pervasive Developmental Disorder-not otherwise specified (PDD-NOS), Asperger's syndrome, and high functioning autism. The present study included any form of ASD, mostly because there is no research-evidence that reported different experiences of mothers when their children have different types of ASD. What past research has suggested is that characteristics of children with ASD, such as lack of social competence, challenging behavior, and type of care, influence the experiences of parents (Duarte et al., 2005; Meadan et al., 2010; Smith et al., 2010). These characteristics can be seen in any type of ASD.

The study was limited to biological mothers but open to mothers of any ethnicity, race, religion, or socioeconomic status especially in the U.S. Although adoptive mothers' experiences would be greatly influenced by whether they knew of the child's special needs before adopting or not; adoptive parents tend to have different experiences from biological parents psychologically and physically (e.g., more available supports and resources; Perry & Henry, 2009).

Description of Participants

A total of 96 mothers of children with ASD participated in this study. In all 47 (48.9%) were recruited from North Carolina in the US and 49 (51%) were from Osaka, Japan. Table 1 shows demographics by sample (US vs. Japan).

Table 1

Demographic Characteristics of the Participants (N = 96)

	US	Japan
Variable	(*n* = 47)	(*n* = 49)
	n (%)	*n* (%)
1. Child's information		
a. Gender		
Boy	44 (94)	39 (80)
Girl	3 (6)	10 (20)
b. Age Mean	8.48	9.36
	(*SD* = 2.17)	(*SD* = 1.83)
c. Ethnicity		
White	31 (66)	0 (0)
Black	9 (19)	0 (0)
Latino	3 (6)	0 (0)
Asian/Pacific Islander	0 (0)	47 (96)
Mixed	4 (9)	1 (2)
Others	0 (0)	1 (2)
d. Diagnosis		
High functioning ASD including Asperger's	22 (46.8)	9 (18.4)
Autism	23 (48.9)	15 (30.6)
Severe case of autism with moderate to severe intellectual disabilities	1 (2)	25 (57)

d. Type of school program

Regular public school class	24 (51)	6 (12)
Public school, special class	8 (17)	23 (47)
Regular private school class	3 (6)	0 (0)
Special school	4 (9)	20 (41)
Others	8 (17)	0 (0)

2. Mother's information

b. Age Mean	39.8	40.7
	$(SD = 5.47)$	$(SD = 3.64)$
25-34 years	8 (17)	1 (2)
35-44 years	30 (64)	42 (86)
45-54 years	9 (19)	5 (10)

c. Ethnicity

White	33 (72)	0 (0)
Black	10 (22)	0 (0)
Latino	3 (7)	0 (0)
Asian/Pacific Islander	0 (0)	48 (98)
Mixed	0 (0)	0 (0)
Others	0 (0)	1 (2)

d. Highest level of education

High school	1 (2)	17 (35)
Some college	3 (6)	19 (40)
Undergraduate	16 (34)	12 (25)
Graduate	26 (55)	0 (0)

Others	1 (2)	0 (0)
e. Employment outside of home	36 (77)	13 (27)
f. Religious affiliation		
Christian	33 (70.2)	1 (2)
Jewish	2 (4.3)	0 (0)
Buddhism	0 (0)	3 (6.1)
None	7 (14.9)	44 (89.8)
Others	3 (6.4)	1 (2)
g. Marital status		
Married	42 (89)	45 (94)
Single	3 (6)	0 (0)
Separated	1 (2)	0 (0)
Divorced	1 (2)	3 (6)
3. Household information		
a. Adults who live with the child		
Mother & father	41 (87)	41 (84)
Mother	3 (6)	4 (8)
Parent(s) & grandparents	2 (4)	2 (4)
Mother & Others	1 (2)	1 (2)
Parents & grandparents & others	0 (0)	1 (2)
b. Mean number of children in the home	2.13	2
	($SD = 0.99$)	($SD = 0.81$)
c. Family income		
Less than $10,000	0 (0)	2 (4)

$10-20,000	0 (0)	0 (0)
$21-35,000	4 (9)	10 (20)
$36-50,000	10 (21)	13 (27)
$51-75,000	7 (15)	12 (24)
$75,000 or higher	26 (55)	12 (24)

Their ages ranged from 29 to 54 years (US: $M = 39.8$ years) and 31 to 52 years

(Japan: $M = 40.7$ years). Ethnicities of the US mothers were 33 White (72%), 10 Black

(22%), and 3 Latino (7%), while ethnicities of Japanese mothers were 48 Asian (98%).

There were significant differences among groups on demographic variables of their

highest level of education, employment status, religious affiliation, and family income

(see Table 2).

Table 2

Demographic Characteristics of the Participants that Showed Significant Differences (N = 96)

	US	Japan	
Mother's information	n (%)	n (%)	Chi-square
Highest level of education			
Some college and below	4 (8)	36 (75)	$\chi^2 = 40.83,\ p < .001$
More than university	42 (89)	12 (25)	
Employment outside of home	36 (77)	13 (27)	$\chi^2 = 24,\ p < .001$
Religious affiliation			
None	7 (15)	44 (90)	$\chi^2 = 59,\ p < .001$

Some religion	38 (81)	5 (10)
Family income		
Less than $50,000	14 (30)	25 (51)
More than $51,000	33 (70)	24 (49)

$\chi^2 = 4.48,\ p < .05$

A majority of the US mothers graduated from university (34%) or graduate school (55%), while a majority of Japanese mothers' highest level of education were some college or below (75%) (χ^2 (1) = 40.83, $p < .001$). None of the Japanese mothers graduated from graduate school. Also, a majority of the US mothers (77%) were employed outside of the home, while a majority of Japanese mothers (73%) were not employed outside of the home (χ^2 (1) = 24, $p < .001$). Religious affiliation was also significantly different between the two groups (χ^2 (1) = 59.09, $p < .001$): 38 mothers from the US (80.9%) were religious, and 33 of them (70%) were Christian; 44 Japanese mothers (89.8%) did not have any religious affiliation. Thirty-three US participants (70%) and 24 Japanese participants (49%) responded that their family income as higher than $51,000 ($\chi^2$ (1) = 4.48, $p < .05$).

Their child with ASD included 83 boys (86.5%) and 13 girls (13.5%): 44 boys (94%) and 3 girls (6%) from the US and 39 boys (80%) and 10 girls (20%) from Japan. The mean ages of the children with ASD were 8.39 (US, $SD = 2.17$) and 9.36 (Japan, $SD = 1.83$) years. Ethnicities of the children of the US participants were 31 White (66%), 9 Black (19%), 3 Latino (6%), and 4 mixed (9%), while ethnicities of Japanese children with ASD were 47 Asian (96%), 1 mixed (2%), and 1 other (2%). Twenty-two children

of the US participants (46.8%) and 9 Japanese participants (18.4%) were diagnosed as

high functioning autism including Asperger's without having cognitive impairments.

Twenty three (48.9%) children in the US site and 15 (30.6%) children in Japanese site

had Autism. Twenty-five (51%) of Japanese children were diagnosed as either having

severe case of autism and moderate to severe intellectual disabilities. Finally, 27 US

children (57%) with ASD went to regular classroom in public or private schools (24:

public school, and 3: private school). Forty-three (88%) Japanese children with ASD

went to special education classrooms in regular public school or special education school.

Only 6 (12%) Japanese children went to regular classrooms in a public school.

Sample Design and Recruitment

This research used a random sampling method with two sampling frames. A

random sampling is a procedure to select "a group of subjects (a sample) for study from a

larger group (population) so that each individual (or other unit of analysis) is chosen

entirely by chance" (Vogt, 2005, p. 262). The sampling frame is a road map to the

population of interest from which a sample is to be drawn (Shapiro, 2008). The

"population" of this study consisted of American and Japanese mothers who have

children with ASD at an elementary school age. The first sampling frame was

geographical region: North Carolina and Osaka. The geographical areas were matched by

population size. North Carolina had population with approximately 9,656,400, while

Osaka prefecture had population with about 8,865,000. Sufficiently large population sizes

allows to produce similar random samples in accordance with the central limit theorem

(Howell, 2007). American mothers and Japanese mothers who live in these two

geographic regions were invited regardless of residential area, community type, or socioeconomic status.

The second sampling frame was organizational units, which consisted of the Autism Society of NC and the Autism Association of Osaka, both of which were non-profit organizations run by parents who have children with ASD. Sample population were accessed through these organizations. The organizational units were matched based on organizational stance, size, and publicity. Although there are many small parent organizations in both North Carolina and Osaka, these two organizations are the largest and most key organizations in the areas. The researcher contacted one of the parent advocates in the Autism Society of Charlotte-Mecklenburg County and a parent liaison in Guilford County in North Carolina, and the vice president of Autism Association of Osaka and asked them if they would agree to inform their members about the research. Later, the researcher contacted a principal in the Yao special education school in Osaka. For survey participants, an incentive was offered in the form of $100.00 gift cards. One participant from each group (American and Japanese) was selected to win the gift card by a random drawing among all entries.

Link to electronic surveys were sent to the leaders of the Autism Society in Charlotte Mecklenburg County, a parent liaison in Guilford County, and Autism Association of Osaka with a brief invitation letter explaining the research. The leaders of the Autism Society in NC posted the link in their monthly e-newsletter and on their website, and emailed the link to their members. In addition, 125 surveys packets containing invitation letters, consent forms, and stamped return envelopes were

distributed at the annual conference for Autism Society of NC. A total of 54 surveys were collected from the US site: 20 hard copied surveys (16% return rate) and 34 online surveys. Seven surveys were removed from the analysis as not meeting the inclusion criteria: six participants had a child older than 12 years old and one participant was not a biological mother.

The vice president of the Autism Association of Osaka also posted the survey link on their website and distributed the survey link to their members via email. Forty-eight packets of invitation letters, surveys, and consent forms were sent to the Yao special education school in Osaka via mail along with stamped return envelopes. A total of 49 surveys were collected from the Japanese site: 15 hard copied surveys (31.2% return rate) and 34 online surveys. All collected surveys in Japan met the inclusion criteria.

Site of Research

North Carolina public schools statistical profile of 2009 reported that 9,549 students ages 3 to 21 received special education services under ASD category. The statistical profile (2009) also reported that 821,134 students were enrolled in K to 6th grades, and this reports included charter schools. By using the prevalence ratio of ASD (1 in 88) reported by the Center for Disease Control and Prevention (2012), 9,331 children in K-6th grades in North Carolina were estimated to have ASD.

Osaka prefectural Government statistic information from 2008-2009 showed that 500,246 students were enrolled in elementary schools (1st to 6th grades) in Osaka. By using the prevalence ratio of ASD in Japan, 13 in 10,000 (Sun & Allison, 2010), approximately 650 children in 1st to 6th grades in Osaka were estimated to have ASD.

Measurement

Instruments. Surveys were conducted in the participants' native languages: English and Japanese. The survey consisted of five parts: demographic information, severity of ASD, maternal perceptions, experiences, and the mother's belief regarding the cause of her child's special needs. The demographic information collected basic descriptive information about the child, mother, and household (see Table 1). The other four parts of the survey questions used a 5-likert-scale ranging from 1 (strongly disagree) to 5 (strongly agree). The survey was piloted with a sample of American mothers ($n = 3$) and Japanese mothers ($n = 3$) to establish validity and revised according to the participants' feedback on the structure and wording. Survey questions regarding maternal perceptions and experiences were developed to answer the following sub-research questions.

Are there similarities and differences in:

1. Maternal stress or well-being

2. Burden of care giving related to social stigma

3. Difficulties in social relationships

4. Support availability

in regard to their children with ASD between the US and Japan?

The survey questions were developed based on an extensive review of the literature (see Appendix A). Some items were adopted and modified from the Questionnaire on Resources and Stress (QRS-F; Friedrich, Greenberg, & Crnic, 1983),

the Caregiver Burden Inventory (CBI; Novak & Guest, 1989), and the Kansas Inventory

of Parental Perceptions (KIPP). The short-form version of the QRS-F (Friedrich et al.,

1983) was developed in order to measure the impact of children with developmental

delay on family life. The QRS-F has been widely used in family research including a

cross-cultural study involving an Asian country (McConkey et al., 2008). The CBI

(Novak & Guest, 1989) was an instrument to measure caregiver's perceptions on time-

dependence, developmental, physical, social, and emotional burdens when caring for

individuals with Alzheimer's disease. The KIPP was developed to measure positive

perceptions of participants (Behr, Murphy, &Summers, 1992) based on the ABC-X

model, which offers a helpful framework for understanding stressors of families who

have a child with a disability and how they use their resources and perceptions in order to

cope with the stressor events (McCubbin, Cauble, & Patterson, 1982). Some questions

from the KIPP also were used to assess positive experiences of mothers.

Severity of ASD. Seven questions regarding the severity of ASD were developed

based on the Checklist for Autism Spectrum Disorders (Mayes & Calhoun, 1999; Mayes

et al., 2009). The Checklist for Autism Spectrum Disorders contains a comprehensive list

of clinical symptoms associated with ASD. The checklist comprises six categories: (a)

problems with social interaction; (b) perseveration; (c) somatosensory disturbance; (d)

atypical communication and development; (e) mood disturbance; and (f) problems with

attention and safety (Mayes et al., 2009). From each category, the ASD-specific

characteristics linked with the chronic demands of care were selected and combined into

seven questions based on past research (Baker-Ericzén et al., 2005; Davis & Carter, 2008;

Pisula, 2007; Tomanik, Harris, & Hawkins, 2004). These behavioral characteristics

included chronic sleep deprivation, becoming upset with change, feeding problems,

hypersensitivity, aggressive behavior toward themselves and/or others, and stereotypies.

Daily caregiving demand were measured by the first two questions in this

category: "My child is dependent on me to complete all daily tasks," and "I have to watch

my child constantly." These questions intended to measure actual experiences of mothers

according to caregiving demands, because the seven questions about child's behavioral

characteristics do not necessarily tell us how demanding the daily caregiving can be. The

two questions were adopted from the Caregiver Burden Inventory (CBI; Novak & Guest,

1989). The last question in this category was "It is easy to communicate with my child."

Past research reported difficulty in communication can cause frustration to both the

parents and the child with ASD (Davis & Carter, 2008; Gray, 1998). By adding this

question, all characteristics of ASD were covered in this section. In this study, data on the

severity of ASD and mothers' caregiving demands were compared between two groups

(US vs. Japan) and shared as descriptive information. For future research, these data will

be used to examine if nationality had a strong effect on mothers' experiences regardless

of the severity of ASD.

Maternal well-being. There were four survey items to measure maternal well-

being. These questions asked if participants felt physically and psychologically tired or

stressed. The physical burden question was, "I'm physically tired," and the emotional

burden question was, "I'm emotionally tired." The first item was adopted from the CBI

(Novak & Guest, 1989). Two questions concerning maternal stress included, "Having a

child with ASD adds stress to my life" and "When I am with my child, I feel less effective and competent as parent." The latter question was adopted from QRS-F (Novak & Guest, 1989).

Burden of caregiving. This subscale had seven items pertaining to the burden of caregiving in relation to social stigma. This subscale was intended to help understand mothers' feelings and experiences in coping with their child with ASD in public. Items to assess their caregiving burden related to social stigma, for instance, included questions such as; "I feel guilty or less competent as a parent when I need to ask for support from someone," "I have given up things I have really wanted to do in order to care for my child," and "Sometimes I feel embarrassed because of my child."

Social burden. This subscale was designed to measure mothers' difficulties in social relationships and social isolation. It was intended to depict mothers' experiences in sharing their concerns with their family members or people outside of their family. Some questions overlapped with items from the burden of care giving subscale, which asked about mothers' experiences on missing out on life in order to care for their child with ASD. Sample items pertaining to the social burden were: "I feel it's difficult to share my concerns about my child with people outside of my family," "I have guests over to our house less often than I would like to because of my child," "I had to quit my work in order to care for my child," and "I feel isolated from society."

Support availability. This subscale had four questions that asked about the availability of physical and emotional support from either family members or people other than their family. Emotional supports included encouragement, understanding, or

having someone who could listen to them. Physical supports included helping with chores, emergency child care, or resources. Survey questions included: "I receive emotional support from my family (e.g., encouragement, understanding, or listening to you)," and "I receive physical support from people other than my family (e.g., help with chores, emergency child care, or resources)." These items were developed by consulting past research, which reported or implied uneasy feelings of Asian mothers when asking for support (Braun & Browne, 1998; Chang et al., 2007; Li et al., 2004; McLaughlin & Braun, 1998; Park et al., 2010).

Causal attributions. The causal attributions category had 13 questions, which were directly pulled from a section of the KIPP. This category assessed what mothers' beliefs were in regard to the cause of their child's ASD. Two large frameworks in this category included locus (internality vs. externality) and stability (Behr et al., 1992). The locus concerned participants' perceptions to their child's special needs as being caused by oneself (self-blame; 6 items) or by external forces (physiologic cause; 3 items, and professional blame; 3 items). The second framework, stability, described participants' perceptions toward the child's special needs as being either changeable or not (Fate/Chance; two items, and special purpose; two items). However, this stability category failed to meet the reliability. This causal attribution category was to assess a theme in searching for meaning; searching for the explanation as to why the event happened to them. As discussed earlier, how American and Japanese mothers understand their children's disabilities and the causes of disability is influenced by cultural contexts

(Bennett et al., 1995; Huang, 2009; Miles, 2002b; Poston & Turnbull, 2004; Schumm & Stoltzfus, 2007).

Lastly, there were four questions that were intended to ask about the positive experiences of participants. These items were adopted from the KIPP. Sample items for this subcategory are: "because of my child our family has become closer," and "because of my child I attend religious services more frequently." However, an analysis of internal consistency of the subscale of the questions did not meet acceptable level to prove reliability (Japan: Cronbach's α = .548, US: Cronbach's α = .524). They were analyzed and the findings are provided descriptively.

Reliability

Internal consistency coefficients (Cronbach's alpha) were calculated to assess the reliability of subscale scores of the survey by using the SPSS software package. Cronbach's alpha measures internal consistency of the items: how closely related the items within the same groups (Vogt, 2005). Given that this was a cross-cultural study, Cronbach's alpha was calculated for each country for each subscale: (a) maternal well-being, (b) burden of caregiving, (c) social burden, (d) support availability, (e) causal attributions, and (f) positive experience (see Table 3). The interpretation of this analysis follow the guidelines identified by George and Mallery (2003); $\alpha \geq 0.9$ = excellent, $0.8 \leq \alpha < 0.9$ = good, $0.7 \leq \alpha < 0.8$ = acceptable. All subscales met acceptable to good levels of internal consistency coefficients (ranging from $0.71 \leq \alpha \leq 0.88$) except for positive experience.

Table 3

Cronbach's Alpha Coefficients for the Subscales (N = 96)

Subscales	Cronbach's Alpha Coefficient	
	US	Japan
Well-being	0.802	0.879
Burden of care giving related to social implications	0.769	0.793
Difficulties in social relationships	0.839	0.802
Support Availability	0.71	0.766
Causal Attributions:		
Internal	0.845	0.852
External	0.845	0.749
Positive experiences	0.524	0.548

Validity

Evidence for the validity of the content of survey instruments can be inferred based on the procedures used for developing them. Most questions were obtained from existed survey instruments with proven validity. Extensive reviews of the theoretical and research literature were used to decide what questions should be included in the survey. The survey instruments were also examined by a pilot study with a sample of American mothers ($n = 3$) and Japanese mothers ($n = 3$) to establish validity and revised according to the participants' feedback on the structure and wording.

Method of Data Analysis

All data were entered into electronic spreadsheets. By using the online survey program, Qualtrics, transferring the row data into Microsoft Excel spreadsheets and SPSS formats were done automatically. Qualtrics also provided descriptive statistics results (percentages, means, and standard deviations). The independent variable of this study is the nationality of the participating mothers: the United States or Japan. Dependent variables were the experiences and perceptions of the participants, which include five subcategories: (a) maternal well-being, (b) burden of caregiving, (c) social burden, (d) support availability, and (e) causal attributions.

The survey responses were analyzed for each subscale by using two-sample independent t-tests to compare the difference between the means of two independent groups (American and Japanese mothers). When conducting any statistical analysis, it is critical to ensure the level of power ($1 - \beta$) to minimize the possibility of Type I error. Power can be defined as "the probability of correctly rejecting false Ho when a particular alternative hypothesis is true" (Howell, 2007, p. 214). For the current research, it meant finding mean differences between American and Japanese mothers when the differences were not due to chance. In order to minimize Type I errors, α of the test (the probability of a Type I error: rejecting the null hypothesis when it is true) and the effect size d, labeled Cohen's d were calculated for each subscale and some independent items.

The effect size d (Cohen's d) were computed for t-tests with two independent means with the following equation.

$$d = \frac{\mu 1 - \mu 2}{\sigma}$$

This indicates that *d* is a measure of the degree to which $\mu 1$ (means of *n*1: American) and $\mu 2$ (means of *n*2: Japanese) differ in terms of the standard deviation (σ) of the population. Post hoc power analyses (Cohen, 1988) was performed using actual means and standard deviations of populations using a program called G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007). G*Power is a stand-alone power analysis program for various statistical tests developed by Faul and his colleagues (2007). This study used a two-tailed *t*-test with two independent groups. Two-tailed *t*-tests were used in order to examine the difference between two group means without saying which of the two was bigger (Vogt, 2005).

Finally, the Mann-Whitney *U* test, which is an equivalent test to the Wilcoxon rank-sum test, was performed to examine if there were significant differences in average responses to particular survey questions under each subscale. The Mann-Whitney *U* test is a non-parametric test that does not rely on parameter estimation or distribution assumptions (Howell, 2007; Hollingsworth, Collins, Smith, & Nelson, 2011). Running *t*-test for each survey question increases the probability of a Type I error: the probability of finding mean differences due to chance. By using the Mann-Whitney *U* test, which uses the sum of the ranks in one of the groups as the test statistic, it can examine if differences exist between groups while minimizing the chance of Type I errors.

CHAPTER IV

RESULTS

The purpose of this study was to explore and understand differences or similarities in maternal experiences and perceptions with regard to their children with ASD between two sample populations from the US and Japan. Survey data were analyzed to answer the following sub-research questions:

1. Are there similarities and differences in maternal stress or well-being between two groups?

2. Are there similarities and differences in burden of care giving related to social stigma between the two groups?

3. Are there similarities and differences in difficulties in social relationships between the two groups?

4. Are there similarities and differences in support availability between two groups?

5. How do Japanese and American mothers understand the cause of their child's ASD?

Tables 4 summarizes the statistical results for all four subscales and Table 5 provides the Mann-Whitney U tests results for survey questions that showed significant differences between groups.

Table 4

Statistical Results of Mothers' Survey Responses Across Five Subscales (N = 96)

Subscale	US (M)	Japan (M)	t (df)	p (2-tailed)	Cohen's d
Well-being	3.54	3.44	0.46 (94)	.647	.09
Burden of care giving related to social implications	2.59	3.14	2.88 (94)**	.005	.61
Difficulties in social relationships	2.33	2.94	3.03 (94)**	.003	.62
Support Availability	3.33	3.42	0.412 (94)	.681	.08
Causal Attributions of ASD					
Internal	1.55	2.04	2.55 (94)*	.012	.52
External	1.84	2.03	1.07 (94)	.288	.22

*p < .05. **p < .01. ***p < .001.

Table 5

Mann-Whitney U Tests for Questions that Showed Significant Differences Between Groups (N = 96)

Question	US (M)	Japan (M)	U	p (2-tailed)
SQ1: Having a child with ASD adds stress to my life.	4.19	3.55	802.5***	.007
SQ2: When I am with my child, I feel less effective and competent as parent.	2.62	3.24	838.5*	.018
SQ5: I feel guilty or less competent as a parent when I need to ask for support from someone.	2.17	3.04	733.5***	.003

SQ8: I feel isolated from the society.	2.15	3.00	736***	.002
SQ12: I have guests over to our house less often than I would like to because of my child.	2.15	2.81	853*	.033
SQ13: I have given up things I have really wanted to do in order to care for my child.	2.64	3.29	887*	.047
SQ14: I had to quit my work in order to care for my child.	1.89	2.59	892*	.038
SQ16: I receive physical support from my family.	3.09	3.8	819*	.012
SQ21: Because of my child I attend religious services more frequently.	2.23	1.21	621.5***	.00
SQ22: The presence of my child confirms my faith in God.	3.81	1.44	257***	.00
CA1: because of an injury that occurred during birth.	1.38	1.84	925.5*	.04
CA2: God's will.	2.62	1.71	774***	.004
CA3: Some special purpose	3.08	1.93	670.5***	.00
CA9: Fate	2.4	3.22	796.5**	.007
CA11: a chemical imbalance.	2.21	2.94	811**	.007
CA12: my overall state of mind (my attitude).	1.34	1.82	922*	.038
CA13: because of something I did.	1.62	2.22	881.5*	.026

$*p < .05. **p < .01. ***p < .001.$

Data on the severity of ASD were collected for the future phase of the study, this data is also provided briefly for reference (see Table 6). Overall, there were not significant differences in the severity of ASD between the two groups ($t = 0.64$, $p = .64$).

However, Japanese mothers reported significantly higher caregiving demands related to the severity of ASD ("My child is dependent on me to complete all daily tasks," and "I have to watch my child constantly," $t = 2.48$, $p < .05$).

Table 6

Statistical Results of Severity of ASD (N = 96)

| | US | Japan | | | | Cronbach's α | |
| | (n = 47) | (n = 49) | | | | | |
	M (SD)	*M (SD)*	*t*	*p (2-tailed)*		US	Japan
Overall severity of ASD	3.07 (.709)	3.17 (.780)	0.64	.52		.786	.833
Caregiving demand related to severity of ASD	2.58 (1.19)	3.16 (1.09)	2.48	.015*		.799	.841

*$p < .05$. **$p < .01$. ***$p < .001$.

      1. Are there similarities and differences in maternal stress or well-being between the two groups? Mother's well-being was represented by three 'negative' indicators: stress, negative impact on feelings about parenting, and physical or emotional fatigue. There were no statistically significant differences between American mothers and Japanese mothers in this subscale ($t = 0.46$, $p = .65$). Responses for this subscale were high for both groups, including stress in regard to raising a child with ASD (US: $M = 4.19$, $SD = 0.95$; Japan: $M = 3.55$, $SD = 1.23$), and physical (US: $M = 3.68$, $SD = 1.24$; Japan: $M = 3.33$, $SD = 1.13$) and emotional fatigue (US: $M = 3.66$, $SD = 1.34$; Japan: $M = 3.65$, $SD = 1.2$). However, more Japanese mothers reported stronger feelings about being

less effective and competent as a parent than mothers from the US (US: *M* = 2.62, *SD* = 1.68; Japan: *M* = 3.24, *SD* = 1.23, *U* = 802.5, *p* = .007).

2. *Are there similarities and differences in burden of care giving related to social stigma between the two groups?* Japanese mothers scored significantly higher on caregiving burden related to social stigma or rejection than US mothers (*t* = 2.88, *p* = .005). Especially, Japanese mothers felt guilty or less competent as a parent when they needed to ask for support compared with American mothers (US: *M* = 2.17, *SD* = 1.15; Japan: *M* = 3.04, *SD* = 1.41, *U* = 733.5, *p* = .003). There were also significant differences in their experiences in regard to missing out on life because of their child with ASD between the two groups. More Japanese mothers responded that they had guests over to their house less often than they wanted to because of their child with ASD than did US mothers (US: *M* = 2.15, *SD* = 1.35; Japan: *M* = 2.81, *SD* = 1.52, *U* = 853, *p* = .03). Japanese mothers also scored higher on their experiences giving up things they really wanted to do (US: *M* = 2.64, *SD* = 1.52; Japan: *M* = 3.29, *SD* = 1.51, *U* = 887, *p* = .04) or having to quit their job in order to care for their child than the US participants (US: *M* = 1.9, *SD* = 1.35; Japan: *M* = 2.6, *SD* = 1.64, *U* = 892, *p* = .03).

In this subscale, however, three questions did not show significant differences across the two groups. Although more than half of participants in the US did not feel embarrassed because of their child and 45% of Japanese mothers reported they did feel embarrassed because of their child, the differences were not significant between two groups (US: *M* = 2.6, *SD* = 1.28; Japan: *M* = 3.1, *SD* = 1.3, *U* = 913.5, *p* = .07). Both groups strongly felt that it was their responsibility to care for their child even if they had

to sacrifice their own life. Seventy-five percent of both US and Japanese mothers responded that they either agreed or strongly agreed with this statement (US: $M = 4.19$, $SD = 1.13$; Japan: $M = 4.14$, $SD = 1.04$). Approximately half of Japanese mothers and 38% of American mothers reported that they sometimes avoided taking their child into public, and group differences were not significant (US: $M = 2.55$, $SD = 1.35$; Japan: $M = 3.02$, $SD = 1.42$, $U = 945$, $p = .12$).

The qualitative question that asked why mothers avoided taking their child into public, however, received different answers between Japanese and American mothers. Eighteen US mothers and 32 Japanese mothers provided their reasons to the qualitative question. A majority of both American and Japanese mothers wrote the reason was for the purpose of protecting their child from stress or unpleasant situations or environments. More Japanese mothers (28.1%) than American mothers (22.2%) responded that social stigma or rejection was their reason to avoid public (e.g., "his behavior would not be socially acceptable in some environments"). While some American mothers (16.6%) reported that they avoided taking their child into public for themselves, as it was easier to do grocery shopping by herself; no Japanese mothers reported a similar reason. On the contrary, 25% of Japanese mothers responded the reason was for the benefit of others, for example, because they were afraid that they would bother people in public.

3. Are there similarities and differences in difficulties in social relationships between the two groups? This subscale was intended to illustrate participants' difficulties with sharing their concerns with others or feelings of social isolation. Overall, Japanese mothers experienced more difficulties in their social relationships and felt more socially

isolated than American mothers ($t = 3.03$, $p = .003$). Particularly the scale of social

isolation was significantly higher in Japanese participants compared to the US

participants (US: $M = 2.14$, $SD = 1.18$; Japan: $M = 3.0$, $SD = 1.33$, $U = 736$, $p = .002$).

When looking at each question closely, it appeared that a majority of participants from

both groups (62% US mothers and 47% Japanese mothers) did not feel like it was

difficult to share their concerns about their child with ASD with their family. Although

Japanese mothers reported slightly more difficulty sharing their concerns about their

child with ASD with people outside of their family (US: $M = 2.53$, $SD = 1.2$, Japan: $M =$

3.08, $SD = 1.44$), statistical significance between the two groups was not found ($U =$

899.5, $p = .059$).

Qualitative questions in the survey asked why participants chose their responses

regarding their difficulties with sharing concerns about their child with family or with

people outside of their family. Twenty-four Japanese and 19 American mothers provided

responses about their own family, while 25 Japanese and 18 American mothers provided

responses pertaining to people outside of their families. A majority of both American and

Japanese mothers wrote that both their family and people outside of their family just did

not or could not understand their concerns (e.g., "My husband just doesn't understand it").

In regard to their difficulty with sharing concerns with their family, about 16% of both

American and Japanese mothers wrote their response as being because their family did

not care or was ignorant about their concerns or about ASD. While some Japanese

mothers (16.6%) reported that it was difficult to share their concerns about their child

with their family because of lack of time of their family members (mostly husband) to

spend with their child with ASD, no American mothers reported a similar reason. In

addition, about 16% of both Japanese and American mothers wrote that it was difficult to

share their concerns with people outside of their family because of the prejudice non-

family members had toward them or their child with ASD (e.g., "I feel that they have

prejudice against us"). Finally, 40% of Japanese mothers and 22.2% of American

mothers indicated that they were able to share their concerns only with mothers who also

have a child with ASD.

4. Are there similarities and differences in support availability between two

groups? There were no statistically significant differences between American mothers

and Japanese mothers in this subscale ($t = 0.41$, $p = .68$). Responses from both groups

indicated that they received support fairly overall (US: $M = 3.33$, Japan: $M = 3.42$). More

specifically, a majority of participants from both groups (support from family; US: 73%,

Japan: 51%; support from other than family: US: 68%, Japan: 66%) received emotional

supports from their family (US: $M = 3.83$, $SD = 1.39$, Japan: $M = 3.47$, $SD = 1.36$) and

people outside of their family (US: $M = 3.74$, $SD = 1.33$, Japan: $M = 3.63$, $SD = 1.27$).

More Japanese participants reported high on physical support availability from their

family than the US mothers (US: $M = 3.09$, $SD = 1.47$, Japan: $M = 3.8$, $SD = 1.41$, $U =$

819, $p = .01$). Both Japanese and American mothers reported low on physical support

availability from people outside of their family (US: $M = 2.66$, $SD = 1.52$, Japan: $M =$

2.75, $SD = 1.66$).

5. How do Japanese and American mothers understand the cause of their child's

ASD? This subscale was analyzed by using two frameworks: internality and externality of

the causal attribution of their child's ASD. In addition to the subscale, a framework of "special purpose" – mothers' belief that their child's ASD has some special purpose, was assessed. Overall, maternal belief in heredity as a cause of ASD got the highest score in this section from both groups (US: $M = 3.4$, $SD = 1.2$, Japan: $M = 3.53$, $SD = 1.19$). About half of Japanese mothers (49%) and 44% of American mothers either agreed or strongly agreed that their child's ASD was because of heredity, while 20% of Japanese and 13% of American mothers either disagreed or strongly disagreed with that statement.

Most of the external reasons attributed to the cause of ASD received very low scores, means ranging from 1.38 to 2.93 across both groups. There was no statistical significance in difference between groups in the external causal attribution category (US: $M = 1.84$, Japan: $M = 2.03$, $t = 1.07$, $p = .29$). On the other hand, statistically significant group differences were found in internal reasons of the causal attribution of ASD ($t = 2.55$, $p = .01$). More specifically, Japanese mothers reported their beliefs related to self-blame more than American mothers (US: $M = 1.55$, Japan: $M = 2.04$). Although participants from both groups scored relatively low in self-blame items, Japanese mothers scored significantly higher in following items: "my child's special needs are because of my overall state of mind (my attitude)" and "because of something I did" compared to the American mothers (Item 1: $U = 922$, $p = .038$, Item 2: $U = 881.5$, $p = .026$).

There were four questions under the causality section that asked about participants' beliefs in their child's ASD as being brought for special reasons such as God's will or some special purpose. However, the Cronbach's alpha coefficient did not meet the acceptable value to prove internal consistency of the questions for this subscale.

Yet, group differences were observed in some items in this category. For instance, compared with Japanese mothers, more US mothers scored high on beliefs in their child's ASD as being because of God's will (US: $M = 2.61$, $SD = 1.6$, Japan: $M = 1.7$, $SD = 1.15$, $U = 774$, $p = .004$) or some special purpose (US: $M = 3.08$, $SD = 1.5$, Japan: $M = 1.93$, $SD = 1.31$, $U = 670.5$, $p = .000$). On the other hand, more Japanese mothers strongly agreed or agreed that their child's ASD as being because of fate (US: $M = 2.4$, $SD = 1.4$, Japan: $M = 3.22$, $SD = 1.4$, $U = 796.5$, $p = .007$).

Finally, there were four questions intended to ask about positive experiences of participants, but failed to prove internal consistency of the questions in these particular groups. Two questions asked about positive impacts on family relationships: "because of my child our family has become closer," and "because of my child my social life has expanded by bringing me into contact with other parents." Two other questions asked about their experiences as related to religious beliefs: "because of my child I attend religious services more frequently," and "the presence of my child confirms my faith in God." When looking at each question closely, however, there were strong differences between the two groups.

In the items that asked about positive impacts on family relationships ("Because of my child our family has become closer"), responses from both groups were somewhat flatly distributed. Both groups had approximately 30% (Japan: 29%, US: 26%) of responses falling under "neutral/unknown." About half of Japanese mothers and 34% of American mothers agreed or strongly agreed that their family had become closer because of their child with ASD, while 41% of American mothers and 24% of Japanese mothers

disagreed or strongly disagreed with the statement. Both groups shared the ambivalent responses, and there was no statistically significant differences between groups. In the items that asked about positive impacts on social relationships, both Japanese and American mothers reported that their social life has expanded by bringing them into contact with other parents because of their child with ASD (US: $M = 3.38$, $SD = 1.42$, Japan: $M = 3.61$, $SD = 1.22$, $U = 990.5$, $p = .22$).

One of the most significant differences between groups for the survey questions overall were responses about religious beliefs. Eighty three percent of Japanese mothers chose "strongly disagree" to the question "the presence of my child confirms my faith in God," and 94% of Japanese mothers also strongly disagreed that they attended religious services more frequently because of their child. On the other hand, 45% of mothers in the US strongly agreed with the statement about strengthening their faith in God because of their child. The group difference was statistically significant (US: $M = 3.81$, $SD = 1.36$, Japan: $M = 1.44$, $SD = 1.05$, $t = 4.46$, $p = .000$). Although about half of American mothers (47%) strongly disagreed that they attended religious services more frequently because of their child, the group difference was statistically significant for this item as well (US: $M = 2.23$, $SD = 1.35$, Japan: $M = 1.21$, $SD = 0.82$, $t = 9.51$, $p = .000$). These responses reflected demographic information that showed, 89.8% Japanese mothers were non-religious, while 85.1% of American mothers were religious.

Overall both Japanese and American mothers experienced stress and physical and emotional fatigue while little support was available from people outside of the family. It is also shown that Japanese mothers experience more caregiving burden related to social

stigma or rejection than do US mothers, experience more difficulties in their social

relationships, and feel more socially isolated than American mothers. Concerning the

causal attributions of their child's ASD, both American and Japanese mothers did not

show strong belief that external reasons attributed to the cause of ASD (e.g., medications,

medical treatment, or something professionals did). More Japanese mothers reported

strong beliefs related to self-blame when compared with American mothers. On the other

hand, more American mothers reported stronger beliefs in their child's ASD as being

because of God's will or some special purpose than Japanese mothers did. In regard to

positive experiences, both American and Japanese mothers expanded their social life

because of their child with ASD. Finally, a majority of Japanese mothers did not perceive

that their child confirmed their faith in God or increased their attendance to religious

services, while a majority of American mothers felt the opposite about their faith in God.

CHAPTER V

DISCUSSION

The purpose of this study is to explore and understand the differences or similarities in maternal experiences and perceptions in regard to their children with Autism Spectrum Disorders (ASD) between the United States and Japan. Results indicated that both groups experienced high levels of stress and physical and emotional fatigue while little support was available from people outside of the family. Differences between the two groups were found in their caregiving burden in relation to social stigma and social relationships. There were also differences between the two groups concerning the causal attributions of their child's ASD; Japanese mothers reported beliefs in self-blame, while American mothers reported beliefs in their child's ASD as being because of God's will or some special purpose. Both groups experienced an expanded social life and stronger family ties. This chapter will discuss findings in the following areas: (a) stress and well-being, (b) social implications, (d) support availability, and (e) causal attributions within the theoretical frameworks of the ABCX model within Bronfenbrenner's human ecology theory (Bronfenbrenner, 2005; Hill, 1949). A brief discussion of the positive experiences of mothers, including association with religious beliefs and practices, is also included. Finally, limitations of the study and implications for practice and future research will be discussed.

More children than ever before are classified as having autism spectrum disorders. The most recent report by the National Survey of Children's Health (NSCH) conducted by CDC's National Center for Health Statistics estimated that 1 in 50 school-age children (6 to 17 years) have ASD (Blumberg et al., March, 2013). This indicates that professionals and educators who work for children have a higher possibility of working with children who have ASD and their families than ever before (Medan et al., 2010). Families, particularly mothers who are often the primary care givers, experience challenges in raising their child with ASD due to their autism specific characters, such as limited verbal communication, challenges in social skills, and unpredictable behavior (Baker-Ericzén et al., 2005; Meadan et al., 2010; Pisula, 2007). Their burden of care giving is also related to social stigma because of the invisibility of the disability and the lack of understanding of the behavior associated with ASD by the public (Bourke-Taylor et al., 2010; Gray, 2002; Green 2007; Phelps et al., 2009). All of these mothers' experiences, including positive aspects of having a child with ASD, take place within the culture where they live.

It is necessary for professionals who work with mothers to understand and respect the diversity of experiences and reactions of mothers from different cultural contexts in order to develop culturally competent collaborative relationships (Harry, 2008; Lunch & Hanson, 2011; Muscott, 2002). Yet, there is not enough research that has studied the experiences of mothers in cultures other than Western, English-speaking countries (Chang & McConkey, 2008). There are especially few cross-cultural comparison studies for mothers of children with ASD (Medan et al., 2010; Neely-Barnes & Dia, 2008). This

study aims to contribute to the area of cross-national comparison research by examining the experiences and perceptions of mothers in two different cultures.

Stress and Well-being

Results of the present study concur with the past research which repeatedly discussed significantly high levels of stress and low levels of well-being experienced by mothers of child with ASD (Meadan et al., 2010). Both American and Japanese mothers reported stress and physical and emotional fatigue. As previous studies indicated, raising a child with ASD can be physically and psychologically high demand due to the ASD-specific characteristics of their children (Baker-Ericzén et al., 2005; Meadan et al., 2010; Pisula, 2007). Mothers often experience relentless and intensely demanding daily life in regard to taking care of their child (Bourke-Taylor et al., 2010; Phelps et al., 2009; Tomanik et al., 2004). The findings of the present study, which participants scored high on stress and fatigue regardless of their nationalities, makes sense because the autism specific characteristics should not be dependent on location. This suggests that regardless of where you are, raising a child who has ASD can be challenging and is both physically and emotionally demanding.

Furthermore, that there were no significant differences in the severity of ASD between the two groups as measured in this study may help to explain why there was no significant difference in participants' stress and low well-being between the two countries. However, considering the fact that Japanese mothers scored higher in caregiving demands related to the severity of ASD than the participants from the US, there may be other factors influencing their stress and well-being. When thinking about the framework

of ABCX model (Hill, 1949), these high levels of stress and low levels of well-being can also be explained as being related to low levels of resources, such as support availability, as will be discussed in further detail later in this chapter.

Regarding negative feelings about parenting, the present study found that Japanese mothers felt less effective and competent as parents than the American mothers. Although it is not specified by the survey data, it is possible that the negative feelings about parenting that Japanese mothers experience can be attributed in part to the Confucian-based culture of Japanese society. As past research indicated that Asian mothers tend to hold strong sense of obligation to meet their expected roles as a mother (Chang et al., 2007; Li et al., 2004; McCabe, 2010; You & McGraw, 2011). In the Confucian-based society, being 'right and proper' in a relationship with others is the most important social role, and failing to meet the expectations can mean 'loosing face' for the individuals as well as for entire families (Chen, 2001; Law, 2005; Li et al., 2004). Individuals are obligated to fulfill their role expectations as father, son, elder, younger, husband, or wife. For example, one of the woman's expected roles is to be "good wives and wise mothers (ryōsai-kenbo)," who serve as true guardians and educator of their children and are true companions to their husband (Fujimura-Fanselow, 1991). Mothers are expected to care for their children and educate them to meet the good children's' roles, and not acting accordingly brings great shame to the family name. In a collectivistic society like Japan, individual's self-esteem is shaped strongly by their relationships with others and judgments that others make about them (Markus & Kitayama, 1991). In studies with Korean mothers of a child with ASD in South Korea, You and her colleague

(2011) also reported mothers' struggle with meeting a role of 'good' mother while others blamed them for not raising their child "right" (p. 588). Japanese mothers might also have a similar experience as those Korean mothers. Future qualitative research might facilitate the understanding of these responses.

Social Implications

As Bronfenbrenner's human ecology theory (1979) illustrated, experiences and perceptions of mothers occurred within external factors such as family or friends (microsystem), community (exosystem), and society (macrosystem). The findings from this study indicated some similarities and differences in the social dimensions of the caregiving experiences and social relationships of mothers of a child with ASD in the US and Japan. Overall, Japanese mothers experienced and perceived the caregiving burden related to social stigma or rejection more than the US mothers. They also felt more difficulties in their social relationships and that they were missing out on life in order to care for their child with ASD more than the participants in the US. The differences between Japanese and American mothers' responses can be explained from several different aspects.

Mothers of children with ASD often experience stigmatizing reactions from others (e.g., blaming or criticizing parents for their child's behaviors) which isolates them from some social activities (Bourke-Taylor et al., 2010; Gray, 2002; Green, 2007; Lam, Wong, Leung, Ho, & Au-Yeung, 2010; Phelps et al., 2009). For instance, the present study found that Japanese mothers had guests over to their house less often than they wanted to because of their child with ASD while US mothers did not have this issue to

the same extent as Japanese mothers. The stigmatizing reactions by others were reported

to be associated with lack of understanding or knowledge about ASD (Bourke-Taylor et

al., 2010; Phelps et al., 2009; Pisula, 2007). When people do not understand the

conditions of ASD, they more likely show negative attitudes toward the individuals with

ASD and/or their families (Gray, 2002; Tachibana & Watanabe, 2004). The classic idea

about ASD being caused by a failure of bonding between the mother and child, which

introduced the term 'refrigerator mother' to describe cold interactions between mothers

and their child, led to a social stigma about mothers of child with ASD historically

(Baron-Cohen & Bolton, 1993; Gray, 1998). However, the misunderstanding was

dismissed long ago, and the understanding ASD as neurodevelopmental disorder has

gained recognition in the public (Gray 1998; Gray, 2002). Yet, public awareness of ASD

conditions may be inadequate to dismiss the social stigma, especially in Japan.

The stigma and shame attached to disability often prevents the mothers from

seeking and obtaining support from others (Park et al., 2010). In fact, Japanese mothers in

the present study scored high in the question asking if they felt guilty or less competent as

a parent when they needed to ask for support compared with American mothers. A

collectivist culture may also help explain this kind of reaction by Japanese mothers. In

terms of help-seeking, there is an expectation that all help should be provided from

within the family in Japan (Braun & Browne, 1998; Li et al., 2004; McLaughlin et al.,

1998). Not meeting the expected roles as a mother or as a family may have caused

feelings of guilt for mothers when seeking supports. Also, the collectivistic idea about the

preservation of harmony, which is a belief that problems should be kept private from

others in order to preserve the harmony of the group (Oyserman, Coon, & Kemmelmeier, 2002), may have some influence on mothers feeling guilty and incompetent when seeking support from others. Moreover, expressing problems or concerns verbally is not welcomed and could threaten the preservation of harmony. Therefore, parents of children with disabilities in Asian cultures tend to conceal their negative emotions or concerns instead of speaking out (Chang & Hsu, 2007; Oyserman et al., 2002). As is consistent with prior research, Japanese mothers in the present study indicated that they had slightly higher difficulty sharing their concerns about their child with ASD with people outside of their family than with their family members. For example, a Japanese mother wrote in the qualitative question column that she did not feel comfortable sharing some private family problems with others.

On the other hand, more than a half of mothers in the US reported that it was not difficult to share their concerns with people outside of their family. In an individualistic society like the US, expressing feelings or emotions directly to others is encouraged because people do not expect others to read their minds in social exchanges (Markus & Kitayama, 1991). This cultural context may explain why mothers in the US struggled less when sharing their concerns with others than Japanese mothers did. Also, this result may be influenced by the fact that about half of participants from the US were reached through the Autism Society annual conference. These people who decided to come to the conference are more likely to have strong connections with the Autism Society organization or other parents of children with ASD. As the qualitative responses provided

in the survey indicated, they felt especially comfortable with sharing their concerns with other parents who had a child with ASD.

Regarding mothers' experiences in missing out on life in order to care for their child with ASD, the current research found some notable differences between the groups. More Japanese mothers gave up things they really wanted to do, and had to quit their job in order to care for their child than participants from the US. Their demographic information in their employment status confirmed this group difference. A majority of the mothers in the US were employed outside of the home, while a majority of Japanese mothers were not employed outside of the home. This may have some relation to the differences in their education level. Most of the US mothers either graduate from university or graduate school while a majority of Japanese mothers' highest level of education were some college or below.

The lower levels of education and employment status of mothers in Japan reflect the gender role expectations in Japanese society. Although more Japanese women have begun to explore higher education and professional careers recently, the general public continues to carry the traditional gender expectations of marriage and motherhood for female, and women themselves comfortably choose to stay home in order to care for their child (Anzai & Paik, 2012; Priest, Edwards, Wetchler, Gillotti, Cobb, & Borst, 2012). As introduced in the chapter two, a comment by a Chinese mother of child with ASD who quit her job to take care for her child represented this attitude well: "There's really no satisfied or not satisfied (about her employment status), because caring for a child is a respected mother's responsibility you know" (McCabe, 2010, p. 127). On the other hand,

women in the US hold nontraditional beliefs and behaviors in regard with their gender

roles (Priest et al., 2012). These demographic backgrounds influenced by cultural

contexts may have strong implications for the participants' reactions to the subscales.

In the present study, a slight difference was observed between two groups in the

statement: "sometimes I avoid taking my child out in public." Although the difference

was not statistically significant, it appeared that a majority of American mothers

answered either disagree or strongly disagree with the statement, while approximately

half of Japanese mothers either agreed or strongly agreed with it. The noteworthy

findings came from their qualitative answers to the question in the survey. Among those

who provided the qualitative responses, the major reason they avoided public situations

were different between groups. More specifically, for the majority of Japanese mothers,

their worries about bothering or disturbing others or what others think of them was the

primary reason why they avoided the public. For instance, a mother wrote that "I cannot

bear other peoples' cold stares at us." On the other hand, for the majority of American

mothers, their reason to avoid some public situations were for their child with ASD,

mostly protecting them from stressful situations. A mother stated that "I do (avoid the

public) to protect my son from sensory overload." This finding may imply again that

Japanese society is less accepting of individuals and their families with disabilities and

less aware of ASD conditions. It may also indicate the collectivistic culture of Japan that

favors collective well-being and social harmony over individual well-being (Hamamura,

2012; Reader & Tanabe, 1998; Traphagan, 2004). While in an individualistic society,

individuals' behaviors are motivated strongly by their own preferences, needs, and rights (Triandis, 1995).

Finally, as opposed to the researcher's initial hypothesis, group differences were not found in mothers' perceptions on sacrificing their life in order to take care for their child with ASD. A majority of both American and Japanese mothers responded that it was their responsibility to take care for their child even if they had to sacrifice their life. This result might be influenced by how the question was worded. The question contained two points: their belief in taking care of their child as their responsibility, and willingness or acceptance of sacrificing their life in order to take care of their child. It is not clear how many participants agreed only with the first part of the question and chose agreed or strongly agreed with it. Also, the definition and the degree of 'sacrifice' was not clearly stated in the question. A later phase of this research needs to find out what the participants meant when they chose their responses. It is also reasonable to suppose that this result reflected universal ways of parenting behavior. It is natural that mothers invest so much in their offspring from both evolutional and biological perspectives (Bjorklund, Yunger, & Pellegrini, 2002; Numan, 2010). Mammalian parenting behavior is characterized by taking care of their children even if they have to sacrifice themselves sometimes (Numan, 2010).

Support Availability

The resources mothers can access to use is one of the critical aspect of the ABCX model. The resources can come from within the family (e.g., financial resources or help with child care) and from the outside of the family (e.g., community services). These

resources, including both emotional and physical supports, are important stress buffers for mothers of children with ASD (Banach et al., 2010; Bourke-Taylor et al., 2010; Davis et al., 2009; Guralick et al., 2008; Phelps, 2009; Turnbull et al., 2006; Weiss, 2002). The findings from this study indicated that both American and Japanese mothers received a fair amount of emotional support overall. Particularly both groups received emotional support, such as encouragement or understanding, from both their family and people outside of their families. This finding may be influenced by the sampling procedure of the participants. A majority of participants in this study were recruited through either the Autism Society of NC or the Autism Association of Osaka. Both of these are organizations developed by parents for advocating for individuals with ASD and their families. It is reasonable to suppose that mothers who are a part of these organizations are more likely to have access to emotional support from people outside of their families, and are more likely to try to reach out for support from others when they need it.

There was a notable difference between the groups in physical support availability from their families. More Japanese mothers reported that they received more physical support from their family than mothers in the US. Although this study did not clarify the reason behind their responses, Japanese family's strong feelings of obligations to take care of themselves (Li et al., 2004) may be one of the reasons why Japanese mothers found more physical supports from their family than the US mothers. Another important finding is that a majority of the participants from both groups did not receive physical support from people outside of their family. Therefore, the difference in physical support

accessibility from family members between the US and Japan were not necessarily because US mothers had access to support from the outside sources.

Results of the present study concur with previous research, which reported that receiving support from outsiders has been challenging for mothers of children with a disability (Bourke-Taylor et al., 2010; Chang & McConkey, 2008; Phelps et al., 2009). For instance, Bourke-Taylor and her colleagues (2010) reported that many formal services were difficult to access or retain and were inadequate in their quality. Also, lack of funding for receiving the support services was one of the common issues for the family (Bourke-Taylor et al., 2010; Phelps et al., 2009). The previous research suggested that parents with low levels of education and low-income backgrounds found more difficulty accessing supports or services from outside of their families due to financial constraints (Meadan et al., 2010). Contradicting the previous research, a majority of participants in this present research were from middle to high-income families with high levels of education (especially American group), and yet they reported that they did not receive support from outside of their families. The next phase of this study needs to find out why they did not receive support from outsiders and why emotional supports were more accessible to mothers than physical supports.

Causal Attributions

When mothers discover that their child has a disability, they look for a reason as to why their child was born with a disability by asking a question like, "why me?" (Bennett et al., 1995; Poston & Turnbull, 2004). Religion is one of the most important aspect of culture that helps mothers to make some sense of the event of having a child

with disability (Bennett et al., 1995; Poston & Turnbull, 2004). The most significant findings in this section were group differences in internal reasons of the causal attribution of ASD. Japanese mothers associated the cause of ASD more particularly to self-blame than American mothers. For instance, Japanese mothers scored high in the items such as "my child's special needs are because of something I did," or "my child's special needs are because of my overall state of my mind (my attitude)."

The concept of 'cause and effect' called 'Karma' may help explain this self-blaming perceptions by Japanese mothers. The concept of 'Karma' explains that the anticipated effect of an action is stored in our lives and when the right circumstances appear then the effect will be delivered (Chen, 2001). This concept of karma was transformed into the belief that disability was an effect of something their parents did (Deepak, 2001). For instance, Taiwanese mothers of children with disabilities expressed their belief in the relationship between karma and disability, such as their believing that their child was born with a disability because of something wrong they did (Huang et al., 2009). This tendency of mothers to blame themselves for their children's special needs were reported repeatedly from previous research from Asian countries (Huang et al., 2009; Park et al., 2010; You & McGraw, 2011).

Other notable differences between the groups in causal attribution were American mothers' stronger beliefs in their child's ASD as being brought by God's will or some special purpose. This finding may be explained by the participants' religious background as Christian. Christianity helps mothers of a child with a disability through attributing meaning to disabilities. Past research reported that parents' beliefs that their child with a

disability was a gift from God because He knew that they could handle it (Bennett et al., 1995; Poston & Turnbull, 2004). In addition, many parents believed that this gift was given by God as a blessing or as a test of their faith (Poston & Turnbull, 2004). The demographic information in the present research indicated that most of the participants in the US were Christian, while most of Japanese mothers did not have any religious affiliation. This difference in religious background in the two groups explains the variation in responses for this section.

Finally, more Japanese mothers believed that their child's ASD was because of fate than American mothers. The coping strategy, "shikata ga nai," observed in Japanese culture may help to explain this perception of Japanese mothers. "Shikata ga nai," which indicates the attitude of accepting the fate as the way it is, is a common coping strategy in Buddhism. Although Japanese individuals usually perceive themselves as non-religious, their culture is strongly shaped by a Buddhism doctrine (Roemer, 2009). For instance, Taiwanese mothers in Chang and McConkey's study (2008) perceived difficulties in taking care of their child with a disability as a matter of their fate. The way mothers perceive their child's special needs is strongly correlated with how they cope with the stresses and challenges of caring for their child with a disability (Hastings et al., 2002). Future research needs to investigate how differences between these two groups affect the mothers' coping strategies.

Positive Experiences

First of all, this subscale failed to prove the internal consistency of the questions in US participants because of the nature of questions. The questions asked about positive

impacts on family and social relationships as stating "because of my child" their family had become closer or their social life has expanded. It is reasonable to suppose that there are participants who disagreed or strongly disagreed with the statement because their family relationship was already close or was already distant, regardless of their child with ASD. In the same way, there may be participants who disagreed or strongly disagreed that they attended religious services more frequently because of their child with ASD. For those participants, the presence of their child may not have changed their religious practices. The extreme discrepancy in responses between the questions asking about their attendance in religious services and the other positive experiences lowered the internal consistency of the questions in the US participants. In addition, the extreme discrepancy in responses between questions asking about religious beliefs and other positive experiences in the Japanese participants also lowered the internal consistency of this subscale. The questions about religious beliefs and practices got extremely low scores among Japanese mothers, because religious practices were not necessarily correlated with positive experiences in Japan. This subscale fails to meet the reliability standard partly due to cultural differences and partly due to the wording problems.

Yet, there are some noteworthy findings from each question. Both groups reported that their social life has expanded by bringing them into contact with other parents who have a child with ASD. Again, this may be explained by the sampling procedure. As a member or participant of the Autism Society conference or Autism Association of Osaka, their social life would have been expanded by meeting other

parents of children with ASD. This result may be very different if participants were sampled through local schools randomly.

One of the most significant differences between the two groups in this study was shown in their perceptions and experiences about religious beliefs. As discussed earlier, most of the Japanese mothers were non-religious and the majority of them did not perceive that their child's presence confirmed their faith in God or enhanced their religious practices. While a majority of American mothers perceived the presence of their child as confirming their faith in God. This response reflects their beliefs in their child's ASD as being brought by God's will or some special purpose. Previous research reported that Christian parents believed that their child with a disability was a gift given by God as a blessing or as a test of their faith (Poston & Turnbull, 2004). Analyzing the responses to the religious beliefs in relations to participants experiences with social relationships or well-being may illustrate how religious background influences their experiences in the future phase of this research.

Limitations of Study

One of the limitations of this study was the selection of participants. A majority of participants in this study were recruited through either the Autism Society of NC or the Autism Association of Osaka. Both of these are organizations were developed by parents for advocating for individuals with ASD and their families. It is reasonable to suppose that mothers who are a part of these organizations are more likely to have access to emotional support from others, and are more likely to try to reach out for support from others when they need it. The sampling procedure also influenced the demographic

characteristics of participants in this study. A majority of participants in this present

research were from middle to high-income families with high levels of education,

especially the American group. This also may be because 20 participants were recruited

at the annual conference for Autism Society of NC, which had high registration fees. We

need to be aware of that these samples may not be representative of all families in the US

and Japan.

The geographic limitation in the sampling procedure also needs to be considered

since this is a cross-cultural research. Both North Carolina and Osaka are just one

geographic area in large nations. If participants were recruited from, for instance, New

York City (more urban area in the US) or Hokkaido (more rural area in Japan), their

responses might be different from the present study. The notion of geographical

limitation also reminds us of the danger of equivalent use of 'social address' to ethnicity

or culture (Rogoff, 2003). In fact, culture is dynamic in its nature and varies within a

community (Rogoff, 2003). Future research conducted in different geographic regions in

the US and Japan will identify new aspects of the two cultures and thereby provide a

more realistic view.

Finally, the current phase of this research has a methodological limitation. First,

there were two subscales (positive experiences and special purpose in causal attribution)

that failed to prove internal consistency of the questions in these particular participant

groups. Therefore, the findings reported were mainly descriptive. For the positive

experience subscale, the number of questions under this scale was probably too small.

Although questions were adopted from an inventory that had previously proved internal

consistency across various research studies, the fact that the present research selected some questions in order to keep the number of survey questions small must have some effects on the reliability. Moreover, some of the questions did not match the cultural background of the participants in this study. Religious practices were not necessarily considered as positive in Japanese participants. Increasing the sample population or adjusting the survey questions might have helped to avoid this problem. Second, quantitative data using a 5-likert-scale has limitations because they can only provide close-ended information, which does not explain why participants chose their responses (Creswell & Clark, 2007). The future phase of this study will explore the contexts of the participants and the reasons behind their responses to the survey questions.

Implications for Practice

The current study ensured that cultural and social contexts have significant influence on the experiences of mothers. Professionals who work with families need to understand and consider the diversity of family experiences or perceptions in order to provide appropriate services or supports benefitting them. Federal law and research have suggested the use of collaboration between special education professionals and families in order to provide the most effective services or education for students with disabilities (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Coots, 2007; Harry, 2008). Understanding the critical needs of families from diverse perspectives helps practitioners improve their culturally competent collaborative relationships with families. The information from the present study can serve as one of the diverse perspectives to share in the pre-service and in-service teacher preparation programs. For instance, the results

from the study can be introduced in undergraduate courses as an example of how cultural

differences influence the experiences of mothers. The results from the study also can be

used for students to exercise critical thinking skills by challenging the students'

assumptions about mothers' perceptions. Pre-service and in-service teachers or

professionals can apply the information to improve their culturally competent

collaborative relationships with families.

Although family-professional partnerships in the school-aged years heavily focus

on academic achievement and functional life skills outcomes for children, for families,

their ultimate goals are to improve quality of life for their children with a disability and

for themselves (Blue-Banning et al., 2004). It is important for professionals who work

with mothers to listen to their perspectives, understand their experiences, and

accommodate the educational goals of the child but also consider the family goals.

Supportive relationships between parents and professionals help to improve effectiveness

of educational services (Dinnebeil, Hale, & Rule, 2000) and may ease the stressful

experiences of children and mothers.

In fact, this study also suggests the need for social supports for mothers of school-

age children with ASD both in the US and Japan. Using support or having access to

necessary support is one of the most significant resources, as was indicated by the ABCX

model. In the ABCX model, "stress may never become a crisis if the family is able to use

existing resources and defines the situation as a manageable event" (Seligman & Darling,

2007, p. 38). In fact, social supports help mothers to gain a sense of hope in their views of

the future (Banach et al., 2010; King et al., 2009; Schuengel et al., 2009). Future-oriented

hope allows parents to regain a sense of control, which brings them self-efficacy (Banach et al., 2010). Making more supports easy to access for families of a child with ASD physically and financially is necessary. Practitioners need to keep in mind that mothers have needs for support in addition to the needs of the child with ASD.

Findings of the current research also illuminate the existence of social stigma related to individuals with ASD and their parents. Public awareness of ASD conditions seems to be inadequate yet, especially in Japan. Spreading the awareness of ASD and appropriate knowledge about the ASD conditions to the public is necessary. Educating the public about ASD through the media or autism awareness events can be a vehicle that may contribute to reducing social stigma. Also, as the demographic information of the present study indicates (88% of the children of Japanese participants went to either a special school or a special class in public school) that inclusive practices for children with ASD are not common in Japan. Including children with ASD into the general classroom may result in a reduction in social stigma in the long term by increasing the social contact between children without a disability and children with ASD.

Finally, this study also provides helpful information for practitioners and researchers from countries outside of the US. Regarding the initial reason why the researcher launched this study: understanding what's behind the conflicts when importing educational programs developed in the US into Japan, the current study suggests that differences in experiences and perceptions of mothers may be one of the factors that caused the conflict. It is important to consider cultural contexts when importing educational programs or policies from a different country, and make cultural adjustment

in order to maximize the effectiveness of the programs. This information also can be applied when adapting a new program into different communities within the US, especially if the program is not specifically developed for that area.

Implications for Future Research

Future research investigating stress factors (e.g., mother's age, socioeconomic status, child's birth order in family, severity of ASD, or coping style) could provide information about mothers' experiences in more detail with regard to resources, supports, and coping strategies. Findings in the present study were not informative in regard to the factors that contributed to their stress. Qualitative data that explains contexts of the participants and the reasons behind their experiences and perceptions will add more in-depth and comprehensive information.

This cross-cultural study can be expanded by including the experiences of fathers and siblings. Additional and comprehensive understanding of the experiences and perceived needs of fathers and siblings of individuals with ASD may help develop effective supports for the whole family. In addition, it would be helpful to examine the bi-directional influence between mother and child well-being in the cross-cultural settings. Mothers' stress or well-being must have some impact on their child with ASD. Finally, this cross-cultural research should be expanded to study positive experiences of mothers. The current research focused on issues or challenges of mothers rather than on the positive impacts of having children with ASD. Studying the positive impacts of having children with disabilities across countries or within the US (e.g., between low and high socioeconomic status families) will provide a more comprehensive picture of the

experiences of mothers. A potential area of further research should include mothers from varied socioeconomic and educational backgrounds and within varied communities. Research might investigate the real impact of different supports systems, laws and policies, education interventions on parents of child with ASD in various communities.

In conclusion, raising a child with ASD can be stressful and physically and emotionally demanding, regardless the cultural differences. Yet, physical supports were not sufficiently available for both Japanese and American mothers, especially from outside of their family. It was also found that Japanese mothers experience more caregiving burden related to social stigma or rejection than do US mothers, experience more difficulties in their social relationships, and feel more socially isolated than American mothers. Concerning the causal attributions of their child's ASD, more Japanese mothers reported strong beliefs related to self-blame when compared with American mothers. On the other hand, more American mothers reported stronger beliefs in their child's ASD as being because of God's will or some special purpose than Japanese mothers did. Practitioners need to keep in mind that we need to support the needs of mothers, and not just the needs of the child, in order to maximize the effectiveness of education or related services.

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APPENDIX A

SURVEY FOR THE US MOTHERS

Directions:

- Thanks for participating in this survey.
- Please provide complete information for each item.
- Choose only one answer that best describes your experiences for each statement.

The answers and their meanings are:

| 1 = Strongly Disagree |
| 2 = Disagree |
| 3 = Neutral/Unsure |
| 4 = Agree |
| 5 = Strongly Agree |

| For Survey Questions 4 to10 |
| 1 = Never |
| 2 = Very Rarely |
| 3 = Occasionally |
| 4 = Very Frequently |
| 5 = Always |

Survey Questions

Demographic information

1. Child's information

a. Gender: ❏boy   ❏girl

b. Age: _____

c. Grade level: ____

d. Ethnicity:

❏White   ❏Black   ❏Latino   ❏Asian/Pacific Islander   ❏Mixed   ❏Others

e. Birth position in the family:

❏Youngest   ❏ Middle   ❏Oldest   ❏Only child

f. Diagnosis: _____

g. When did she/he receive the diagnosis? : _____

h. Type of school program your child attends:

❑Regular public school class
❑ Public school, special class
❑ Regular private school class
❑Special school

2. Mother's information

a. Age: __

b. Ethnicity:

❑White   ❑Black   ❑Latino   ❑Asian/Pacific Islander   ❑Mixed   ❑Others

c. Highest level of education

❑High School   ❑Some college   ❑Undergraduate   ❑Graduate

d. Employment outside of home:

❑ Yes   ❑No

e. Religious affiliation: _____

f. Are you your child's biological mother?

❑Yes   ❑No

g. Present marital status:

❑Single ❑Married ❑Widowed ❑Separated ❑Divorced ❑In a relationship

3. Household information

    a. Adults who live with the child

    ❑Mother   ❑Father   ❑Grandparents   ❑Others

    b. Number of children in the home (Under the age of 18): _____

    c. In what range is your annual family income?

    ❑Less than $10,000
    ❑$10-20,000
    ❑$21-35,000
    ❑$36-50,000
    ❑$51-75,000
    ❑$75,000 or higher

Survey Questions

Questions about your children	**Strongly Disagree**		**Neutral/ Unknown**		**Strongly Agree**
1. My child is dependent on me to complete all daily tasks.	1	2	3	4	5
2. I have to watch my child constantly.	1	2	3	4	5
3. It is easy to communicate with my child.	1	2	3	4	5
	Never		**Occasionally**		**Always**
4. My child has sleep disturbance (e.g., difficulty falling asleep, waking during the night, waking early in the morning).	1	2	3	4	5

	Never		Occasionally		Always
5. My child is distressed by change (e.g., change in routine or schedule, parent takes a different car route home from school, furniture or child's toys are moved, etc).	1	2	3	4	5
6. My child insists on doing things the same way every time.	1	2	3	4	5
7. My child has feeding problems (e.g., very picky eater, limited food preferences, hypersensitivity to textures, eats inedible substances, etc).	1	2	3	4	5
8. My child has unusual hypersensitivity to some sounds, (e.g., distress or covering ears in response to loud noise, motors, vacuum cleaner, hair dryer, baby crying, sirens, clapping, alarms, toilet flushing, people singing) smell, light, or temperature.	1	2	3	4	5
9. My child has mood disturbance (e.g., over reactivity, irritability, low frustration tolerance, agitation, tantrums, meltdowns, explosiveness, aggression, or self-injurious behavior, etc).	1	2	3	4	5
10. My child has stereotypies (unusual repetitive movements such as hand flapping, toe walking, body rocking, head shaking, body tensing, teeth grinding while awake, finger movements, repeatedly running back and forth, twirling or spinning, pacing, playing with saliva, skin picking, etc.).	1	2	3	4	5

Questions about your perceptions	Strongly Disagree		Neutral/ Unknown		Strongly Agree
11. Having a child with ASD adds stress to my life.	1	2	3	4	5
12. When I am with my child, I feel less effective and competent as parent.	1	2	3	4	5
13. Sometimes I feel embarrassed because of my child.	1	2	3	4	5

	Strongly Disagree		Neutral/ Unknown		Strongly Agree
14. I feel that it is my responsibility to care for my child even if I have to sacrifice my own life.	1	2	3	4	5
15. I feel guilty or less competent as a parent when I need to ask for support from someone.	1	2	3	4	5
16. I feel that it's difficult to share my concerns about my child with my family. (Why?:)	1	2	3	4	5
17. I feel that it's difficult to share my concerns about my child with people outside of my family. (Why?:)	1	2	3	4	5
18. I feel isolated from the society.	1	2	3	4	5

Questions about your experiences

	Strongly Disagree		Neutral/ Unknown		Strongly Agree
19. I'm physically tired.	1	2	3	4	5
20. I'm emotionally tired.	1	2	3	4	5
21. Sometimes I avoid taking my child out in public. (Why?)	1	2	3	4	5
22. I have guests over to our house less often than I would like to because of my child.	1	2	3	4	5
23. I have given up things I have really wanted to do in order to care for my child.	1	2	3	4	5
24. I had to quit my work in order to care for my child.	1	2	3	4	5
25. I receive emotional support from my family (e.g., encouragement, understanding, or listening to you). (Who?:)	1	2	3	4	5

	Strongly Disagree		Neutral/ Unknown		Strongly Agree
26. I receive physical support from my family (e.g., help with chores, emergency child care, or resources).	1	2	3	4	5
27. I receive emotional support from people other than my family. (Who? : _____)	1	2	3	4	5
28. I receive physical support from people other than my family.	1	2	3	4	5
29. Because of my child our family has become closer	1	2	3	4	5
30. Because of my child my social life has expanded by bringing me into contact with other parents.	1	2	3	4	5
31. Because of my child I attend religious services more frequently.	1	2	3	4	5
32. The presence of my child confirms my faith in God.	1	2	3	4	5

Questions about your personal beliefs about your child's special needs

MY CHILD'S SPECIAL NEEDS ARE:	Strongly Disagree		Neutral/ Unknown		Strongly Agree
1. because of an injury that occurred during birth.	1	2	3	4	5
2. because of God's will.	1	2	3	4	5
3. because of some special purpose.	1	2	3	4	5
4. because of chance.	1	2	3	4	5
5. because of medications or medical treatments received (hormones, birth control pills, X-rays, etc.).	1	2	3	4	5

	Strongly Disagree		Neutral/ Unknown		Strongly Agree
6. because of heredity.	1	2	3	4	5
7. because of something professionals did (doctors, nurses, etc.).	1	2	3	4	5
8. because of something I failed to do.	1	2	3	4	5
9. because of fate.	1	2	3	4	5
10. because of something someone else in my family did.	1	2	3	4	5
11. because of a chemical imbalance.	1	2	3	4	5
12. because of my overall state of mind (my attitude).	1	2	3	4	5
13. because of something I did.	1	2	3	4	5

Thank you so much for your contribution to this study!

If you would like to enter a drawing for a $100.00 gift card, please provide your contact information in the next page. The contact information will be removed from the survey responses when the survey is received. Also, if you agree to participate in the interview stage of the study, please check "Yes," and fill out the contact information as well.

If selected, I agree to participate in the interview: ❑ **Yes** ❑**No**

Contact information for the drawing or for the interview:

Your Name: _____

Address:_____

Phone number: _____

Email address (optional): _____

Thank you so much!

APPENDIX B

SURVEY FOR JAPANESE MOTHERS

研究へのご参加誠にありがとうございます。

記入方法:

- 　　　回答には黒色か青色のペンをお使いください。
- 　　　もし質問項目があなたやお子様に当てはまらない場合、空いたスペースに「該当なし」とご記入ください。
- 　　　お答えいただける範囲でお答えください。

各項目を読み、最も当てはまる答えの前にある❏にチェック✔を入れるか、最も当てはまる番号を丸で囲んでください。番号の意味は以下の通りです:

1 = 全くあてはまらない 2 = あてはまらない 3 = どちらとも言えない、または分からない 4 = あてはまる 5 = 非常にあてはまる

お子様に関する質問の 4 〜10 1 = 全く無い 2 = あまり無い 3 = 時々 4 = よくある 5 = いつも

アンケート

基本情報

1. 自閉症のお子様について

a. 性別: ❏男　　　 ❏ 女

b. 年齢:_____　c. 小学校の学年：____

d. 人種:

❏ 白人　 ❏ 黒人　❏ラテン系　❏アジア人　❏2つ以上の混血　❏その他

e. 何番目のお子さんですか?

❏一番下　　　❏真ん中　　　❏一番上　　　❏一人っ子

f. お子様に付けられた診断名: _____

g. 診断された時期：_____

h. 通学している学校のタイプ：

❏公立の一般校の一般学級
❏公立の一般校の支援学級
❏私立の一般校
❏支援学校

2. <u>お母様について</u>

a. 年齢：__

b. 人種：

❏ 白人　❏ 黒人　❏ラテン系　❏アジア人　❏2つ以上の混血　❏その他

c. 最終学歴：

❏ 高等学校　　❏ 専門学校・短大　　❏4年制大学　　　❏大学院

d. 現在、家の外で仕事をしていますか？

❏ はい　　　　❏ いいえ

e. 何か宗教に属している場合、その宗教は何ですか？:_____

f. お子様の生みの母親ですか？

❏ はい　　　　❏ いいえ

g. 現在の配偶者状況：

❏独身　　❏既婚　　❏未亡人　　❏別居　　❏離婚　　❏交際中

3. <u>ご家族について</u>

a. お子様と同じ家に住んでいる大人にチェックを入れてください

❏ 母　　　　❏父　　　❏ 祖父または祖母　　　　❏その他

b.お子様のご兄弟は何人いますか？:＿＿＿＿＿＿＿＿＿＿＿＿＿＿

c.年間家計所得はどのカテゴリーに入りますか？

❑100 万円以下
❑100 万〜200 万円
❑210 万〜350 万円
❑360 万〜500 万円
❑510 万〜750 万円
❑750 万円以上

自閉症のお子様と過ごす上での経験や思いについて

お子様について：	全くあてはまらない		どちらとも言えない/分からない		非常にあてはまる
1.身の回りの事など日常の全てにおいて私の助けが必要	1	2	3	4	5
2.常に目を離せない状態	1	2	3	4	5
3. 会話のやり取りが容易にできる	1	2	3	4	5
	全く無い		時々		いつも
4．睡眠障害がある（寝つきが悪い、夜に目覚める、朝早く起きるなど）	1	2	3	4	5
5．変化を嫌がる（日課やスケジュールの変更、学校へ行く時にいつもと違う道を通る、家具やおもちゃが移動しているなどの変化を嫌がる）	1	2	3	4	5
6．何かをする時、いつも同じようにすることにこだわりがある。	1	2	3	4	5
7．摂食に問題がある（偏食、食感に過敏に反応する、食べられない物を食べようとするなど）	1	2	3	4	5

	全く無い		時々		いつも
8．過敏に反応する音や、臭い、光や気温がある（大きな音、車の音、掃除機の音、ヘアドライヤー、乳幼児の泣き声、サイレン、拍手、目覚まし時計の音、トイレの水洗音、誰かの歌う声などを嫌がり耳をふさぐなど）	1	2	3	4	5
9．気分に乱れがある（癇癪、イライラしやすい、興奮、パニック、感情の爆発、他傷や自傷行為などがみられる）	1	2	3	4	5
10．常同行動がある（手を叩く、つま先歩き、身体を揺らす、頭を振る、身体の緊張、起きている時の歯軋り、指を動かす、走ったり歩いて行ったり来たりを繰り返す、くるくると回る、唾液で遊ぶ、皮膚をむしるなど）	1	2	3	4	5

自閉症の子どもとの生活の中であなたの感じていることに関して：

	全くあてはまらない		どちらとも言えない/分からない		非常にあてはまる
11.自閉症の子どもを持つことが私の生活にストレスを加えている	1	2	3	4	5
12.子どもといる時、親として力不足や失格と感じ自信が持てない	1	2	3	4	5
13.子どものことで恥ずかしいと感じることがある	1	2	3	4	5
14.例え自分の生活を犠牲にしても、この子の世話をするのは私の義務だと思う	1	2	3	4	5
15.誰かに助けを頼む時、親として力不足を感じたり、罪悪感を感じる	1	2	3	4	5

	全くあて はまらない		どちらとも言え ない/分からない		非常にあて はまる
16. この子に関する私の心配を家族と共有する（分かち合う）ことは難しいと感じる [理由（もしお答えいただけるなら）：	1	2	3	4	5
17. この子に関する私の心配を家族以外の人と共有する（分かち合う）ことは難しいと感じる [理由（もしお答えいただけるなら）：	1	2	3	4	5
18. 社会から孤立していると感じる	1	2	3	4	5

あなたの経験に関して：

19. 身体的に疲れている	1	2	3	4	5
20. 精神的に疲れている	1	2	3	4	5
21. 子どもを人前や公共の場に連れて行くのを避けることがある。 [理由（もしお答えいただけるなら。）：	1	2	3	4	5
22. この子がいるので以前より人を家に呼ばなくなった。	1	2	3	4	5
23.この子の世話をするために、自分のやりたかったことをあきらめたことがある	1	2	3	4	5
24. この子の世話をするために仕事を辞めなければならなかった	1	2	3	4	5
25. 家族からの精神的なサポートがある（例：話しを聞いてくれる、理解してくれる、元気付けてくれるなど） [主に誰ですか？	1	2	3	4	5

	全く同意 できない		どちらとも言え ない/分からない		非常に同意 できる
26. 家族からの物理的なサポートがある（例：家事のサポート、急用の際子守りをしてくれる、子どもに関わる金銭的なサポートなど） [主に誰ですか？	1	2	3	4	5
27. 家族以外の人から精神的なサポートがある [主に誰ですか？	1	2	3	4	5
28. 家族以外の人から物理的なサポートがある [主に誰ですか？	1	2	3	4	5
29. この子のおかげで家族のつながりが強くなった	1	2	3	4	5
30. この子のおかげで他の親との出会いなど交友範囲が広がった	1	2	3	4	5
31. この子がいることで、宗教活動により頻繁に参加するようになった	1	2	3	4	5
32. この子の存在が、私の神への信仰を確かなものにしてくれている	1	2	3	4	5

お子様の自閉症に関するあなたの個人的な考えに関して：

お子様の自閉症は…：

1. 出産時の外傷によるものだ	1	2	3	4	5
2. 神の意思によるものだ	1	2	3	4	5
3. 何か特別な意思によるものだ	1	2	3	4	5
4. 偶然によるものだ	1	2	3	4	5

	全く同意 できない		どちらとも言え ない/分からない		非常に同意 できる
5. 薬や医学的治療を受けたことによる ものだ（ホルモン治療、避妊薬、X線 など）	1	2	3	4	5
6. 遺伝によるものだ	1	2	3	4	5
7. 専門家（医者や看護婦など）のした ことによるものだ	1	2	3	4	5
8. 私のミスによるものだ	1	2	3	4	5
9. 運命によるものだ	1	2	3	4	5
10. 何か家族のしたことによるものだ	1	2	3	4	5
11.（脳内の）化学物質の不均衡によ るものだ	1	2	3	4	5
12. 私の精神状態や私の態度によるも のだ	1	2	3	4	5
13. 何か私のしたことのせいだ	1	2	3	4	5

質問は以上です。

　研究へご協力いただき誠にありがとうございます。インタビューの参加に同意していただける場合は、次の質問に「はい」とお答えいただき、次項にご連絡先をご記入ください。ご記入頂いた個人情報は、受け取り後すぐに質問用紙とは切り離され、別に保管されます。

　インタビューは質問用紙の回答を元に無作為に選ばれた数名の方に実施されます。

＊インタビューの参加に同意します：　　❏　はい　　　　　❏ いいえ

インタビューの参加に同意してくださる方は、この用紙に連絡先をご記入の上、アンケート用紙と共に封筒に入れて担任までお返し下さい。

お名前: ＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

電話番号: ＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿＿

E メールアドレス（携帯アドレス可）: ＿＿＿＿＿＿＿＿＿＿

ご協力ありがとうございます。

APPENDIX C

SUBSCALES MATRIX

Literature Review	Sub Research Questions	Subscales	Survey Questions
Mothers of children with ASD experience significantly high levels of stress and lower levels of well-being.[1, 2, 3, 4, 5, 6, 7, 8, 9, 10]	Are there similarities and differences in maternal stress or well-being between two groups?	Maternal well- being	SQ1, SQ2, SQ9, SQ10
Mothers of children with ASD experience intense demand of care. Their burden of care giving could be related to social stigma/rejection. [5, 6, 9, 11, 12, 13, 14, 15, 22]	Are there similarities and differences in burden of care giving related to social stigma between the two groups?	Burden of caregiving	SQ3, SQ4, SQ5, SQ11, SQ12, SQ13, SQ14
Asian families experience difficulties in social relationship, sharing their concerns with family members/others and social isolation. [21, 22, 23, 24, 25, 26, 27]	Are there similarities and differences in difficulties in social relationships between the two groups?	Social Burden	SQ6, SQ7, SQ8, SQ11, SQ12, SQ13, SQ14
Internal and external supports are significant factors for mothers/parents to gain positive perceptions. [14, 16, 17, 18, 19, 20]	Are there similarities and differences in support availability between two groups?	Support Availability	SQ15, SQ16, SQ17, SQ18
Cultural contexts influence how mothers perceive the cause of their child's ASD. Their beliefs on causal attributions influence their experiences with their child. [25, 27, 28, 29, 30, 31, 32, 33, 34]	How do Japanese and American mothers understand the cause of their child's ASD?	Internal	CQ8, CQ12, CQ13
		External	CQ1, CQ5, CQ7, CQ11

SQ: Survey Questions, CQ: Causality Questions

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