

# Islamic Religiosity in Families of Children with Autism Spectrum Disorder

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## Islamic Religiosity in Families of Children with Autism Spectrum Disorder

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### Abstract

The aim of the study was to provide an overview of the Islamic religiosity of parents of children with ASD based on the theory of religiosity (Huber & Huber, 2012) & Islamic education (Suwaid, 2010). This study employed a qualitative method with in-depth interviews to 9 participants characterized by parents of ASD children and Moslems. Participants were selected from parent communities in PLA (Autism Service Center) Solo, DIY, and SLB Semarang. The results of the interviews were analyzed using the Interpretative Phenomenological Analysis (IPA). The main findings are parents of ASD children: (1) carry out public practice by maintaining *habluminnas* and conducting small *da'wah* by joining Islamic community; (2) conduct private practice by implementing Islamic *fiqh*; (3) instilling the knowledge *akhlak* and *aqidah* in the family for their religious experience; (4) instilling *tawhid* by expressing gratitude to Allah *Subhanahuwata'ala* and believing in His destiny; and (5) instilling religious intellectual dimension by continuing to study Islam, *tarbiyyah*, *tahsin* and *tajwid*. The results of this study can be used as the considerations for future researchers who are interested in the dynamics in families of children with ASD.

*Keywords:* ASD, IPA, Islamic, Religiosity

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### Introduction

The number of people with autism in the world continues to grow. As stated by (Simsek & Koroglu, 2012), the number of people with autism in 1987 was 1 child per 5000 births. The prevalence continued to increase for 10 years, recorded as 1 child per 500 births. Then, in 2000, the prevalence increased to 1 child per 250 births. The data is in line with the incidence of autistic children mentioned by Santosa (2003) that the incidence of autism in the USA, UK, Middle East, and Asia are 1: 250 children. The prevalence of people with autism disorders in Indonesia has also increased yearly (Desiningrum, 2016). The number of children with ASD, aged 5-14 years, was estimated to be approximately 90 thousand in 2010. The total population of Indonesia in 2010 reached 237.5 million with a growth rate of 1.14 percent, referring to data from the Central Statistics Bureau. People with autism spectrum disorders in Indonesia in 2015 were estimated to reach 134,000 and according to the Central Statistics Bureau in 2015 the population of Indonesia reached around 250 million people (Tamba, 2018). The increasing prevalence of children with ASD, including in Indonesia, has created considerable interest for researchers in conducting studies on ASD, including understanding the family circumstances of children with ASD.

According to some researches, parents of children with autism spectrum disorder (ASD) are experiencing stress (Petrongolo, 2014; Weiss, 2002), anxiety and depression (Eturnaud, 2017; Hartley et al., 2010) compared to parents of children with other developmental disorder. Contributing factors to increased stress levels in parents of children with ASD are related to the uncertainty of the child's behavior,

because parents are often unable to predict the behavior of children with ASD, such as the onset of tantrums that can occur at any time (Benson, 2006; Blacher & McIntyre, 2006), and might continue in their adolescence (Allik, Larsson, & Smedje, 2006; Saini et al., 2015). In addition, stress and depression in mothers when caring for children with ASD can be caused by learning difficulties or limited cognitive abilities in children (Bebko, Konstantareas, & Springer, 1987) and low communication skills (Moes, 1995).

External factor which contributes to maternal stress is lack of understanding from the community about ASD, causing parents to get negative reactions from the surroundings, such as scolding children, insinuating parents and even leaving out children with ASD. (Farrugia, 2009; Gr<sup>19</sup> 2003). Besides, conflicts in marital relationships due to children might trigger stress and depression in **mothers of children with ASD** (Hartley et al., 2010; Pottie et al., 2009). All the contributing factors to stress levels of parents of children with ASD pose challenges for parents in caring for their children. Researchers are interested in observing what parents really need in the care of children with ASD.

Positive attitudes in parenting are needed especially in caring for children with ASD. These attitudes, according to several previous research results, are self-efficacy in parenting (Siswati & Desiningrum, 2019), compassionate love in parenting (Desiningrum et al., 2020), self-acceptance in parenting (Rachmayanti & Zulkaida, 2007).

The quality of parenting is also influenced by religiosity. The results of the study suggested that religiosity has a modulatory role in the adverse effects of parenting-related stress on family wellbeing. (Valiente-Barroso & Lombrana-Ruiz, 2014). Meanwhile, the wellbeing of parents can affect the quality of their care for children with ASD. (Cachia et al., 2016). Another research suggested that an individual's behavior is basically influenced by individual's attitude towards religion, both collectively and individually (Behroozi & Pashakhanlu, 2015). Individual behavior is inseparable from the personality.

Research on religiosity related to ASD caregivers has not widely conducted. In Indonesia, whose population is religious, religion is considered as an important factor in daily life, including for mothers of children with ASD, who really need religious guidance to sincerely taking care of their children (Timmons & Ekas, 2018). This research will explore the religiosity of parents in caring for children with ASD.

Islamic parenting begins with choosing a husband or wife who is pious. This is in accordance with a statement by Al-Said (2004) that a man or woman who wants to get married should look for a pious partner. Al-Said (2004) also mentioned several criteria as exemplary parents, namely: a) forgiving and calm, b) gentle and away from rudeness in muamalah, c) merciful heart, d) pious, e) always pray for children, f) gentle in dealing with children, g) managing anger, h) being fair and not favoritism. In addition, regarding to the education of children with ASD in accordance with Islamic principles, there are several items that can be instilled in parents of children with ASD, namely: a) akhlaq and aqidah development, b) worship development, c) community development, d) parental mental development, e) physical development of <sup>33</sup>ents, f) intellectual development of parents, g) health maintenance (Suwaid, 2010). <sup>6</sup> The purpose of this study was to explore in-depth information about the overview of Islamic religiosity of **parents of children with autism spectrum disorder (ASD)**.

### Method

This qualitative research employs a phenomenological approach. Qualitative research methods aim to describe the experiences experienced by individuals (Smith et al., 2009). The purpose of phenomenological research is to capture as closely as possible how the phenomenon is experienced in the context of the occurrence of a phenomenon (Smith et al., 2009). The analytic technique used in this research is Interpretative Phenomenological Analysis (IPA). Interpretation in IPA is conducted in two stages. The first stage is the **participants interpret their life experience** and the second stage, the **researcher interprets the results of the participants' experience** which is commonly called a double hermeneutic (Smith et al., 2009).

The participants in this study were parents of children with ASD in the area of Central Java & DIY, Moslems. Those participants were from parent communities in the PLA (Autism Service Center) in Solo (3 participants), DIY (3 participants), and from SLB Semarang (3 participants). The total number of

participants was 9 participants. All participants were given informed consent.

### Research Instruments

This study employs the theory of religiosity from (Huber & Huber, 2012). Religiosity is a person's ability to interpret and live the teachings of the religion, as well as practice it in worship and daily behavior. (Huber & Huber, 2012; Joseph & DiDuca, 2007).

Religiosity measures the importance of religion and the meaning of religion in an individual's personality. According to Huber & Huber, (2012), religiosity consists of five dimensions, namely::

- (1) Public practice, refers to the social expectation that religious individuals belong to religious communities which is manifested in public participation in religious rituals and in community activities.
- (2) Private practice, which refers to the social expectation that religious individuals devote themselves to transcendence in individual activities and rituals in private space.
- (3) Religious experience, which refers to the social expectation that religious individuals have “some kind of direct contact with the ultimate reality” that affects them emotionally.
- (4) Ideology, which refers to the social expectation that religious individuals have beliefs about the existence and essence of transcendent reality and the relationship between transcendence and human beings.
- (5) Intellectual dimension, which refers to the social expectation that religious people have religious knowledge and they can explain their views on transcendence, religion, and religiousness.

The researcher uses the dimensions of religiosity mentioned above together with the concept of Islamic education theory according to Suwaid (2010), namely: a) akhlaq and aqidah, b) tawhid or monotheism, c) habluminannas, d) tarbiyyah, e) tahsin and tajwid, f) fiqh, and g) da'wah.

### Results and Discussion

The researcher conducted in-depth interviews to 9 participants (one of the parents of children with ASD). The mentioned items below are detailed information regarding the interview.

- The participants consisted of 7 mother participants (5 housewives, 2 employees) and 2 father participants (entrepreneur and government employee).
- The age range of participants was 29-42.
- The age range of children was 4-12, who were diagnosed with ASD supported by medical records from the therapist and field observation based on CARS and CHAT tools (Chlebowski, 2010; Wong et al, 2004) to establish a diagnosis of ASD.
- The interviews were conducted directly (face-to-face interview) at the participants' residences (3 participants living in Semarang) and conducted through video calls using WhatsApp and Zoom (6 participants living in other cities) for 1-1.5 hours for each participant.
- The results of 25 interviews were analyzed using Interpretative Phenomenological Analysis (IPA) method (Smith et al., 2009).

Table 1.  
Findings of Themes in Research

Dimensions of Religiosity	Islamic Dimensions	Themes
<b>Public Practice</b>	Habluminannas Da'wah	1. Joining Islamic community of fellow ASD parents. 2. Sharing experiences and knowledge regarding ASD.
<b>Personal Practice</b>	Fiqh	1. Performing worship according to Islamic fiqh with spouse and children with ASD. 2. Reciting prayers for the wellness of children with



		ASD children and all family members.
<b>Religious Salience</b>	Akhlaq and Aqidah	<ol style="list-style-type: none"> <li>1. Educating children with ASD about helping others.</li> <li>2. Initiating the usage polite words in daily conversations</li> <li>3. Teaching children with ASD to respect their parents.</li> </ol>
<b>Ideological</b>	Tawhid	<ol style="list-style-type: none"> <li>1. Developing a sense of gratitude towards spouse and children with ASD.</li> <li>2. Believing in Allah's destiny.</li> </ol>
<b>Intellectual Dimension</b>	Tarbiyyah Tahsin and Tajwid	<ol style="list-style-type: none"> <li>1. Setting regular time to learn about Islam in the family with children with ASD</li> <li>2. Reciting the Koran together with children with ASD.</li> </ol>

Religiosity affects mother's attitude in raising children (for example in mothers of children with ASD). In Indonesia, a country whose population is religious, religion has remain an important factor that is commonly observed (Padjrin, 2017), including in mothers of children with ASD, who need religious guidance to sincerely taking care of their children. Religiosity is a person's ability to interpret and live the teachings of the religion, as well as put into practice in worship and daily conducts (Huber & Huber, 2012; Joseph & DiDuca, 2007).

Individual spirituality is related to dominant emotional state and spirituality is determined by individual's personal relationship with God. As a result, spiritual and religious components in individuals affect the potential in a person's personal development (Degil & Régnier, 2014).

Religiosity acts as a modulator against the adverse effects of parenting stress which might affect individual well-being and, in turn, the quality of parenting (Valiente-Barroso & Lombraña-Ruiz, 2014). Basically, a mother's behavior is influenced by her attitude towards religion, both collectively and individually, through the basic components of female personalities which are dominated by the affective dimensions (Behroozi & Pashakhanlu, 2015).

Religiosity is considered effective in improving psychological and physical well-being as well as a strategy to deal with stress. Therefore, it can be an important therapeutic aid during parenting process. (Koenig et al., 2004; Koenig, 2009).

In personal practice, according to Huber & Huber (2012), there is a social expectation that religious individuals devote themselves to transcendence in individual activities and rituals in private spaces. Individuals who perform rituals of worship, including in relationships with God and others, will gain the deepest serenity, and cultivate positive attitudes and behaviors. (Valiente-Barroso & Lombraña-Ruiz, 2014). Islam perfectly regulates detailed worship guidelines that must be carried out by its people, which are known as the Fiqh. Parents of children with ASD will realize the essence of solemnity and sincerity in worship, and *istiqomah*. If the parents conduct worship according to the guidelines, then Allah Subhanahuwata'ala will give them the best destiny known as the children with ASD that Allah has entrusted them with is a place of worship and will take them to heaven. Parents who are religiously Islamic are faithful and devoted parents who always pray for the best for their family.

In addition, individuals who have undergone many religious experiences will increase their belief in the existence of God their awareness of their limitations, continuing with their intellectual dimension, so that they believe more in God's love. (Huber & Huber, 2012). The religious experience can also be obtained from an individual's childhood when receiving religious teachings from their parents then the teaching is continued to be practiced and applied in an individual's life after getting married and having children. (Forrest-Bank & Dupper, 2016). Parents of children with ASD have their belief in the existence of Allah Subhanahuwata'ala with His destiny and provisions, so that they are more confident in carrying out worship and living the guidance to live in the way of Islam, namely in akhlaq and aqidah, so that they will be afraid to do things prohibited by Allah and always behave in accordance with Islamic law. The

house will be in line with Islamic guidance that reassure the day, such as teaching children and spouses to always speak politely, respecting the elders and loving the younger ones, telling the truth, taking care of each other between siblings and friends.

In caring for children with autism, parents should be patient. In religious terms, patient is often expressed as sincerity because they only hope for God's love to ease the burden of having children with autism (Behroozi & Pashakhanlu, 2015). Adaptive responses to distressing and stressful events – such as child abuse – are partly determined by an individual's religiosity (Dupper et al., 2015). In parents of children with ASD, religiosity is needed when coping with burdens and stress, as well as fostering positive attitudes in caring for children.

Public practice refers to social expectation that religious individuals belong to religious communities which is manifested in public participation in religious rituals and in community activities. (Huber & Huber, 2012). Parents of children with ASD who are prone to stress and depression need individual closeness to the Creator and with fellow parents of children with ASD. In the community, parents will share experiences about their children, including how they take care of their children and carry out their therapy. In this case, the togetherness builds self-assurance that the parents are not alone (Dieleman et al., 2018). There are many parents who have experienced similar thing, so gratitude will be embedded. The gratitude can be shared to other parents of children with ASD, so that it can be a medium of da'wah which is full of merits.

Ideological dimension refers to the social expectation that religious individuals have beliefs about the existence and essence of transcendent reality and the relationship between transcendence and human beings (Huber & Huber, 2012). When a mother of children with ASD understands her religious ideology, it can be said she needs full awareness of her essence as a creature with limitations. When parents of children with ASD realize their limitations in the midst of awakened gratitude, it will form faith and piety, belief in the oneness of Allah Subhanahuwata'ala. Parents of children with ASD will accept God's destiny sincerely and believe that there will be many lessons and merits. Parents of children with ASD will also teach their spouses and children to always return and surrender to Allah Subhanahuwata'ala.

In intellectual dimension, individuals recognize the social expectations in which religious people have religious knowledge and they can explain their views on transcendence, religion, and religiousness. (Huber & Huber, 2012). In Islamic Studies, parents of children with ASD will cultivate a culture of learning Islam in their families of children with ASD. Parents will always be curious for Islamic knowledge to be learned through various Islamic studies on YouTube channels or on Islamic television broadcasts, visiting various recitations, or reading Islamic books. In addition, the priority of studying the Koran is a priority in the family, such as deepening the knowledge of tahsin and tajwid, which are also taught to children with ASD by sending them to Islamic schools. There were few complaints from some participants who stated that they have not undergone Islamic autism therapy, and this could be a suggestion for further development of Islamic psychology related to ASD interventions.

This study has two limitations. The first is the challenge in determining the schedule of the interview due to the activities of the participants in caring for their children and conducting their routines at work. Second, there are obstacles in obtaining participants with the diagnosis of ASD. Researchers had tried to contact the hospital and therapists as well as visited participants who were in the same city as the researcher. As a result, the research data was diverse, due to differences in interview media (face to face and via Zoom/WhatsApp video calls) which might affect the results of observations of participants and children with ASD.

### **Conclusion**

This qualitative study suggests an overview of Islamic religiosity of parents of children with ASD, which is a combination of the theory of religiosity according to Huber & Huber (2012) and Islamic education according to Suwaid (2010). The main findings are that parents of children with ASD: (1) carry out public practice by maintaining habluminannas and conducting small da'wah, namely by joining the Islamic community with fellow parents of children with ASD and sharing experiences and knowledge related to ASD; (2) conduct private practice by practicing Islamic jurisprudence, especially in terms of

performing Islamic religious rituals; (3) live a religious experience, by instilling akhlaq and aqidah in the family; (4) have an ideological understanding by instilling monotheism in the form of gratitude to Allah Subhanahuwata'ala and believe in His destiny; and (5) instill religious intellectual dimension by continuing to study Islam, tarbiyyah, tahsin and tajwid by studying the knowledge of Islam and reciting the Koran. The results of this study can be considered for future researchers and other scientists who are interested in the ASD family and the Islamic dynamics within it. For example, observing the influences of deep understanding of Islamic knowledge on the development of children with ASD and family welfare.

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