Parental stress coping strategies used by parents of children with Autism Spectrum Disorder and the role of Nurses

Mona Mahamed Abudllahi
### Abstract

Autism Spectrum Disorder (ASD) is a long-lasting disability that affects 1 in 160 children in the world. It has been reported that Autism begins in childhood and remains in adolescence and adulthood while some people live with it independently, others may develop severe impairment that requires long-term care and support. Parents raising children with ASD encounter numerous challenges that may lead to stress, anxiety, and depression.

The purpose of the study is to investigate what stress coping strategies can be used by parents of children with ASD in order to manage stressful situations and maintain a better life for their children. Also, the study investigates the role of nurses in caring and supporting children with the Spectrum as well as educating and guiding their parents with accurate information and resources about ASD. The study is done through a qualitative literature review using an inductive approach. Nine articles were analyzed and used for the study.

Resilience Model for Family Stress, Adjustment, and Adaptation is used for this study as a theoretical framework.

Results of the study show that parents of children with ASD can adjust the situation by using certain types of coping strategies through personal, family, or friends and community resources. The study also found that religious coping strategies were thought to be effective for some parents. Nurses play an important role in caring, advocating, and supporting children with ASD. Nurses also have basic responsibilities in educating and guiding the parents who are desperate for answers and comfort when going through adversity.

### Keywords:

- Autism Spectrum Disorder
- Parental stress
- Coping strategies
- Nursing role
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<td>Autism Spectrum Disorder</td>
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<td>CDC</td>
<td>Centers for Disease and Prevention</td>
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<td>NIH</td>
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<td>HUS</td>
<td>Helsingin ja Uudenmaan Sairaahoitopiiri</td>
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<td>WHO</td>
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1 INTRODUCTION

Children with Autism Spectrum Disorders (ASD) are not physically ill or disabled such as someone with brain injury. ASD are mostly characterized by some or all of the followings: 1. Difficulties interacting with others or socializing with other people 2. Communication challenges and 3. Repetitive behaviour (National institute of Mental Health 2017).

The term ’’Spectrum’’ refers to the wide range of symptoms, skills, and levels of impairment that people with ASD can have (National institute of Health 2017). The symptoms of ASD might be more severe on someone and less on the other. The below picture illustrates the primary symptoms of ASD and other medical conditions and challenges that are associated with it. These might also be different in severity (Viscidi et al. 2013).

Evidences suggest that some children might develop very noticeable ASD issues such as Gastrointestinal Disorders, Seizures, Anxiety and Sleep Disorders while others might not. However, the core symptoms are differences in communication, social skills and behaviour challenges, compared to those who are not on the ASD (Viscidi et al. 2013). However, Hodge et al. (2014) presented that sleep disorders are not part of ASD diagnostic criteria although it is more common in children with ASD than atypical child.

The main focus of this study is not to explore ASD, its cause and treatment, but rather to investigate ways in which parents of children with ASD cope with the challenging situations related to the child’s ASD. The researcher has also focused on examining literature evidence supporting the role of nurses in supporting, caring and protecting of parents of children with ASD and their loved ones. The study is commissioned by Kiki Metsäranta, the head nurse of the HUS Pasilan nuorisopsykiatria kuntoutuspoliklinikka.
2 BACKGROUND

According to the study of Tek & Landa (2012), Autism Spectrum Disorder (ASD) is a name for a group of developmental and behavioral problems that affects how the brain works. ASD occurs universally, regardless of race, nationality, culture and social class, it has a tremendous impact on the individuals it affects, their families and society. These next chapters discuss ASD and its impacts on parents of affected ones, as well and what coping mechanisms are used in order to diminish parental stress and maintain family functioning.

2.1 AUTISM SPECTRUM DISORDERS

The World Health Organization has described Autism Spectrum Disorder (ASD) as group of complex disorders of brain development that include impaired social interaction such as difficulties in verbal and non-verbal communication and speech along with repetitive or stereotyped behaviors and often narrow range of interests and activities that are both unique to the individual. Individuals with autism can experience a type of sensory sensitivity to different sensation such as touch, sounds, taste, light and tempera-ture and pain. For example, different background sounds of environment which rarely interrupts other people may make autistic person sound harsh and distracting while causing them feel anxiety as well as physical pain (WHO 2017).

It is estimated that 1 in 160 children has an ASD globally, this estimate however represents an average number and reported incidence differs significantly across studies as some successfully studied restudies conveyed higher prevalence figures of ASD. The incidence of ASD appears to be increasing globally due to better awareness as well as better diagnostic tools (WHO 2017). The In addition to this, Centers for Dis-ease Control and Prevention (CDC) has estimatedtve identified that in Europe, Asia and North America the rate of individuals with ASD is between 1 % to 2 % (CDC 2017). A recent study revealed that ASD has no known etiology or cause, but genetic factors and gene-erironments are beleived to play an important role in developing an ASD (March.2017). The
diagnosis of ASD is initially based on patient assessment and can be done as early as the age of one year if there is severe intellectual and language impairment (March 2017).

In Finland, 1% of the population is said to have ASD which is estimated to be about 54,000 of the people in the country. Diagnosis, support and rehabilitation for individuals with ASD as well as other services provided by the society vary in different parts of Finland. Individual support can be needed in all stages of life but the nature of support may change with age whilst rehabilitation aims at promoting the ability to function and maintain self-confidence in everyday life tasks. These services need a multi-professional cooperation between autistic individuals, their families and the staff at their environments (Austisimi-ja Aspergerliitto 2017a).

2.1.1 ASD in Finland, treatment, support and rehabilitation

Keilinen (2005) has studied the significance of assessment, habilitation and treatment of children and adolescents with ASD, because those children need special help and adjustment of daily activities to reduce the risk of social and educational failure. School settings being one of the most challenging places, therefore, professionals at schools, in hospitals, daycare centers and other institutions were trained to use therapeutic interventions in everyday life. ASD has no actual treatment but since depression is common in children with ASD, doctors may prescribe antidepressant medicine for some children.

According to Keilinen (2005), in Finland, children with ASD are offered treatment, care and rehabilitation programs. In addition to that, therapeutic interventions based on understanding the condition and the special-need support are highly accessible for both children and adolescents. Such therapies include speech therapy, social skill interventions, sensory based therapies that involve the body’s abnormal response to the external stimuli and occupational therapy, however, children with ASD have the choice to whether participate such therapies or not (Keilinen 2005).

Keilinen (2005) also outlined the importance of assessment, habilitation and treatment of children and with ASD, because those children need special help and adjustment of daily activities to reduce the social and educational failure. School settings being one of the
most challenging places, therefore, professionals at schools, in hospitals, daycare centers and other institutions were trained to use therapeutic interventions in everyday life. Evidences suggest that an assessment concerning the assistance and support need by the child with ASD and his or her family is the first step to be made. During the assessment, the parents of the child can talk about their situation and reveals their own concerns but family-based care plan must be made first. This includes helping child’s parents to be more active in consultations, making-decisions and professionals being mindful and informative whilsts guiding them to the best possible plan for their child. After the assessment is completed, its necessary to combine the perspectives of the healthcare professionals and that of the parents in order to decide what form of support and services can be found for the situation, meanwhile, the goals set by the parent guide the planning and the finding of the support (Autismi-ja Aspergerliitto 2017b). Home visiting and follow-ups are also provided for such children and their families, these has been reported to have a good outcome with normal or near normal social life despite certain difficulties in social relationship at school and other places (Keilinen 2005).

2.1.2 ASD and parental stress

Dabrowska & Pisula (2010) have described the challenges of family functioning. They noted that parenting a child with disability specifically a child with ASD can be very stressful and challenging. There are many studies investigating the impact of a child with ASD in the family system. Parents caring a child with ASD are reported to have higher risk of stress, anxiety and depression that could affect negatively family functioning and martial relationship (Weiss et al. 2014, Hartley et al.2015).

The aspects of family life that may be affected by the child's disability include:
Family recreation - this is one area that can be affects by the ASD because due to the unpredictable behaviour of the child that some children with ASD often exhibit. Emotional and mental health of the parents is also an area affected by the child's ASD. parents may feel depression and social-phobia in addition feeling of guilt, anxiety, loss and anger in reaction to many of the challenges they face (Weiss et al 2014).
The word “stress” has been defined by many researchers in different ways. Researcher and endocrinologist Selye (1978, p.4) has defined stress as “The non-specific response of the body to any demand for change”. Equally, Humphrey (1992, p.15) found that “stress can be considered as any factor, acting internally or externally that makes it difficult to adapt and that induces increased effort on the part of the person to maintain a state of equilibrium both internally and with the external environment.

As narrated by Weiss at el. (2014), studies have shown that parents of children with ASD have reported higher level of stress, depression anxiety that could to poor parenting. Any source that makes change in the family system is seen as “stressor”. These changes may have the possibility to change the family functioning in many ways including rela-tionship between parents as well as relationship between siblings and health status of the family members (Hall et al. 2012). Clearly parenting a child with ASD can be a source of huge stress and the level of family stress is higher compare to families of typi-cal development child. In addition to that, the challenge faced by the parents is extreme if their child poses atypical ASD symptoms such as emotional, behavior and communi-cation problems (Dabrowska & Pisula 2010).

ASD is a long-life developmental disability that takes away some of the most rewarding aspects of human experience from those that it affects, Language and communications skills as well as the ability to give and receive love are noticeably impaired. They have also difficulty in sharing ideas while establishing relationship with others. However, it not only the individuals with autism who experience these defeats, but also his or her family. Parents of children with ASD endure more complications because caring an autistic child require extra guidance, support and supervision for child’s distinct needs. It is also worth noting that these burdens and stresses mostly fall more heavily on mothers than on fathers (Marshall & Long 2009). Likewise, Weiss et al (2014) studied that parents of children with ASD have higher levels of emotional and psychological well-being due to the demands of caring a child that has a complex needs while trying to balance and manage the responsibility and the well-being of the rest of the family. These chal-lenges can sometimes cause arguments, fatigue and stressful events resulting family crisis. Bluth et al (2013) have also found that couples parenting children with autism suffer higher rate of separation and divorce compare to other couples of children with other
disabilities. The researchers thought that this is caused by the ability to adapt stressful situations where couples struggle to manage stable relationship between them. When come to Caring for the disabled child, couple’s separation and divorce make the situation harder. Another study shows parents raising a child with ASD are exposed to stressors within the family as well as stressors from external sources when campaigning health, social and educational services for their child. It is also common that parents of children with ASD have limited number of contacts within the community because friends, families, teach-ers and the community as whole may not fully understand behavior characteristics of an autistic child (Twoy et al. 2007). Regarding this even if children with ASD get proper health care services, autistic disturbing behaviors often continue making socializ-ing challenging and limited for families (Hall 2012).
3 THEORETICAL FRAMEWORK

Stress and Coping Theory, Resilience Model of Family Stress, Adjustment and Adaptation is used for this study. The Resilience Model is a capacity based model from the family stress theory, adjustment and adaptation (McCubbins & Thomp-sons 1983). The importance and emphasis of the model is family’s ability to maintain health stability in spite of adversity. It provides ways in which family functions and copes with stressful situations such as loss, gains, strains and transitions as well as acute and chronic illness. The author has chosen the resiliency model because it helps to explain one's ability to restore or adjust to stressors arising from life-events and changes (McCubbins & Thomp-sons 1983).

McCubbins’ Resiliency Model for Family Stress, Adjustment, and Adaptation is com-posed of two distinct phases: the Adjustment Phase and the Adaptation Phase. Each phase describes the family's ability to cope with illness, or stressors looking at family resources, problem copin/solving abilities or strengths.

Adjustment phase: family inter into an adjustment phase when a stressor is intro-duced in to the family system or family unity and health status is changed. In the adjustment phase, the family is highly vulnerable to crisis situation because of life changes and other factors (pileups) that might already be present before the diagnosis (McCubbins & Thomp-sons 1983). The Model suggests that the family’s vulnerability is manipulated by a pile-up of stress and tension that are present at the same time as the stressor

Adjustment phase: family recovering, re-silience, balance and their patterns of function-ing, stressor appraisal, problem-solving and coping strengths, and family’s resources act together to formulate the level of adjustment in the family (Twoy et al. 2007 the study also noted that fami-ly’s interpretation (appraisal) of the stressor interacts with family’s problem-solving and coping strategies. How family interprets the stressor affects the family’s ability to adjust to the stressor. The family may see the situation as being either minor or major(McCubbins & Thomp-sons 1983).
McCubbin's & Thompsons (1983) explained that during the adjustment phase the family tries to protect itself from change by engaging three adjustment coping strategies: a) avoidance b) elimination and c) assimilation. Avoidance involves in ignoring or denying the presence stressor and its demands expecting that it will finally disappear. Elimination involves taking action to remove the demand by elimination or changing the stressor. Using assimilation, the family captivates the demands created by the stressor. If the family gains positive coping strategies, bonadjustment will occur, meaning that the family progressing through the situation by achieving maximum potential needs for the functioning of the family and its interaction with the community e.g. Health care system, school and workplace. If the family is unable to adjust the stressor events positively (bonadjustment), then maladjustment will occur and the family will need to learn and utilize new strategies that might help.

**The adaptation phase** is very challenging phase in which the family attempts to meet the child’s unique needs (Twoy et al. 2007). Family goes under process of accepting the ASD diagnosis as well as the challenges resulting from the childs ASD, and main family values and goals. Since adaptation phase is crucial for survival, the family tries to gather new approaches to patterns of functioning, appraisal, problem solving, resources and coping strategies (McCubbins & thompsons 1983).
Figure 2 illustrates McCubin Resilience Model for family stress, Adjustment and Adaptation.

![McCubin Resilience Model](image-url)

**Figure 2**: Resiliency Model (McCubbin & McCubbin 1996).

The Model illustrates the two phases which parents responses to the stressful events. In phase 1, McCubbin highlights these patterns: First phase:

1. Illness/stressor
2. Family Vulnerability due to life changes and pileups
3. Family types and established patterns of functioning.
4. Appraisal of illness stressor and its severity.
5. Problem solving and coping
6. Family resistance resources
7. If family has positive coping patterns of resilience, family strengths and resources
bonadjugment will occur. (Bonadjugment: Meeting both the needs of individual
family members to enable them to achieve their maximum potential and also the
functioning of the family system and its transactions with the community (work-
place, school, health care system).
8. If the family is unable to cope, or adjust then the pattern is one of maladjustment,
or a crisis situation.
9. The family then enters the second phase of the stress and coping process: the ad-
aptation phase.

Patterns of the second phase of the Model include:

1. Family crisis situation
2. Pile-up: Stressors, strains, and transitions.
3. Family types and newly instituted patterns of functioning.
4. Family schema appraisal and family meaning
5. Situational appraisal of family's capabilities
6. Problem solving and coping
7. Social support
8. Family resources
9. Bonadaptation (positive coping and adaptation)
10. Maladaptation or continued crisis situation and need for referral and assistance.
4 AIM OF THE STUDY AND RESEARCH QUESTIONS

The main purposes of this study is to ingestigate the stress coping strategies that could be used by parents of children of Autism Spectrum Disorder in order to overcome stressful situations as well as challenges relating to the child’s symptoms. The study ingestigates the nursing role among children of ASD and their families as whole. The searcher do this by exploring the most recent scientif peer-viewed arctiles about this phenomena. Therefore, the study seeks answers for these two questions:

1. What are the stress coping strategies for parents of children with ASD?
2. What is the role and what are the responsibilities of nurses in caring, protecting, supporting and guiding these children and their parents?
5 METHODOLOGY

Methodology philosophical framework within which the research is conducted or the foundation upon which the research is based (Sherri 2011). This chapter of the thesis will explain the method in which the author has collected the data from existed literature and how it has been analyzed.

The author has conducted literature review of the interest topic that is based on existed literature through a qualitative research method ‘Literature review evolves in searching the published studies to ensure that you have a gasp of all the research that has been conducted in that area that might have been relevant to your intended study’ (Sherri 2011).

The content analysis used in this work is inductive contact analysis. Elo and Kyngäs (2007) explained that content analysis method has been used in nursing process for a long time and in an inductive analysis, the researcher has to organize the qualitative data by coding, creating categories and abstraction. This means that the author has summarized and investigated relevant previous studies on coping strategies for families with autistic children and role of nurses in order to find out answers for the research questions.

5.1 Data collection

Relevant articles were searched from Arcada university of applied science by using nursing search engines Academic search Elite (EBSCO), Science Direct, Sage Journals and PubMed articles. Also Google scholar is used in cases where full articles were not successful to get through arcada libguides.

Initially the heading of the articles were checked and abstracts of the suitable articles were read in order to access and assess the relevant ones. After that all the articles concerning autism in children, Impacts of autism, family stress and autism family coping were chosen for thesis work. Furthermore, studies focusing on mainly Europe where taken a plus. The keywords used in the research field were ‘Autism, children, impact of autism, family/parents, stress, coping strategies, role of nurse, autism care. Then under each category were searched same meaning words, for example Autism AND family, Autism AND coping strategies.
In EBSCO and CINHL the combination of AND/OR were used such as: Autism AND Family or Autism OR autism spectrum disorder. In Google scholar, PubMed, SearchGate and Sage, articles were searched in a sentence form like: Coping strategies for families with autistic children, role of nurse in supporting parents of autistic children. All together these searches produced a total of 245 articles about autism and family issues which were too much for the author to review. The author then observed precisely and chose those articles that aim at the main search questions rather than Autism as general.

The author has used variety keywords and phrases in to various search engines for data retrieval. The first keywords used were: ‘Autism spectrum disorder’ AND “stress” And “family” in Academic search Elite (EBSCO) and in (CINHAL), resulting 11, 43 and 534 articles. After that, advanced search (peer viewed articles, full free text and journals published between the years 2000-2017) were conducted which resulted 21 articles, then ONLY 4 articles that seemed relevant to the main questions of the thesis were selected from these 21 articles. Another search was done in ‘Science Direct’ with the keywords; ‘Autism impacts’, 18,245 results limited to the years 2010-2017 were found but ONLY 2 articles were selected for the study.

The second search was ‘Sage journals’. In the advanced search, 6042 articles were generated. The published years were limited to 2000-2017 and ONLY articles having concerning ‘autism and parental stress’ were selected. After exclusion, 4 articles selected for reviewing.

The final search engine was ‘PubMed database’ with the advanced search and the same above procedure was used. Keywords used were: ‘Autism Coping strategies’Impact of autism ‘Autism and Role of nurse’. Which produced 58 articles. The number of articles were reduced according to the relevancy of the thesis topic as well as latest 17 years. The relevant results were adjusted to 2 articles. Altogether, 12 articles has been reviewed and implied for the exclusion and inclusion process by reading titles and abstracts. In the last phase of the process, 10 articles were selected for this thesis. This is done by applying inclusion and exclusion criteria as seen in Table 1.
Table 1. Inclusion And Exclusion Criteria

<table>
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<th>INCLUSION</th>
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<tr>
<td>Articles written in English language</td>
<td>Not free accessible articles</td>
</tr>
<tr>
<td>Free and full PDF</td>
<td>Articles published before 2001</td>
</tr>
<tr>
<td>Articles focus on coping strategies for families of children with ASD</td>
<td>Articles focus on mainly ASD as general disorders, diagnosis, management</td>
</tr>
<tr>
<td>Articles focus on stress coping strategies for parents</td>
<td>and medication</td>
</tr>
<tr>
<td>of children with ASD</td>
<td>Articles written other languages than English</td>
</tr>
<tr>
<td>Articles containing role of nursing in support autism families</td>
<td>Articles focus ASD in older people</td>
</tr>
<tr>
<td>Articles published from 2001 onwards</td>
<td>All articles that were not relevant to the topic</td>
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After applying the above criteria of exclusion and inclusion, the following ten articles were chosen to answer the research question of the study:


5.2 Content analysis

Researchers Elo & Kyngäs (2007) classified content analysis as a method of analyzing written, verbal of visual communication messages. In a research method, content analysis is systemic and objective means of describing and qualifying phenomena. In nursing it is mostly used in psychiatry, gerontological and public health studies. It is a process of making replicable inferences from data to their context with the purposes of proving new insights, knowledge, representation and parcticalical guide to action which allows the researcher to test theoretical issues to enhance under-standing of the data. Content analysis can be used with either qualitative or quantitative data together with inductive or deductive way and the type of these is used determines the study. If there is no enough knowledge about the phenemon or if this knowledge is fragmented, then inductive method is recommended (Elo & H. Kyngäs 2007). Therefore, as a result of the above statements, inductive content analysis was used to analyze the data collection of this study. The method of inductive content analysis included open coding, creating categories and abstuctions. Hence, the author started the analysis process by reviewing the research questions and searching relevant content. Questions of the study were first laid out correctly correspondingly to the topic of the study. As for question one of the study: 1. What are the stress coping strategies for parents of children with ASD? The main focus was achieving appropriate/relevant content for stress coping strategies for families with ASD. The second question of the study: How can nurses support and guide parents of children with ASD? The main focus was nurses responsibilities in supporting, caring and managing both children with ASD and their parents

5.3 ETHICAL CONSIDERATION

Collections and data analysis of all research studies are subjected to ethical considerations. The researcher must outline and provide accurate information about his work and avoid any risk of inconveniences and embarrassment of the study as it is not only im-
important for the ethical rule but also for the practical rule which can lead to rejection of work by the supervisors, criticism and low mark (Candy 2005).

In consideration of foregoing, the author has tried to follow minimize any risk of invalidation and bias by following Arcada thesis writing guidelines. The author discussed about the topic and the process of the writing with the supervisor as well as the commissioned clinic. All the materials in this study were collected from Academic databases and the collected articles used in the study were referenced according to Harvard referencing style.
6 FINDINGS

This study investigates and focuses on how families with an autistic children can cope with the condition and what kind of support and services are available for them. In this chapter, the author will discuss parental stress caused by the child’s autism and what coping strategies have been used over the past by parents of ASD children. Many re-searchers have discussed coping, stress and families but there were no single conclusion of how parents with autistic children can cope with the challenging situation. As seen above, studies have shown that parents raising children with ASD can use variety coping strategies depending on their appraisal of the stressor. Both formal and informal supports were very helpful for family coping and adaptation.

6.1 Parental Stress coping strategies used by parents of children with ASD

As the number of children diagnosed with autism is increasing globally, parents of children with ASD and their families must be provided with resources in order to get help for their unique circumstances and decrease anxiety and stress levels by using beneficial coping strategies for the whole family (Hall et al. 2011). As a matter of fact, managing the challenges of the stressors is important as the outcome can result uncontrollable or even crisis.

Coping strategies have been noted as one mechanism by which individuals tend to respond to intimidators of stress such as stressors related with parenting a child with autism (Benson 2012). Based on Benson’s study there are two general types of coping strategies for parents of autistic children: Problem-based coping (strategies designed at solving the problem or doing something to change the cause of stress) and emotion-based coping (strategies used at reducing or managing feelings of distress related with stressors). According to Benson (2012) parents who use emotion-based coping strategies have found to face high psychological distress and emotional well-being while those parents who use the problem-.based coping strategies such as taking about the problems and planning have mostly but not all experienced positive outcomes such as improved mental health as well as less stress endeavors.
Benson (2012) indicated his research that burdens and challenges caused by raising a child with autism can cause emotional distress for some parents. Nevertheless, it is also important to mention that parents vary in considerable amount on how to successfully react the challenges associated with their child’s autism. Some parents experience huge mental health problems and physical distress while some parents experience relatively few of these distresses. In addition to that, even though the level of stress experienced by parents of children with autism is high, many families have coped the unique challenges of ASD successfully (Gray 2006). Some parent’s report that despite the distress caused by autism, their children had positive effects on coping with stress (Hall 2012). Parents may use different approaches when coping with stress caused by child’s ASD. Meadan et al (2010) described the two approaches of coping; problem-avoidance and problem – oriented approaches. In the oriented approach of coping, parents conform to the situation by look for information about it, observing it and trying to resolve it, whereas in avoidance – oriented approach, parents try to take no notice of, the stressor, by denying or minimizing. A recent study conducted by Roberts et al. (2017, p.4) suggested that these parents could think of ”factors leading to positive changes including developing support systems, diminishing child's troubling behaviors, and focusing on the child's positive attributes. Parents may rely on friends and spirituality for support and use techniques to reframe the situation in a positive light, such as minimizing the impact of other people's opinions about their child”

Bruth et al. (2013) illustrated three levels of family resources that are available to the family in order to support when demanding or stressful situation is introduced into the family system. These resources include: a) Personal or individual resources b) Family system resources and b) Community resources.

**Individual resource:** According to study of Bruth et al (2013) individual resources play an important role in family's ability to perceive and adapt stressful life events. Individual resources are described as "personality variables and cognitive coping strategies and beliefs, as well as more demographic factors such as education and employment status” (Bruth, et al 2013). Bruth et al. (2013) investigated how individual resources can influence coping strategies of autism spectrum disorder. As has been noted, parents who practice positive coping strategies (e.g. seeing the stressor in optimistic way, task-oriented)
diminish the degree of positive outcome and hence increase the degree of positive outcomes. Apart from this, Bruth et al. (2013) also looked at how other individual characteristics such as education and employment status can affect the outcomes experienced by both parents of children with ASD. With regard to that, evidence showed that mothers of children with ASD experience negative outcomes compared to fathers of children with ASD. Altogether, individual resources play major role how parents of children with ASD experience stress and cope with it (Bruth et al. 2013).

**Family resources:** Parents of children with ASD need variety range of coping strategies that are relevant for the stress and challenges they face (Hall 2012). Family support is seen to have positive role in family’s coping and adapting the stress caused by the child's ASDs. Another literature reveals that parents who use supports that come from both within the family and outside family have adapted to the stress and challenges more easily by applying positive coping strategies (Meadan et al. 2010). According to Bruth et al (2013), family is viewed as one unit, therefore families who are connected to each other more closely as a functioning style use positive coping mechanisms.

**Community resource:** Research presented that community resources such as support from social or health institutions as well as religious groups improves family coping and adaptation (Hall 2012). Community support is known to be an effective strategy for easing parental stress and improve coping. Community support may not sometimes be available or accessible for every parents of children with autism equally therefore, professionals could help in improving family adaptation by offering reinforcement and supporting intervention programs and community and family-support meetings. Families who surrounded by devoted resourceful support systems are capable of coping and adapting to the challenges better than with little or no support. Parents often report that the most effective support usually comes from a partner or spouse and the second most effective comes from informal kinship including children, friends and other parents or religious organizations. Hall & Graff (2011) also revealed that according to the parents’ opinion, social support such as schools, day-care, social clubs, parent groups and co-workers were the least helpful support of coping with their child’s autism (Hall & Graff 2011). These authors also stated that availability to and use of social support could lead to decrease in
stress, anxiety and depression for parents of children with ASD along with improved life satisfaction for both mothers and fathers.

Apart from the those resources mentioned, study has revealed that some parents of children with ASD used religious or spiritual resources as a coping strategies (Tarakeshwar & Pargarment.2001). Researchers Mohsen et al (2015, p.141)) defined the term religion coping as “a technique through which people exploit religious beliefs and rituals to deal with the problems and pressures of life”.

Tarakeshwar & Pargarment (2001) discovered the role of religion as coping mechanism in families of children with ASD. The study discussed the effectiveness of religious coping among parents of children with ASD and other disabilities. The study has identified certain forms of religious coping such as seeking support from clergy or church members, benevolent religious appraisals, seeking spiritual support, discontent with congregation and God, negative religious reframing and expressing interpersonal religious discontent. Some parents of children with ASD perceive the illness as a will of God or as an opportunity for spiritual growth. Mohsen et al (2015) also found out that parents who used religion as stress coping strategies have reported both positive well as negative outcomes.

6.2 Role of nurses

It is obvious that grief, confusion, frustration and shock are the initial reactions of parents of children with ASD after the ASD diagnosis, as they realize the unending nature of this disability as the child grows through developmental stages (Lutz et al. 2012). Studies presented how nurses could ease the distress that parents of children with ASD experience these parents usually have many questions and much to learn as they manage the disorder and try to create meaningful lives for their children and themselves. Therefore, helping families understand both features of autism and the diagnostic process is key to supporting family acceptance of the diagnosis. Nurses can also assist families in navigating the common process of grief and adjustment right after diagnosis. Nurses at all practice levels regardless of what settings they are working are repeatedly asked ISSUES related to the health and development of the child, thus nurses are expected to work with parents and
children closely so that they can help educate, advocate for and adequately manage the care of the children (Dodd Inglese et al. 2009). As we have seen in the above literature, psychological and physical needs and the energy and time required to care for a child with ASD presents numerous trials for the parents (Lutz at el 2012). With regard to this, it is also important for nurses to research the impact of ASD with in the family. Heiddi and colleagues believe that nurses should carry on family based nursing research by focusing on the child within the context of the family, this could led them understand the family unit well. In addition to that, nurses should be able to educate parents, support families, manage general issues relating ASD and advocate those children and their families (Inglese M. 2009). Addition to that, the study described the importance of early identification of children with ASD to ensure that they get target support for both parents and their children for better quality of life. According to Dodd Inglese et al (2009), it is important that parents raise any concerns about their child’s milestone development to the primary care nurses, but whether these con-cerns are raised or not, it is crucial for nurses to know that the power of observation is often greatly underestimated. The nurses are in the best position when interacting with the child and particular attention should be paid on how the child interacts with his or her parents. It should be observed whether the child responds to the parents when called by name as well as whether the child makes an eye contact, looks at things when they are pointed at and any behaviors that may appear in a hypersensitivity to stimuli such as sounds, light and touch. On the other hand, nurses should try to obtain additional in-formation from the parents by asking specific questions targeted to obtain helpful in-formation. Another study conducted by Pinto-Martin et al (2005) has found that in order nurses to care for children with ASD, they should be well prepared, being creative and humble with sense of humor smooths the process of care as well as the interpersonal re-lationship between nurses, the child and his or her parents. To reach an optimal care, nurses need to do an assessment prior the actual visit of the primary care setting by enquiring the child’s parents because parents are more knowledgeable and are an excellence resource for nurses providing care for the child.

Authors Dodd Inglese at el. (2009) has identified the roles and responsibilities of school nurses towards children with ASD and their families. The study suggested that nurses working with schools have considerable role when working with those chil-dren and their parents. The nurse must knowledgeable and careful assess the child’s need because every
child with ASD is unique and therefore have unique needs (Dodd Inglese et al 2009). Some of important the responsibilities of school nurse for children with ASD include: Safety, the child may have some health related issues relating with ASD such as epilepsy and seizures, it is therefore important for school nurses to assess and aware of any injuries. Furthermore, school nurses, should assist parents, children, and school personnel in planning, intervening, and coordinating services for these families and their children, who are at risk for academic failure and social isolation (Lobar et al 2008). On the other hand, research conducted by McIntosh et al (2015) has indicated that the primary role of school nurse is to improve children’s health and learning success by giving support and understanding the disability. Some of the roles and responsibilities of school nurse include:
7 DISCUSSION

The study shows that the child's ASD can have a huge impact on the entire family on a day-to-day basis.

This study aimed at describing the stress coping strategies that can be used to manage stressful situations and accept the challenges caused by the child’s ASD. First, results found show that raising a child with ASD puts huge strain on parents due to the challenging characteristics of the child and tremendous demands such as time, energy, welfare and future parents of children with ASD tend to have challenging situations while every child with ASD is unique with unique needs and represents unique challenges. Children with ASD may exhibit symptoms of physical and psychological deficits which cause anxiety, emotional distress, depression as well as negative parenting and parent/child interactions. Furthermore, parents of children with ASD have reported difficulties in searching for resources, societal isolations, confusion, burnout and financial strains compared to parents of children without ASD. In addition, studies have shown that parents of children with ASD have higher risk of depression and other mental problems resulting from the multiple autistic symptoms and behavior challenges of children with ASD which may contribute high parental stress, particularly with regard to their ability to relate the child (Boberts et al. 2017).

Studies also have shown that parenting child with ASD adds huge responsibility to the family’s day life, because parents have usually enormous obligations in caring and nurturing other members of the family plus taking care of the autistic child and managing his or her problematic behaviors (Weiss et al. 2014). Low marital satisfaction was also common among those parents. This may be the fact that the parents caring for children of ASD constantly suffer from fatigue resulting arguments between the couples. Stress from extended family, discrimination and stigma from the larger community may also contribute to the parental stress. Parental stress and psychological distress is a common factor among these parents although the level of stress and psychologic distress could be measured differently depending on the parents' adaptation to the stressor, coping strategies
and availability of support. Secondly, stress coping strategies used by these parents included: Problem focused strategies such as Seeking for social support such as support from internal and external families, friend’s special groups and healthcare professionals and emotional focused coping strategies whereby parents try to evade negative responses that may lead to stressful events, feeling guilty, anxiety, depression and frustration.

Findings of the study also show that parents of children with ASD have two phases of coping strategies when a stressor is brought into the family’s life; Adjustment phase and adaptation phase of the stressful situation. In both phases, parents of children with ASD either adjust/adapt the stressful situation positively or negatively depending on the family’s strength and relationship, goals and values, interpretation of the stressful situation as major or minor and availability of coping resources. Sources from the findings also show that religious coping strategies was significant in some cases. One study has shown that parents who practiced religion as a method of coping strategy have reported positive outcome (Tarakeshwa & Pargament 2001). The study suggested that in some families, religion as serve as a source of coping strategy of stress and grief. Some parents of children with disabilities including children with ASD have reported that religion helped them accept their difficulties as gift from God However, religious coping could also result in negative outcomes ((Shokoohi-Yekta et al., 2015)).

7.1 Relationship with the theoretical framework

The Resilience Model for Family Stress, Adjustment and Adapation explains differences in how parents of children with disability react to the same stressors or stressful situations and crisis. Parents who use this model as resilience for managing stressful situations are reported to progress both effective and ineffective coping strategies. Both The model and the literature similarly outlined that, when a stressor is introduced into the family system, the family's reactions to the stressor can be either positive (family sees the stress as manageable one) or negative (family sees the stress unmanageable). Both reactions are influenced by some factors such as family resources and susceptibility to the stressful situations. (McCubbins & thompsons 1983). Moreover, the Model highlights the significance of family adaptation rather than adjustment. Findings of the articles present that coping stra-
egies used for stressful events can vary depending on family’s strengths, beliefs, situational appraisals and their problem solving and coping. McCubbin’s Model fits the aim of the study, because it is created for families to acquire equilibrium when faced difficulties in life.
8 CONCLUSION

The study investigated and collectively analyzed what coping strategies parents of children of Autism Spectrum Disorder could use in order to cope with the stressful situation they face caring raising children with ASD. The study found that coping strategies are based on family appraisal of the stressors, family strength, coping and adaptation. (Twoy et al. 2007). Findings of the study suggest that parents of children with ASD used either negative appraisals of coping strategies such as believing that they can not change the outcome of the child’s symptoms of ASD, and avoidance, or positive appraisals such as seeking for help from family members and friends, community, constitutionals, healthcare professionals, religious groups and self-determination.

The findings of the study also shows the importance of the nurses’ role in caring for children with ASD as well as in assisting their parents. Nurses need to have basic understanding of Autism Spectrum Disorder, its early signs and diagnosis when meeting with children with ASD in the primary care clinics, and hospitals. Many children with ASD also go to school, it is school nurses responsibilities to support these children learning skills and social behaviour when participating in community activities. Nurses should be able to identify abnormalities in development related to ASD and understand how children on the autism spectrum experience the world and advocate for them and their families. Nurses are also required to be able to support and educate parents and able to manage other basic issues relevant to ASD.

8.1 Strengths, Limitations and Recommendations

The strength part of the study is the completeness of answers for the research questions. Although the coping strategies of managing stress among parents of children Autism Spectrum Disorder seemed to be long and look-alike, it was easy for the author to sum up together clearly and concisely. The nursing part of the study provides very important information for nurses as well as nursing students who are willing to work with any type child psychiatric settings, especially children with Autism Spectrum Disorders and their families. McCubbins’ Model for Family Stress, Adjustment and Adaptation was absolutely the best choice to use for this study because it perfectly fits the goal and is linked to the researched answers for the research questions. As any other study, the study
was not without some struggles and limitation. The author found difficult to achieve relevant articles about ASD in Europe, especially in Finland, also articles written other languages than English were excluded, although they seem to contain some useful informations for the study. A lot of researched has been carried and plenty of articles about ASD in general were available, but few seem to have matched the goal of the study.

The author would like to suggest further research relating nursing care for parents of children with ASD, especially early stages of ASD diagnosis when the whole family is vulnerable for crisis.


Candy, L. (2005), Creativity & Cognition. New York: ACM.


Elo, S. & Kyngäs, H. (2007), the qualitative content analysis process. *Journal of*


Appendix 1. Figure 2: Resiliency Model (McCubbin & McCubbin 1996)
<table>
<thead>
<tr>
<th><strong>INCLUSION</strong></th>
<th><strong>EXCLUSION</strong></th>
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<tr>
<td>Articles written in English language</td>
<td>Not free accessible articles</td>
</tr>
<tr>
<td>Free and full PDF</td>
<td>Articles published before 2001</td>
</tr>
<tr>
<td>Articles focus on coping strategies for families of children with ASD</td>
<td>Articles focus on mainly ASD as general disorders, diagnosis, management and medication</td>
</tr>
<tr>
<td>Articles focus on stress coping strategies for parents of children with ASD and other disabilities</td>
<td>Articles written other languages than English</td>
</tr>
<tr>
<td>Articles containing role of nursing in support autism families</td>
<td>Articles focus ASD in older people</td>
</tr>
<tr>
<td>Articles published from 2001 onwards</td>
<td>All articles that were not relevant to the topic</td>
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**Appendix 2. Figure 3: Inclusion and Exclusion**