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**UNDERSTANDING AND CARING FOR CHILDREN WITH
ASPERGER'S SYNDROME**

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ABSTRACT

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<p>Asperger syndrome (AS) is a developmental disorder characterized by significant difficulties in social interaction and nonverbal communication, along with restricted and repetitive patterns of behavior and interests.</p> <p>The purpose of writing this thesis is to explore more about the challenges facing children with Asperger's syndrome and the challenges their parents encounter while giving caring to them. Additionally, the aim of this thesis is to determine the nurse's role in caring for children with Asperger's syndrome and the nurse's support for the parents caring for children with Asperger's syndrome.</p> <p>A literature review study method was used to articulate knowledge to nurses regarding the importance of giving care to children with Asperger's and support their parents as they give care to their children with Aspersers syndrome. Data was acquired from different databases such as, Science Direct, SAGE publications, Emerald, EBSCO and PubMed. 8 articles were selected, as they met the criteria employed by the research findings. The results of this literature review provide critical information to clinical professionals useful in developing appropriate interventions to enhance patient care decisions.</p>		

Key words: Asperger's Syndrome, Challenges, Understanding and Caring, Counselling Support
LIST OF ABBREVIATIONS

AS Asperger's syndrome

ASD Autistic spectrum disorder

AAP American Academy of Pediatrics

DSM-IV Diagnostic and statistical manual of Mental Disorders

PDD-Nos Pervasive development disorder not otherwise specified.

MMR Measles, Mumps and Rubella

EQ Emotional Quotient

IQ Intelligence Quotient

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1 INTRODUCTION

Asperger Syndrome (AS) is a medical condition often referred to as an autistic spectrum disorder (ASD). Other forms of ASD include childhood disintegrative disorders, autism, the rates syndrome, and the pervasive development disorder. This health condition was initially named after a Viennese pediatrician Hans Asperger who first noticed certain behaviors among boys who were part of his patients. In as much as the boys seemed to have a standard form of language and intelligence, they encountered difficulties communicating efficiently with their peers. In other words, the boys were found to have poor social skills and physical awkwardness. According to Dr. Asperger, this condition remains three to four times prevalent in boys unlike girls, an aspect that some studies are alleging that two in every 10,000 suffer from AS (Donoghue, Stallard & Kucia 2010).

Asperger's Syndrome, observed Winter-Messiers (2013), remains one of the several ASD inhibited by stereotyped patterns of behavior, difficulties in social interactions and the lack of interest in activities. Winter-Messiers (2013), posits that the Asperger's Syndrome is mainly a developmental disorder that falls within the autistic spectrum, thus affecting a two-way verbal and non-verbal communication, social interactions, and the reluctance to accept changes and inflexibility in a child's thought patterns. Given this, it is essential to establish that there are several severity symptoms associated with this syndrome, with mildly affected children likely to go undiagnosed since they appear eccentric or odd. Whilst the AS is considered being more common among children than autism, it's still perceived as a rare condition, with few professionals having the capacity and the experience to address it effectively.

The problem that gives rise to autism has not yet been established according to research even though a number of reasons have been given such as genetically causes, Measeals, Mumps and Rubbella vaccines as well as environmental factors (Heweston 2002), Coming to AS, there is even a theory that links it to a neurological adaptation to the technological era (Alaerts, Nackaerts, Meyns, Swinnen & Wenderoth 2011). A varying estimate exists regarding the number of people with AS of all ages, since its diagnostics is based on behavioral patterns, and the diagnostic assessment is a rather complex and expensive undertaking (Lord & Bishop 2010). According to Klin, Paul, Schultz & Volkmar (2005), there has been an increase of the parental support organizations that are organized around the concept of AS an all indications point to the fact that this diagnosis is given by clinicians more frequently today compared to previous years. It has also been established that this diagnosis is given to children who have normal intelligence but with a degree of social disabilities who hardly qualify as autistic yet overlapping in this way with the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) term pervasive

developmental disorder not otherwise specified (PDD-NOS) (Klin et al.2005). It therefore means that AS is used as a replacement to autism in persons with normal or even superior intelligence quotient (IQ). To this end, it is worth pointing out that the accurate diagnosis of AS is still a difficult endeavor that requires more research on the nature of the condition to enable its easy isolation from other autistic disorders (Klin et al.2005).

The portends to the society is painstaking assessment of children to discern traces of queer behavior that can then be further assessed for AS. Parents, in this regard should be counseled and advised to monitor their children and be the quick to report some of the strange behavior patterns that may point out as AS trigger. It is only then, that the process of providing proper care for these children can start. However, this should only begin once a thorough medical examination has established that indeed the condition is AS in spite of the challenges involved in appropriate diagnostics. Early diagnostic will definitely be beneficial to these children for they will grow up in an atmosphere of acceptance, which can boost their self-confidence going forward. Besides, speech therapy can be started early to at least make it better for them to communicate easily with others in their future lives. Measures of containing their erratic or impulsive behavior should also begin forthwith to attempt a restoration of normal behavior as they grow into adulthood. All this will require specialized care from the nurses and health providers (Molesworth, Che vallier, Happe& Hampton 2015).

It has been established that the affected children find it extremely challenging to make friends since they fail to understand the subtle clues needed to achieve this goal (Molesworth et al.2015). On the other hand, children suffering from this disorder habitually use language in a slightly odd manner as well as take literal meanings from what they hear or read. The children are in most cases happier with routines and within a particular structured environment, an aspect that makes it difficult for them to determine what they need to do, thus making them fall back on activities of their preferences. (Donoghue et al.2010).

Children suffering from AS love winning, praise and being the first in everything and praise. Regarding this, such children find imperfection, losing, and criticism very difficult to swallow. Bad behaviors among victims suffering from this disease in most cases emanate from their inability to communicate and express their anxieties and frustrations effectively. Such children, therefore, need understanding; love, tenderness, care, and patience in handling, an environment that enables them to flourish. What this calls for, is the need for caregivers to master to art of addressing the challenges faced by these children.

Most importantly, the nursing care, which is given by qualified nurses is paramount for these children. Caregivers who are non-medics should consequently purpose to learn the appropriate skills form nurses, to better handle such children. However, the needed care can only be provided when a deeper understanding of the challenges facing these children are known and internalized by caregivers (Horn 2009).

Therefore, purpose of writing this thesis is to explore more about the challenges facing children with Asperger's syndrome and the challenges their parents encounter while giving caring to them. Additionally, the aim is to determine the nurse's role in caring for children with Asperger's syndrome and the nurse's support for the parents caring for children with Asperger's syndrome.

2 THEORETICAL FRAMEWORK

This chapter will define challenges children with Asperger syndrome encounter and challenges encountered by parents with Asperger syndrome. It will also explain nursing care and support for children with AS.

2.1 Challenges Children with Asperger Syndrome Encounter

Children diagnosed with AS encounter several challenges which if left unchecked can severely interfere with their development process. For instance, while such children, in most cases, hardly lose their language of speech patterns as evident their often higher or average grammar and vocabularies, they are likely to fail to understand expressions or slang that several people use in everyday language. Donoghue et al. (2010), Moreover, children with AS usually have normal to above average intelligence. However, there are certain shortcomings that these children experience in their daily lives that most scholars have reviewed. (Donoghue et al.2010).

To begin with, Lowth (2014) observed that children with AS are prone to show poor social skills. Their social skills are hardly developed to cope up with the social demands of children their age. Usually, such children lack the capacity to read social clues, which is indicative of the fact that they lack the right social and emotional responses. Lowth (2014) found out that inadequately developed social faculties of these children inevitably eat into their emotional intelligence (EQ). With such a low EQ, such children are prone to erratic physical behavior that borders bipolar syndrome. This is symptomatic of their lack of interest and the desire to freely share their experiences and information with their peers. At times they may be very high in spirit, talking almost non-stop and within a very short time they become sulky and withdrawn. Dealing with a child that displays this pattern of social behavior can be a very difficult task that requires patience and some care-giving skills (Lowth 2014).

According to Barnhill (2007), studies found that children with AS have significant problems in the areas of overall behavioral symptoms, externalizing behavior, hyperactivity, and typicality. Caregivers perceived these children, found the study, to be at risk in such areas as verbal aggression, depression, attention problems, withdrawal, adaptability, and social skills. A study by Barnhill (2007) that investigated the link between social attributes and depression of the children suffering from AS revealed that a considerably high positive correlation between depressive symptoms and ability attributes for

social failure. In other words, the more these children attributed social failure to their ability or lack thereof, the higher their depressive symptoms score. It means that as young as they are, these children are more likely to suffer from depression than the normal child. This predisposition is evident by their inability to engage in social activities with the enthusiasm of a normal child. Such behavior therefore provides a cue to caregivers to move with speed and help out the child before the depression grows intense (Barnhill 2007).

Barnhill (2007), cites a study by Dunn, Myles Orr (2002), that researched on the sensory integration characteristics of children with AS. It revealed that these children exhibited variable patterns of performance when compared to their normal peers on a measure of sensory functioning. The impairment was found in the areas of emotional reactive, low endurance, oral sensory sensitivity, destructibility, poor registration, and sedentary. The most salient differences were recorded in the sensory-related behavioral and emotional responses of the affected children. A similar finding was confirmed by Elwin, Schröder, Wallsten & Kjellin (2016), who revealed that sensory-related behavior is more pronounced in those with AS is compared to individuals with autism. The author gives an example of emotional and social responses to sensory stimuli that were considered marked, to which these children display overt behavior especially when the sensory experiences are not compatible with their needs. Moreover, the study found that the ability to modulate movement and the sedentary areas as problematic. The affected children who experience difficulties knowing when and how to control activity level, sometimes leading to hyperactive behavior or passive/sedentary behavior (Elwin et al 2016).

It is however essential to note that these social challenges may be less noticeable among parents and adults, thus leading to the children's inability to make age appropriate peers. This in most cases leads to frustrations among the children, thus amounting to subsequent behavioral problems since the world is viewed as a confusing place. Lasser & Corleys (2008) supports this view by establishing that children with AS are often alone while other times they may be happy for a given period. Santosh (2006) add on that some of the affected children tend to focus on small details, thereby failing to identify the overall picture of a situation. In most cases, these children can be seen from afar since they are different from their normal peers. Their naivety and vulnerability make them victims of bullying unless they protected by their caregivers (Lasser et al. 2008).

Another challenge experienced by children with AS is communication. Both verbalized and non-verbalized forms of communication possess a challenge for children with AS. These children may experience difficulty in understanding spoken languages unless such languages are kept simple to their

level. The use of metaphors and similes, therefore, need to be explained since the children are likely to make concrete and literal interpretations of these devices Russell & Pavelka (2013). As such, there should be some effort put on communication such as translation of some terms and phrases to ensure the children understand what is spoken or said. According to Chamak and Bonniau (2016), speaking language for children with AS may be odd since they may lack the local accent or overly speak in monotonous tones. In an instance where a child with AS has a good level of spoken language, then assumptions should not be made on their standard of understanding. These children are bound to experience difficulties in the use of right words to form conversations, an attribute perceived as a semantic-pragmatic challenge. Such children are likely to talk to people rather than to them and in giving information rather than engaging in a proper conversation. Facial expressions and body languages among children with AS appear odd.

(Chamak and Bonniau 2016).

Alaerts et al. (2011) gave a vivid picture of three groups, kind of children with communication problems arising from their autistic condition, which by extension is replicable to those with AS. The first child has got no language ability at all, not even compensating gesture or sign-language. Such a child is susceptible to loneliness and due to his/her failure to speak, deafness may be suspected, albeit can be ruled out sometimes. Even though such a child may be mostly silent, at times, he/she could produce odd vocalizations which hardly resemble speech sounds. The parents may be adapting to such odd vocalizations and would be able to decode them as signals of a child's mood or needs. These odd vocalizations however, can only be understood by the parents of the affected child, but not parents of other children with AS. At times the child may show hearing ability by singing some complex melody heard only once, says Alaerts et al. (2011). Such a child may lack gesture, but does not have to be motionless for he/she can make odd stereotypical movements like flapping his/her hand, walking with toes, among others. (Alaerts et al. 2011).

The second type of children, according to the authors, has some language, though still showing a remarkable inability to communicate. S/He uses words and phrases in a peculiar manner mostly repeated a phrase heard from someone. In these echoed phrases, the speaker's original intonation is often preserved by the child, in contrast to the lack of normal modulation in spontaneous speech. That child may also use single words in a simple, associative way "so that 'Apple' always means 'Give me apple'" (Frith & Happe, 1994, cited in Russell & Pavelka, 2013). Moreover, the child may memorize complex verbal materials which, in most cases, have very little meaning for him/her. It is also not uncommon for such a child to start reading words, sometimes teaching him/her how to read. (Russell et al 2013).

Lastly, the third type of children may have very advanced language skills, like that of a normal adult. The child may have an extensive vocabulary with a formally correct pattern than is typical of everyday speech. However, author points out, content and use of language are mostly bizarre and that it is difficult to hold a conversation with such a child for a no or yes answers dominate the conversation; or sometimes the conversation is taken over by the child's own special interests where monologue ensues. Such a child usually shows over-literal understanding of communication, for instance, asking him to stick his coat somewhere, s/he will ask for glue (Alaerts et al.2011).

It is important to note that these three types of children may be just one child manifesting the different communication characteristics at different stages. Sometimes, each type of a child may represent a single individual child with AS. Parents and caregivers should know where their child lies in terms of the ability to communicate so that they can get the best skills to enable them handle such challenges. Preoccupations and/or narrow interests is also a challenge that children with AS struggle with. For example, they love winning, praise and being the first in everything and praise Chamak et al (2016). Regarding this, such children find imperfection, losing, and criticism very difficult to swallow. Among the prevalent hallmarks of these children is the preoccupation or obsession with different things Chamak et al (2016). In most cases, the children's minds are preoccupied with different themes of transport, dinosaurs, maps, and so on. These preoccupations, with most emphasis on intellectual ideas, however, change over time and are likely to be pursued to the exclusion of other ideas and activities. It is therefore important for parents and caregivers of these children to be very alert about symptoms they show so that they can of help to these children (Chamak et al, 2016).

2.2 Challenges Encountered by Parents and Caregivers of Children with AS

Raising children with AS can be challenging to parents. Children restricted social, communicative and emotional competencies place tremendous stress to the parents. Parents may feel overwhelmed and feel they lack knowledge on how to properly care for their children. Having a child with AS not only affects the parents but also may pose a threat to the whole wellbeing of the family. This may lead to families to give up normal family activities and outings, lack of spontaneity or flexibility in family life. Due to these difficulties' feelings can sometimes become overwhelming and lead to act in ways that may not be good (Griffith, Totsika, Nash, Jones & Hastings 2012).

Making important decisions can be difficult to make, it is important for parents to deal with these feelings, this can be through counseling, support groups or talking to friends and family. Some of these difficult feelings can be stress and depression, anxiety and guilt; and anger, sadness and loss. According to author parents and caregivers of children with AS require psycho-education programs focused on handling stress and emotions, modifying false beliefs and solving routine problems that arise as a result of the condition of their children. Parents of these children go through a great deal of stress as a result of their children's disturbed sleep, agitation and cries, stereotype as well as self-injury (Ruiz-Robledillo & Moya-Albiol 2013).

Other problems that these children suffer that stress up their parents and caregivers are difficulty in feeding and toilet training, epileptic seizures, lack of social or emotional reciprocity, among other problems as a result of these stress, the lives of families of children with AS are often strained in terms of economic well-being, social stability, physical and psychological soundness. More so, the family life is usually organized around the suffering child and his/her future Altieri & von Kluge, (2009). However, there are some parents and caregivers who consider the experience of raising children with AS as of psychological benefit. Liekenbro, Ekas and Whitman (2010) observe that such parents argue that given the challenges they counter in their parental role of children with AS, they get the opportunity to learn and improve. All the same, it is an undeniable fact that most families of children have to choose but to cope with the condition. (Altieri et al. 2009).

Some studies have indicated that the adaptation of parents and caregivers of children with AS is determined both by the symptoms of the condition and by psychosocial factors Altieri et al. (2009) Generally, personality characteristics, spheres of control such as peoples believes about whether or not

what is happening to them is within their control; social support and coping strategies, all affect adaptation. Ruiz-Robledillo et al (2013) showed in their study that social support, internal sphere of control, hardiness, and optimism contribute to positive outcomes. But parents with poor social support and with external sphere of control are likely to be more stressed and prone to clinical depression and anxiety (Siman-Tov & Kaniel 2010).

Regarding anxiety and guilt, Ruiz-Robledillo et al (2013) revealed in their extensive study that the parents and caregivers of children with AS who perceive the condition of these children as under their internal locus; that is, as something that they could have prevented or rather caused by some agency that could have been controlled by them, end up feeling guilty and anxious. Such parents and caregivers find it difficult to adopt to the challenges that caring for these children pose thus they inwardly feel a degree of pain for having not done anything to prevent the children from the condition Sullivan et al. (2012). This is coupled with the inaccessibility of external support system which in most cases is instrumental in training them how to properly care for the affected children. When this is not forthcoming, frustration sets giving way to behavior that manifests anxiety and guilt. Consequently, the affected child does not usually receive the best care since she/he is dependent on a parent or a caregiver who has not fully accepted his/her role to the child (Sullivan et al. 2012).

Anger, sadness and loss have also been found Baker, Lane, Angley & Young (2008) as another set of behavioral traits that parents, who perceive the condition of their affected children as falling within their internal locus, manifest. In Ruiz-Robledillo et al (2013) study, it was found that parental stress is positively correlated to emotional-focused coping strategies and poorer quality of life. These emotional focused coping strategies are what oscillate along the arc of anger, sadness and loss, for it is pretty obvious that these behavioral patterns can hardly sustain a high quality of life to both the parent/caregiver of the affected child (Ruiz-Robledillo et al 2013).

2.3 Nursing Care and Support for children with AS

Children diagnosed with AS remain vulnerable within the school setting to different challenges inasmuch as they appear physically indifferent from other children. In this regard, it is significant to understand that their intelligence quotient (IQ) is average compared to the normal range. However, their inability to face, read, and interpret correctly especially in understanding social issues is perceived as a bizarre action that places them as victims Sullivan et al. (2012). Nurses in several settings encounter children with a different and unfamiliar diagnosis such as AS. This disorder in nursing terms falls on the autism spectrum, an aspect that has received a wide attention because of its inclusion in the society (Sullivan et al 2012).

First and foremost, it is essential to consider that the nurses serve as a liaison between the children with AS and the school's personnel's, the community, their families, and healthcare providers. American Academy of Pediatrics (AAP) (2012) therefore suggests that in schools, nurses need to play a role in ensuring that children with AS achieve their education-related goals and healthcare plans. Nurses need to increase awareness and commitment to the early diagnosis and interventions among children with AS, an aspect that helps in coordinating care services that set the stages for efficient interventions and management of AS Sullivan et al (2012). A growing awareness among nurses and care providers on AS results in developed interventions for the children who learn through behavioral difficulties in schools. This, therefore, helps the nurses build interventions aimed at establishing interactions between these children and others. (Sullivan et al 2012).

According to Reichow & Wolery (2009) children with AS suffer socialization deficit that can easily result in some level of stress and conflict in families given the child's difficulties in meeting the demands of daily life and their problems with educational, vocational, and social relationships. Consequently, there is a need to address these concerns from the nursing perspective to help ameliorate the suffering. In their earlier work, Elder, Caterino, Chao, Shacknai & De Simone (2006) assessed the efficacy of social skills treatment for children with AS. A crash 8-day summer program attracted eight (8) participants whereupon social skills curriculum was to be used. "Recognizing and expressing emotions in self and others, physical and mental feelings, stress and relaxation, this helped initiating conversation, and bullying and teasing" Reichow et al (2009). These are the social interventions that nurses have been employing to care for the children with AS and also pass it on to their parents and caregivers in order to facilitate discharge of appropriate care. In fact, the findings of the above study indicated that parenting

stress drastically decreased after introduction to this form of intervention for the children recorded less problem behavior; increased recognition and expression of emotion in self and others; improved knowledge of physical and mental feelings; ability to initiate and maintain conversation and non-verbal communication; among others. (Reichow et al. 2009).

Specifically, there are communication skills interventions that nurses can be of immense help towards. Many children with AS experience little or no speech; and even those who do have speech, experience difficulties in using language effectively, that is, they suffer from pragmatic language impairment the appropriate nursing intervention in this case would be by a speech and language therapist, working in conjunction with other professional as well as the child's parents/caregivers. According to Travis & Geiger (2010), interventions with visual support to communication were found to increase in spontaneous imitation and social communicative behavior, hence its effectiveness. In fact, the existing literature shows that interventions supporting communication are heterogeneous with reference to intelligibility, reading and writing as a visual support to communication. A handful of studies have also suggested that for the efficacy of communication intervention, the use of visual timetabling, operationalizing through short stories or the use of speech bubbles or cartoons should be used (Boudreau & Harvey 2013).

Physiological interventions by nurses has been sites in the literature as being of beneficial to children diagnosed with AS. They are divided into three categories. The once that aimed at overall and functioning outcomes. Second group and that are aimed at addressing specific behaviors associated with AS, and those that do not fall under mentioned group. The firs group consists of intensive behavioral program with general AS. This involves 20-40 hours a week, with focus early intervention with preschoolers. This is mediated by parents and professionals involved (nurses). The Loovas program which is best known for ABA interventions. (The Loovas Approach is a form of Applied Behavioral Analysis that is used in early intervention programs for children who have developmental delays or who have been identified as autistic and have AS. The second group of intervention aims at specific skills deficit or sensory problems that cause particular behavior patterns (Scottish Intercollegiate Guidelines Network, 2007). A systematic review that examined 251 studies on focal treatments for children with ASD concluded that focal behavioral interventions usually result in positive behavioral outcomes in a number of areas such as aberrant behaviors, language skills, community living skills, daily living skills, social skills, and academic skills Sheas (2005) Accordingly, behavioral interventions are within the nurses' report when handling children with AS. The third group involves interventions that neither falls on first or second group. This involves methods like music therapy, in which listening to music is assisted

in auditory intervention, Paavonen Vehkalahti, Vanhala, Wendt & Nieminen (2008) mentioned that sleep therapy for children with sleep problems and occupational therapy for generic indications such as advice and support in adapting to environments, activities and routines in daily life (Sheas 2005).

Another set of nursing intervention is biomedical and nutrition, Kuusikko, Pullock-Wurman Jussila, Carter, Mattila Ebeling & Moilanen (2008) outlines research done on biomedical interventions that include diets and nutritional supplements. However, a Cochran systematic review conducted by Piwowarczyk, Horvath, Lukasik, Pisula & Szajewska (2018) could not identify evidence for or against casein and gluten exclusion diets. As a matter of fact, some research that was a follow up of the Cochran review revealed that there were no significant benefits that dieting does to children with ASD. That is, there is insufficient proof on the use of casein and gluten exclusion in diets for children with ASD as an intervention. Nevertheless, Piwowarczyk et al (2018) advises that as with all children, nutritional interventions may be required for children suffering from AS, especially those with significant food selectivity and dysfunctional feeding behavior (Piwowarczyk et al 2018).

Apart from the above non-pharmacological intervention that nurses could engage in for children with AS, there are a number of pharmacological interventions that are strictly under the purview of nurses in addressing the needs of children with AS. Nevertheless, as Tsai (2007) put it, any pharmacological treatment for these children should be complemented with some of the already discussed non-pharmacological interventions for holistic care to be attained for the children. Accordingly, nurses may consider pharmacological intervention for treatment of co morbid, psychiatry and/or neuron-developmental conditions associated with AS. Moreover, the intervention may be considered for specific symptoms occurring in these children, hence done within a short to medium terms. However, this pharmacological intervention should be strictly conducted by medical doctors (Tsai 2007).

3 PURPOSE, AIMS AND RESEARCH QUESTIONS

The purpose of writing this thesis is to explore more about the challenges facing children with Asperger's syndrome and the challenges their parents encounter while giving caring to them. Additionally, the aim is to determine the nurse's role in caring for children with Asperger's syndrome and the nurse's support for the parents caring for children with Asperger's syndrome.

The thesis aims to address the following research questions:

1. What challenges children with Asperger's Syndrome Face?
2. What are the nursing needs of children with Asperger's Syndrome?
3. What nursing challenges do parents and caregivers of Children with AS face in providing quality care?

4 METHODOLOGY

This chapter presents the method that was employed to execute the research. The chapter begins by focusing on the literature review, data collection, and data analysis.

4.1 Literature Review

The thesis will be written and carried out as a literature review. The purpose of using literature review method is that it helps in writing down oncoming studies and also gathers a lot of information from the context. It is also a good source that will provide a quick overview of the topic, and it will help in summarizing and appraise all literature and evidence available in this specific research topic which will play an essential role in the development of evidence-based practice and also academic thesis writing Ma Sheng-mei (2015). Literature review entails a lot of research in past written materials, identifying, selecting, analyzing, putting together and writing a good description of all the information on the topic Ma Sheng-mei (2015). The literature review will help to discover more theoretical progress to the research problem, especially when reviewing different kinds of literature (Berger, Willer & Zelditch 2005).

The research method will be limited to literature review which is the evaluating of reports of information found in the study and literature related to the selected area of study. The review primarily describes, summarizes, assesses and clarifies the specific areas of study to provide a theoretical base for the study. The analysis also contributed in determining the nature of the research in the light of reviewing the previously published documents and extant empirical evidence in the literature about Asperger's syndrome health teaching and promotion, as well as best practice nursing care activities. (Berger, Willer & Zelditch 2005).

4.2 Data Collection

The data collection method involved a comprehensive literature search from which to carry out the literature review. The literature review followed the methodology steps provided by Cooper, Patel, and Lindsay (2009), which entails problem formulation, data collection, data evaluation, data analysis and interpretation and lastly, the presentation of the final results as interpreted from the data collected. The search was conducted on various nursing databases available at the Centria University Applied Sciences Website (Finna) as well as other databases that had relevant information about the topic of interest. Other online healthcare sources that were used in the literature review include ProQuest, CINAHL, and Medicine and the limit of the publications was between 2008 and 2019.

4.3 Data Analysis

Based on the primary objective of the literature review of the studies, child suffering from Asperger's syndrome was considered as the primary exposure variable while understanding and caring for children with such illness was regarded as the desired predominant outcome variable. The keywords that were used in the literature review were all related to Asperger syndrome, challenges, support, and understanding and caring. These selected studies focused on understanding the challenges those children with Asperger's syndrome face, problems faced by their parents and caregivers and lastly appropriate nursing interventions that can be used to care for these children. The literature searches revealed a total of 283, of which 123 were duplicates. The remaining 160 articles were then subjected to the inclusion and exclusion criteria. Out of the 160 articles, 82 articles were excluded after reviewing their titles and abstracts; 78 full articles were submitted for assessment to determine their eligibility and 70 of the full articles were omitted for lack of eligibility. In (Table1) only eight full-text articles were critically reviewed against the inclusion and exclusion criteria.

TABLE 1. Inclusion and Exclusion Criteria

Inclusive criteria	Exclusion criteria
-Articles related to Asperger syndrome	Articles not related to nursing and Asperger Syndrome
Articles from 2005-2019	Articles not older than 2005
-Only articles in English were selected	Article in other languages
Articles that were available in full text.	Any article that were not available in full text
Materials based on scientific research evidence.	Materials not based on scientific research evidence.

The inclusion process involved two reviewers while exclusion process involved two reviewers who were blind to each other and the publications were limited to 2010. The inclusion and exclusion process adopted in this present research followed the following steps to select the eight final articles for literature review. The steps, as shown in (Figure 1) below, included identification, eligibility screening, data extraction; synthesis & reporting and lastly quality assessment where the last articles to be used were selected. The inclusion criteria the following conditions were considered; articles published in English language and having original data that relates to Asperger syndrome and caring for Asperger syndrome children, those where the parent and child with Asperger syndrome are in acute healthcare settings and also those studies whose findings pertains to the caring of children with Asperger syndrome. The articles that were excluded from the analysis included discussion papers, literature reviews, editorials and discussion reports. The exclusion criteria adopted in the present research if the articles focused on the parent experience related to receiving the diagnosis of Asperger syndrome for their target child, siblings or measurement tools.

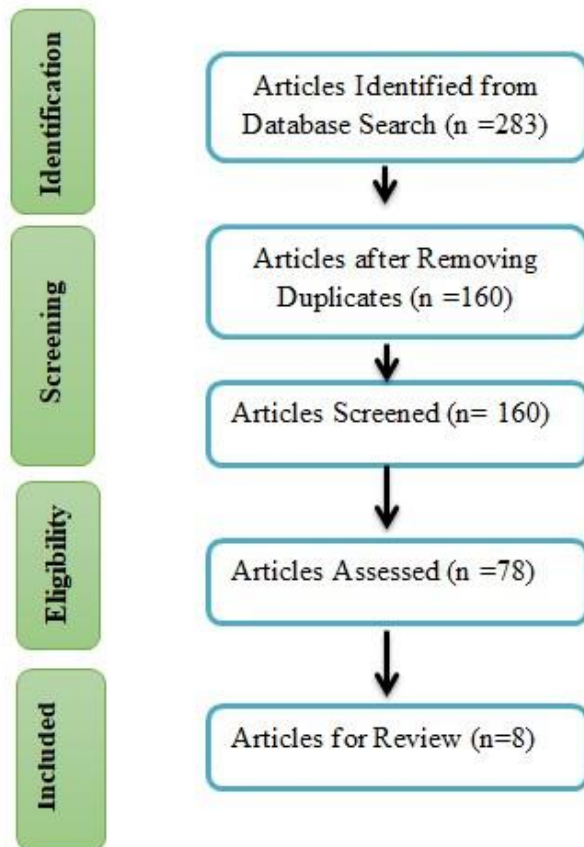


FIGURE 1: Flow chart representation for literature search

The articles included in the literature review comprised of randomized controlled trials (RCT), cohort studies and cross-sectional studies. The combined sample size for all the studies included was 6,776, and the recruitment strategies employed in these studies were similar such as the newspaper adverts or national health agency surveys.

Cummings (2007), it is the responsibility of those conducting research involving human persons always to observe moral and ethical standards, in such studies, the adherence to stipulated ethical considerations is fundamental in ensuring that the participants in the study are not placed in harm's way during the research process. On the other hand, in studies that do not involve direct participation of human character, like is the case in research that is based on secondary data, observance to ethical framework is also vital to make sure that the outcome of the project meets the threshold of integrity, honesty, and legality Broom, Cheshire, Emmison (2009). According to Silverman (2016), studies, especially in the nursing field often influence the practical approach that practitioners conduct their work and therefore, any study in the health sector must be authentic and adequately grounded on ethics to ensure the safety of the recipients and providers.

In any study help in building and promoting general public confidence empirical knowledge for evidence-based practice. The goal of this study was to provide additional insight to health professionals and the community as a whole about support for children with AS and their parents. It aimed to provide encouragement and counselling to both children with autism and their parents on matters relating to caring and supporting the children (Silverman 2016).

While conducting the present study, the researcher took into consideration the ethical requirements in regards to the integrity and reliability of the sources used. The literature reviewed consisted explicitly of carefully selected academic published articles and journals from authentic internet sources. All credits and acknowledgement were accorded to the respective sources of information to ensure that the project is plagiarism free. The article that have also been included in the paper have also been appropriately cited. The sources that were used in the study were then listed under reference section as an assurance that the outcome of the research observed the ethical requirements of any standard research.

5 ETHICAL CONSEDARATION AND VALIDITY

According to Colepicolo (2015), one of the criteria used to show reliability to acquire quality and credibility. This study was done using different scientific databases which helped find reliable articles. Some of the databases used include the following, Science Direct, SAGE publications, Emerald and EBSCO. These databases contained journals for health care sector. The databases also provide free access to various journals that contained full-text articles. In each database, the author used the same procedure and criteria in selection in order to acquire reliability and validity information.

For validity and reliability all information was obtained from reviewed articles that were referenced with the appropriate sources- names of author. All the authors that where associated with the research were quoted. Aspect of plagiarism was taken into consideration. Quotes were not copied and pasted but were paraphrased. Author acknowledged all researchers by writing their names in the referencing. All articles with relevant data were combined according to the guidelines. Information was obtained only from articles that were free to access through the Centria University of Applied Sciences Data Base Guide. This was viewed as an indication of willingness from original writer to allow other scholars access and use their work. (Colepicolo 2015). The aspect of bias was also taken into consideration where by the researcher eliminated any aspect of bias by ensuring that all the articles that had relevant information were appropriately used in the study. It is also vital to note that source of the study information was only obtained from databases that provided free access.

Considering ethics during research work is very important. It is a critical aspect which can be outlined during the research work, going against ethical rules should be completely avoided. All the articles used in the work study are not violating copyright rules. To get information from the academic databases an official access must be used during the process. This means that the process of nursing research should be guided by proper research ethics. No quotes are directly copied from the article and all used quotes are referenced in the reference pages. The main points in the research were and looked at carefully and compared before conclusion. No recommendation was allowed, suggestions were made in the end. To prevent bias all the articles that contained relevant and up to date information were included accordingly. The source of the information was only gotten from databases that gave free access. (Strech, Weissgerber & Dirnagl 2020).

6 FINDINGS

This chapter will present findings from the summary of the articles gathered. According to the research questions, purpose of writing this thesis is to explore more about the challenges facing children with Asperger's syndrome and the challenges their parents encounter while giving caring to them and also determine the nurse's role in caring for children with Asperger's syndrome and the nurse's support for the parents caring for children with Asperger's syndrome.

Table 2: Summary of the data and the primary findings in the included studies

Author/Year	Research Design/Sample	Research Articles	Findings/Conclusion
Jolly A (2015)	Content analysis	Top Ten Tips a Nurse Should Know Before Caring for a Hospitalized Child with Autism Spectrum Disorder	Having acceptable assessment strategies enhances the recovery period of the patients to help cope with Asperger syndrome.
Johnson et al. (2013)	The study used cross-sectional and correlational research design.	Children with Autism Spectrum & Asperger Disorder at a Pediatric Hospital	Higher discrepancy score with regards to family functioning between males and females.
Robisson et al 2015	Literature Review	Parenting a Child with Asperger's Syndrome. A Balancing Act.	Fluctuating child's behaviour hinders effective caring subjecting the parents to some degree of social isolation. Adopted key strategies that are vital in dealing with the situation.

Farmer & Reupert (2013)	The Study adopted the use of self-constructed questionnaire which are administered both pre and post intervention.	Understanding autism and understanding my child with autism: An evaluation of a group parent education program in rural Australia.	Subjecting parents of children with Asperger syndrome to training programs enables their understanding of their children and the medical condition.
DePape & Lindsay (2015)	Literature Review with a Qualitative health research.	Parents' experiences of caring for a child with autism spectrum disorder. Qualitative health research.	The study found out that various themes significantly impacts the parents caring for their children suffering from Asperger syndrome in all stages of their Family LifeCycle.
Ruiz-Robledillo and L. Moya-Albiol (2013)	Literature review	Self-reported health and cortisol awakening response in parents of people with Asperger syndrome: The role of trait anger and anxiety, coping and burden	Parents of children with Asperger syndrome records poor quality of life.
Broadly et al. (2017)	Structured interviews on fifteen sampled carers of children diagnosed with ADS.	Understanding care lived experience of stigma: the voice of families with a child on the autism spectrum. Health & social care in the community.	Carers face stigmatisation in different domains and contexts hence interventions should be tailored to specific pathway
Daniels & Mandell (2014).	Article reviews on 42 studies	Explaining differences in age at autism spectrum disorder diagnosis: a critical review. Autism,	Various factors are associated with autism age diagnosis and early

			detection is important in early medication.
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Table 2, above provides the summary of the data and the primary findings that were obtained from the eight included studies. The following section provides brief overview of findings and conclusion of the particular studies.

7 DISCUSSION.

This chapter discusses the findings of the study in relation to the findings of past researchers. The chapter begins by discussing the methodological considerations and limitations, after which it continues to the explain of the study's findings.

7.1 Methodological Considerations and Limitations

The research was conducted as a literature review. Data was acquired from different databases such as, Science Direct, SAGE publications, Emerald, EBSCO and Pub Med. The search strategy or approach used in the study, as well as publication bias and the number or quantity of databases explored could be the principal limitations to this study. The mentioned factors might have limited articles that were accessible or available for the study's review.

7.2 Discussion

The study by DePape & Lindsay (2015), which was focused on exploring the experiences faced by the parents who care for their children suffering from the Asperger syndrome highlighted various areas of concern that such parents need to take note of to ensure adequate recovery for the children. Using literature analysis based on different themes, the research integrated qualitative evidence which reviewed 4,148 articles out of which 31 were selected for inclusion. The study identified six themes used in exploring the parental experiencing when caring for children with Asperger syndrome and these were prediagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward. The study found out that these themes significantly impacts the parents caring for their children suffering from Asperger syndrome in all stages of their Family Life-Cycle. The findings of this literature study, therefore, provide vital background information that helps parents having children with Asperger syndrome to give a positive approach to the situation. The findings also offer insight for healthcare providers to device appropriate strategies that assist in their advocacy for children with Asperger syndrome. (DePape et al. 2015).

Robisson, York, Rothenberg & Bissell, (2015), conducted a prospective cohort study that illustrates the relationships that exist in parenting stress, support from family functioning and the physical and mental health of the parents that provide care for their children leaving with Asperger syndrome. The authors in this article provide insights on why it is critical for such parents to have a deeper understanding of the disorder to help them identify the best ways to deal with the problem without subjecting suffering from

parenting stress and other related mental illnesses. By using an equal number of both male and female parents, the authors used web-based surveys to examine the perception of the parents with regards to parenting stress, family functioning and the possibility of suffering from physical and mental health. (Robisson et al 2015).

The findings of Wilcoxon signed-ranks test revealed higher female parent discrepant scores in family functioning than the male parents. Using stepwise linear regression for male-female parents, the findings indicated that female were prone to care giving stress than their exposure to physical health when dealing with children with the disorder. The results of the regression further revealed higher discrepancy score with regards to family functioning with males recording lower mental health. The results of this study, therefore, indicate that there exist significant differences in parental perceptions and expectations about supportive family functioning. This, thus, gives rise to the needs that must be addressed by clinicians to help the parents have a good understanding of their expectations in family functioning and this consensus is essential in providing care for their child. The findings of the study thus offer guidelines for healthcare professionals in their assessment and planning for appropriate interventions for parents having children with Asperger syndrome Johnson et al (2013).

The study by Johnson et al. (2013), provides a comprehensive overview of the daily challenges those parents having children with Asperger syndrome face when providing care for their children. The authors carried out research interviews with 20 parents to help explore their experiences, challenges and the possible strategies that enabled them to understand the situation and cope with the problem in the family. The study was based on a thematic analysis which focused on six different categories of challenges, and these included changing routine, handling the challenging child behaviours, dealing with external judgments, lack of support, impact that it has on the family both socially and financially, coping and the importance of appropriate medical help. Based on the responses provided by the respondents, one significant challenge faced by the parents which hinder effective caring was noted to be the fluctuating child's behaviour which often subjects the parents to some degree of social isolation. By sharing their experiences, the authors have indicated that the parents have adopted essential strategies that are vital in dealing with the situation. The findings of the study thus illustrate the areas of concern I finding solutions on how to deal with the social problems facing the parents of children with Asperger syndrome (Johnson et al.2013).

In the article by Jolly (2015) the authors explore the possible challenges that children suffering from autistic spectrum disorders (ASDs), an extended type of Asperger syndrome, face during their

hospitalization. Based on the challenges facing such patients, the article provides acceptable assessment strategies aimed at enhancing the recovery period of the patients to help cope with the situation and be able to regain full health. The study further indicates the suggestions for the plan for care for the clinical professionals. The findings of this article, therefore, provide a good understanding of the unique needs of patients suffering from Asperger syndrome enabling nurses to tailor their care and treatment to suit those specific patient needs Jolly (2015).

In another article by Farmer & Reupert (2013) focusing on the rural health care of Australia, the authors evaluated programs provided to parents having children with Autism to enhance their knowledge of the medical condition. Using self-constructed questionnaires, the results of the study revealed that subjecting parents of children with Asperger syndrome to training programs enables their understanding of their children and the medical condition. Additionally, the training sessions also enhance the parents' knowledge of the communication strategies, sensory, social and learning behaviours of their children and this helps them devise appropriate ways of providing the necessary care. On this basis, therefore, parental education is essential in enhancing the care of children suffering from Asperger syndrome, and it also helps limit the extent of possible family stress that is associated with this medical condition. (Farmer et al.2013).

In a research conducted by Ruize Robledillo & L.MoyaAlbiol (2013), authors examined studies that measure the quality of life among parents that have children suffering from autism spectrum disorder (ASD). The findings of this study revealed that parents of children with ASD have a reduced quality of life as compared to those parents whose children are developing normally. The parental quality of life was measured using lack of social support, child behavioural difficulties, and unemployment. Based on the systematic review on various electronic databases, the study highlighted the complexity of raising children with Asperger syndrome and concluded that several children, parent, and environmental variables significantly influence the quality of life of parents of children with Asperger syndrome. The results of this study, therefore, provide critical information to clinical professionals useful in developing appropriate interventions to enhance patient care decisions. Ruize et al (2013).

The article by Broady, Stoyles & Morse (2017), builds on existing research which identified the possible challenges that are associated with caring for children with autism spectrum disorders. The study focused on the perceived stigmatization that the families are subjected to thereby affecting the quality of life of the patient children and their caregivers. By exploring the perceptions of stigma in caring for children with Asperger syndrome, the study carried out structured interviews with fifteen caregivers with regards

to their care giving experience and possible encounters with stigma in the process. The results indicated that the sampled caregivers experienced stigmatization in different contexts and domains; hence it is essential to have a good understanding on the relationship that exists between the domains and contexts in which the stigmatization is prevalent. Identifying this pathway will, therefore, help in developing appropriate care interventions or support for the children with the disorder. (Broady et al.2017).

In the study by Daniels & Mandell (2014) the authors reviewed studies assessing factors associated with age at autism spectrum disorder diagnosis, providing medication recommendations on the benefits of early detection of the syndrome. Using a total of 42 articles, the findings of this study offered various factors that are associated with early diagnosis of the illness and factors to consider for early detection efforts. The conclusions of this study, therefore, support the notions of the other reviewed articles since it provides background information that enables a proper understanding of the conditions that can expose a child to Asperger syndrome which thus allows identification of appropriate nursing and care interventions. Based on the analysis of the sampled articles, it is important to note that proper understanding of the conditions leading to Asperger syndrome contributes significantly to early detection of the illness hence adequate intervention method for both patient parents and the caregivers (Daniels et al. 2014).

7.3 Conclusion

The present study underlined the complexities that parents and care providers encounter in raising a child with AS with a primary aim to provide an understanding of how to care about these groups of children. Thus, the study revealed that children suffering from AS are often faced with numerous challenges which may have a severe developmental impact on their well-being and growth. The condition may have a drastic effect on their communication abilities, namely their speech patterns or failure to accurately recognize simple expressions that are used in their day-to-day interaction with other people. Besides, when early intervention is not taken, these children are likely to be predisposed to other serious problems such as depression, adaptability challenges and they may find it considerably challenging to engage in social events with other children in their age brackets.

Raising and caring for children with AS also presents numerous challenges to their parents and caregivers. In effect, these parents taking care of these children are often subjects to a lot of stress given the overwhelming social, communicative and emotional competencies of their young ones who may find it hard to socialize with their peers. Many scholars revealed that most of the problems that parents

encounter in regards to their children relate to lack of knowledge of how to properly take care of the children with AS. For these reasons, most families in which a child diagnosed with AS hails are often limited in what they can do to lead a healthy family life since a lot of attention and resources are placed in caring for the sick child.

The study revealed that parents of children with ASD often have a reduced quality of life as compared to those parents whose children are developing normally. The complexity of raising children with the condition has a significant impact on the lives of their parents and caregivers as it hinders them from pursuing their normal day-to-day activities. In effect, the outcome of this study helps provide a reasonable framework within which such parents can adequately care for their children with AS without compromising on their quality of life and even their productivity. Besides, the study provides sights to the areas that have been given attention by the general public as a way of creating awareness of the condition for the children with Asperger Syndrome, and their parents or caregivers can have widespread acceptance and understanding from the public.

A proper understanding of the factors and conditions leading to Asperger syndrome contributes significantly to detecting the situation in its early stages, and this allows for appropriate intervention to assist in caring for children with the illness. In other words, early detection of the condition in a child is fundamental in providing adequate intervention and caring plan to avoid spread and further complications.

7.4 Learning Experiences

The articles we used in our work had a variety of view-points concerning the AS in children. Nevertheless, it was not an easy task to find suitable articles, as the research is still very much concentrated on children who have autism more than the children with AS. It is not well researched because most of the articles we found were relevant and quite old. We found also that most of the children with AS have been misdiagnosed making it difficult to be helped. We learnt that some of parents have had to live with their children without knowing way forward until they are in their adult live that is when the diagnosis is made. For the search of the suitable articles the Ebsco and Sage used. In addition, especially in the early stages of the work book sources were used.

We found quite a lot resource material in English language. There were very little materials in Finnish about Asperger Syndrome. The Finnish articles had good and relevant information. The reviews where

very cautious with the idea of child with the Asperger's Syndrome having a full and almost independent life later on. We chose the articles according to the theme and topic, choosing the articles which focused on the AS and with an approach rooted to the realities of children living with AS and how their parents coped AS and with an approach rooted to the realities of the adult life. Admittedly we are pre-conceived opinion in our research that the children living with AS live a full independent life and they can grow, learn and have careers.

A realistic time frame for our thesis work was about a year. We planned to accomplish the thesis in year 2019. We faced some challenges in compatible schedules as we both had work, families and studies to incorporate while writing the thesis. What we learnt from this obstacle understanding each other, and also the content analysis method takes time because every set of data is different in one way or another and it needed time to analyze. It took a period a of time because of a lot researching reading, thinking, reflection and reviewing this analysis method. The knowledge that we acquired from this research process is going to help us future as nurses in counselling and supporting vulnerable patients and family members. It has increased our desire after graduating to carry out more scientific research. As nurses, this research had helped us to learn about previous information and knowledge that other researchers have discovered in relation to our topic of interest.

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