

Parenting of Children with Autism: An Evolutionary Concept Analysis

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ABSTRACT

Background: Caring for a child with autism as a "developmental disorder of a lifelong nature" is associated with many challenges and has different definitions in the literature. The purpose of this study was to clarify the concept of parenting of the children with autism and its changes over time.

Method: In this study, Rodgers' Evolutionary concept analysis approach has been used. Published articles were reviewed in valid scientific databases without regard to time limit and with the keywords of Autism, children, parenting, parenting children with autism, child parents, and caregiver. Articles were assessed in nursing sciences, psychology, social sciences, and medicine, and was limited to full-text and English-language. A total of 65 articles were selected; then the data were collected and analyzed using thematic analysis.

Findings: The concept of parenting of children with autism is a concept with a process nature which has four attributes including: "demanding and challenging", "unique and multifaceted (guidance, education and socialization of children)", "dynamic interaction between parents and child"; "Personality growth and spiritual journey."

Conclusion: This concept analysis could be a basis for further research to explain the meaning of parenting in a particular group of children for programs of parenting of children with autism.

Keywords: Autism, children, parenting, concept, caregiver

INTRODUCTION

Autism Spectrum Disorder (ASD) is a developmental disability characterized by pervasive disorders of social relationships and communication skills (Blumberg et al., 2013; Hansen et al., 2015). Characteristic symptoms of ASD in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) includes lack of social interactions and communication with others and repetitive, limited behaviors. Also in the DSM-V classification, the symptoms of this disorder are classified as a range from mild to severe, which varies from "low intensity" spectrum 1 to "maximum intensity" spectrum 3, and the severity of the illness in these individuals is defined based on the amount of required support in social and communication disorders and behavioral problems (Duchene, 2015; American Psychiatric Association, 2013). Autism is a complex disorder and there are serious discussions about its causes (such as defects in areas of the brain, the time of onset and the role of genetics and environmental risk factors). Although the exact cause of this disorder is still unknown, extensive research has shown that genetic and prenatal factors play an important role in its formation. Although changes in children's brains are present from birth, they are not detected until the child has developed; therefore, ASD is not usually diagnosed till the age of 3 (Hansen et al., 2015), though screening tests have recently been developed, so that they help diagnose ASD before the age of 18 months and even earlier (Landa et al., 2007; Duchene, 2015). The prevalence of ASD is estimated by the World Health Organization at 1 in 160 children worldwide (Cooke et al., 2020). With the increasing prevalence of autism, many articles were published about the impact of this disorder on the parents of children with autism, who are the main caregivers of these children and have their own economic, social and educational needs (Cooke et al., 2020, Hayes et al., 2013). Parents of children

with autism are more likely to have high levels of stress and mental health problems than those who have children with normal development. High levels of stress affect child-parent relationships, leading to less parental satisfaction, reduced interaction with the child, and poor parenting skills (Hayes and Watson, 2013; Van IJzendoorn et al., 2007; Parsi and Elster, 2012; Burrell et al., 2017). There is little evidence on the concept of parenting in the literature. The literature have examined the impact of ASD on family cohesion, family adjustment ability, and parental mental health (Lee J, 2013; Cantwell et al., 2014; Emerson et al., 2006; Mugno, 2007; Seymour et al., 2017, Chan et al., 2018, Shenaar-Golan et al., 2017, Cook et al., 2020), but limited research have assessed the concept of parenting children with ASD including parenting activities, child-parent interactions, and the way that specific characteristics of children with ASD affect parenting. However, despite the increasing prevalence of ASD and the emphasis on its clinical and experimental features in the last two decades, there is little research on parenting of children with autism, their activities, interactions and challenges, and the concept of parenting in general in these particular children. Such a knowledge can determine the characteristics of parenting these children, the factors affecting it and its consequences to attract the attention of policy makers so that they plan interventions to relatively improve the level of performance of the parents of children with ASD and their families.

Rogers' evolutionary concept analysis is one of the inductive methods of analysis. Rogers argues that concepts evolve over time and are influenced by the context in which they are used; therefore, the concepts are constantly under dynamic development. Despite the diversity and great number of scientific articles on the concept of parenting, there is no single definition in nursing about parenting in children with autism. Therefore, the

present study aimed to clarify the concept of parenting and to better understand its attributes, antecedents, consequences and its changes over time using Rogers' evolutionary approach.

METHOD

In this study, Rogers' evolutionary approach was used. According to this approach, the analysis process is non-linear and includes a series of overlapping steps which its main purpose is to clarify the concept. The study process is flexible in nature and the researcher often goes back and forth at each step and some steps occur simultaneously. Identifying and determining the concept of interest is the first activity. After identifying the concept of interest, the researcher referred to valid and available scientific databases including PROQUEST, SCIENCEDIRECT, PUBMED, CINAHL, PsycINFO, EMBASE, SCOPUS and searched without considering a time limit with the keywords related to parenting. According to Table 1, many articles were identified in various disciplines. Therefore, in order to

limit the search, articles in different disciplines were searched using the key words of Autism, children, parenting, parenting children with autism, child parents, caregiver, in the title, abstract and text of the article. A total of 488 articles were identified and after reviewing their abstracts and removing repetitions, 215 articles were selected which included the words parenting, autism, and children in the main title, were full text and available in "English". It is worthy of mention that the keywords were also searched in Persian databases such as SID, IRANMEDEX and also in Google scholar and after a thorough review of the articles, 5 studies entered the study. Then, as shown in Table 2, articles were classified according to four disciplines of nursing, psychology, social sciences and medicine, and 30% of the articles in each field were selected. Finally, 65 texts (63 articles, 2 dissertations) which were closer to the title of the present study were selected, and then the data were analyzed based on Rogers' evolutionary model.

Table 1: Search results for articles in information databases

Searched databases	sciencedirect	scopus	proquest	pubmed	embase	Total
Search by parenting in title, text, abstract and keywords	875293	34556	246800	21168	7726	1185543
parenting and children and autism in title, text, abstract and keywords	15669	632	19475	423	186	36385
parenting and children and autism in the title	146	94	178	50	28	496
Full text articles in English	29	35	94	48	9	215
Final extracted articles by database	8	9	22	13	8	60
Persian and other databases	Google Scholar		SID	IRANMEDEX		
Parenting of children with autism	4	-		1		5
Total	65					

Table 2: Search results for articles by disciplines

Disciplines	Nursing	Social Sciences	Medicine	Psychology	All Articles
Articles by field	53	20	26	116	215
30% of each field	16	6	8	35	65

Table 3. Summary of the literature related to the concept of parenting of children with autism

author .year	attributes	antecedents	consequences
Kayhan Parsi, and Nanette Elster 2012	<ul style="list-style-type: none"> ➤ raising a child with autism becomes a "full time job" ➤ we see that the challenges of raising a child with autism 	<ul style="list-style-type: none"> ➤ Lost Hopes and Dreams ➤ self-doubt, anxiety and guilt ➤ Financial barriers, educational barriers, communication barriers, and emotional barriers are all evident in these heartfelt stories 	<ul style="list-style-type: none"> ➤ Shumaker talks about the "love and guilt" in raising her son ➤ It may be that these conflicting emotions reflect the conflicts of autism itself with both its blessings and its curses.
Ooe et al.,2016	<ul style="list-style-type: none"> ➤ Parenting a child with autism was depicted as difficult due to challenging behaviors 	<ul style="list-style-type: none"> ➤ lack of awareness and understanding about autism ➤ "normal" appearance of the child 	<ul style="list-style-type: none"> ➤ having to quit their jobs or giving up career opportunities ➤ sense of hope experienced when their child improved also helped parents cope ➤ that they found joy and felt blessed in raising a child with autism/ Stigma ➤ parents stated changed their perspective of life and made them more appreciative of it.
Lindsey Hutchison et al. 2016	<ul style="list-style-type: none"> ➤ They may find their lives greatly altered by the addition of a child into the family who requires extraordinary time and attention. 	<ul style="list-style-type: none"> ➤ poor social or language skills, odd behavior or appearance, developmental delays ➤ poor self-regulatory abilities 	<ul style="list-style-type: none"> ➤ While all parents experience stress while raising children
Crystal R et al. 2013		<ul style="list-style-type: none"> ➤ dysregulated routines ➤ self-injurious behaviors 	<ul style="list-style-type: none"> ➤ often experience serious distress ➤ higher-than-expected rate of marital discord and divorce ➤ parents of atypical children feel stigmatized by society ➤ poorer physical health ➤ anxiety and depression
Pottie et al.2012	<ul style="list-style-type: none"> ➤ Parenting a child with an autism 	<ul style="list-style-type: none"> ➤ disruptive child behaviors and 	<ul style="list-style-type: none"> ➤ experience significantly higher levels

author .year	attributes	antecedents	consequences
	spectrum disorder (ASD) is a unique and challenging experience	behaviors ➤ social support daily emotional support	of parenting stress and psychological distress
Cynthia A. Serrata.2012	➤ Mothers report that caring for a child with autism is a full-time responsibility ➤ grieving process	➤ lack of sleep, genetic factors, caregiver role, acceptance of the disorder, marital stress, financial stress ➤ burden of caring ➤ lack of professional and educational support	➤ impact on the family and marriage systems, financial resources, and the parents' psychological well-being ➤ there is a high degree of parental stress and depression ➤ have feelings of anger and depression ➤ report lower perceived parenting competencies
Angela Sim et al.2018	➤ Co-parenting is the process by which parents support each other and coordinate childrearing responsibilities	➤ Social support has been shown to help alleviate this stress ➤ the distance required to travel to the child's medical facilities	➤ There is documented evidence of increased parenting stress, poor parent-child interaction and low marital satisfaction to report increased family stress associated with having a child with ASD
Phetrasuwan, Supapak; Miles, .2009	➤ Caring for a child with Autism is demanding and presents significant challenges to parents	➤	➤ Parenting stress
LISA M. DIELEMAN.2016	➤ Raising a child with autism spectrum disorder (ASD) is challenging parenting	➤ differences in parental well-being ➤ struggle severely in coping with the daily challenges	➤ persistent feelings of stress
Abbas Heydari et al.,2015	➤ Being a mother of a child with ASD is not easy because these children have very distinct needs and require more care, guidance, supervision, and support ➤ it changed the meaning of their lives. ➤ caring for autistic children because of their particular circumstances is a strain situation for mothers Spirituality guided mothers of this study in the way of growing and refining their lives	➤ gratefulness, surrendering to god, having the divine test ➤ wide variety of crippling, lifelong disabilities in social interactions, verbal and nonverbal communications	➤ having sorrowful tale, unanswered question, escaping from reality, losing hope ➤ Ascent: helping her child is becoming all of the mother's life (to rescue, being hopeful, listening to her inner voice)
Megan M Pruitt.2016		➤ In addition, children's language, cognitive, and social impairments were related to greater parenting stress for parents of a child with ASD ➤ increased depressive symptoms ➤ predicted increased daily negative affect and lower daily positive affect	➤ Parents of a child with ASD are at an elevated risk for experiencing increased depressive symptoms and negative affect ➤ In addition to lower well-being, parenting a child with ASD may present unique challenges that lead to greater parenting

Findings: In this section, the attributes, antecedents, and consequences of the concept of parenting of children with autism are discussed, and the related concepts and surrogate terms and a model case are introduced.

Attributes : In the present study, the concept of parenting of children with autism is a concept with a process nature that was manifested by four attributes including: The process of demanding and challenging, unique and multifaceted care (guiding, educating and socializing children); Reciprocal and dynamic interaction between the parents and the child; Personality growth, and Spiritual journey

The process of demanding and challenging, unique and multifaceted care (guiding, educating and socializing children): According to the literature, parenting of children with autism is a care experience that overshadows the entire life of the parents, and they experience many changes in life due to full-time care of the child. Also, raising such a child is accompanied by care, friendship and guidance from parents (Seay et al., 2014; Rutgers et al., 2007; Hutchison et al., 2016; Dardas and Ahmad, 2015; Desai, 2012; Burrell et al., 2017). Parenting

is the process of raising and educating a child from birth to adulthood, which is performed by parents, and the process of parental performance refers to child care skills or activities (Saovakon Virasiri, 2011). Parents play a role in caring for a child with ASD throughout the child's life (Burrell et al., 2017). Parenting a child with autism is a unique and challenging experience (Pottie et al., 2009), It is a full-time care and responsibility (Parsi and Elster, 2012) in which parents decide on behalf of the child and commit to the daily events related to the child (Lee et al., 2010; Saovakon Virasiri, 2011). Parenting a child with autism is portrayed as difficult because of the child's challenging behaviors that increase stress and affect parental life (Ooi et al., 2016; Myers BJ, 2009; Fletcher PC et al., 2013). The life process of these parents consists of several stages; the first stage begins with shock and disbelief in accepting the diagnosis of autism in a child leading to the expression of sadness, confusion and despair.

At the end of the first stage, the parents must achieve a reorganization and accept their role in caring for the child. In the second stage, parents may become angry and aggressive and blame themselves and their spouse for

having such a child. The third stage of parenting begins when parents experience abnormal behaviors and communication and social deficiencies in the child's daily life and feel that their life is uncontrollable and they do not have the ability to manage it and finally accept their child in the fourth stage (Serrata, 2012; Saovakon Virasiri, 2011). Parents of children with autism are not the only caregivers of the child, but play the role of counselor and educator of the child throughout his/her life (Parsi and Elster, 2012). In the process of parenting, parents of children with autism face communication problems and lack of social interactions and strange and unusual behaviors of the child in which the living conditions become uncontrollable and in addition to managing the situation, they need to acquire educational skills to treat the child properly and make him adapt to the community environment (Zhou and Yi, 2014; Heydari et al., 2015; Duchene, 2015; Desai, 2012). The parents, guide the child toward progress in this process, and ensure the child's ability to live independently and moving forward throughout life. After accepting the child, the parents have responsibilities such as feeding, guiding and protecting the child against external injuries. To facilitate the child's social relations, they take him outside and to park, participate in religious ceremonies, and communicate with relatives and involve the child in group work and give him the chance to play with his peers (Ooi et al., 2016; Desai, 2012; Serrata, 2012). Rutter emphasized that parenting is primarily a duty related to the socialization or education of children, which includes the dimensions of sensitivity to children's needs, their social communication and emotional expression, and also observance of order and regulations, which is one of the most complex, challenging, and potentially valuable tasks that parents can do (Rutter, 1985). In fact, parenting is a multifaceted process that affects different dimensions of being parent and child and affects the care, guidance, support and upbringing of the child (Singh, 2016, Myers BJ, 2009, Fletcher PC et al., 2013).

Reciprocal and dynamic interaction between the parents and the child: The duty of caring, guiding, protecting, educating and socializing children occurs during the daily behaviors of parents and interactions between the child and parents. This relation depends on the parents' understanding of themselves and the child, their emotions, attitudes and values (Harden, 2005, Wyness, 1997, Berg - Nielsen and Holen, 2003). Parenting is the process of child-parent communication that aims to raise and socialize the child. Parenting is an active reciprocal process of interaction between the parents and the child and the child with the parents which is formed during communication and relations with the child. In fact, the basis of the process of parenting and child care is the dynamic interaction of parents with the child, the child with parents or even parents with each other (Blake Snider et al., 2004; Saovakon Virasiri, 2011; O'Connor and Scott, 2007, Dieleman et al., 2016). Parents' good relationship with each other and parental involvement refers to the way of parents' communication with each other and acceptance of their role as caregivers of the child and parents. Supporting a spouse and collaborating with him/her is very effective in managing child care challenges, reducing care stress, and increasing parental performance (Thullen and Bonsall,

2017). Duchene suggested the use of the term "parent-child relationship" instead of parenting, which in fact refers to the reciprocal, dynamic, and interactive process of child care (Duchene, 2015). Poor communication between the parents or between parents and child leads to stress, endangers the physical and mental health of parents, reduces parental self-efficacy, and creates performance problems in the family (McEvoy et al., 2005; Serrata, 2012; Sim et al., 2017, Boonen et al., 2015, Pruitt et al., 2016, Burrell et al., 2017). Raising a child with autism disorder affects not only the parents but the whole family. Olson (2000) identified three dimensions in the family including cohesion, flexibility, and communication. Cohesion refers to the emotional ties between family members and ranges from no emotional involvement to complete emotional involvement of the family members with each other. Flexibility refers to the family adaptation ability and changing aspects of their life that ranges from strict discipline and regulation to disorder and chaos. Finally, communication which facilitates the other two dimensions, and healthy families are usually characterized by a balanced level of cohesion and flexibility, and this balance is facilitated by proper communication (Pruitt et al., 2016).

Spiritual Journey and Personality Growth: The birth of a healthy child is accompanied by great enthusiasm of the parents and envisioning a prospect of the child's life; this ideal image is impaired by recognizing the child's developmental problems and disabilities (Heydari et al., 2015). Most parents experience denial, confusion, anger, and depression when their child is diagnosed with autism. Feelings of incompetence, anger, failure, disbelief, guilt, resentment, and fatigue are often seen in parents after the diagnosis. Other problems such as stigmatization of the child and family, blaming the mother for the disorder, comparing the child with a normal child, doubting the impact of treatment and education programs, and feeling that the child is not equipped with appropriate therapies and the pressure of decision-making for the treatment of the child lead to reduced social relationships and family problems for the parents (McStay et al., 2014, Parsi and Elster, 2012, Serrata, 2012, Phetrasuwan and Shandor Miles, 2009, Hall and Graff, 2010, Dardas and Ahmad, 2015, Stewart et al., 2017, Pruitt et al., 2016, Brobst et al., 2009, Cashin, 2004). Therefore, in dealing with stressful situations, some parents have used adaptation mechanisms such as joining social groups, contacting other parents of autistic children, seeking help for medical tasks and care, receiving information and choosing an appropriate style of parenting and other methods and obtained positive results in caring for a child with autism (Hall and Graff, 2010, Zhou and Yi, 2014). Parenting of children with autism has been associated with, thinking between what it is and what it will be, loss of hope, connection with God, gratitude, submission to God, saving the child, attending religious services, being hopeful, listening to the inner voice, change in looking at the world, and a sense of growth and perfection (Heydari et al., 2015; Boonen et al., 2015; Parsi and Elster, 2012; Cashin, 2004; Phetrasuwan and Shandor Miles, 2009).

Antecedents: Antecedents are the conditions that must exist before the concept occurs.

Causes related to the child -: The nature of the illness

Lifelong illness (Van IJzendoorn et al., 2007; Burrell et al., 2017), lifelong parental dependence (Phetrasuwan and Shandor Miles, 2009; Burrell et al., 2017), and less control over one's life (Burrell et al., 2017) are among the causes related to the nature of the illness that can affect the quality of care and service provided by parents.

Intensity, repetition and complexity of behavioral problems; Lack of social and communication interactions of a child with autism

Repetitive and limited behaviors (Hayes and Watson, 2013, Serrata, 2012, Berg - Nielsen and Holen, 2003, McNeill, 2004, Hamner and Turner, 1985, Helseth and Ulfset, 2005, Wyness, 1997, Harden, 2005, Burrell et al., 2017), External disruptive behaviors of the child such as property destruction (Rutter, 1985), strange behavior and appearance of the child (McEvoy et al., 2005) and hyperactivity (Mayor, 2009; Rodgers, 2000, Levin and Scher, 2016), limited communication with the people around and peers, lack of interest in communication with others (Burrell et al., 2017; Hill-Chapman et al., 2013; Hoffman et al., 2009; Hayes and Watson, 2013, Serrata, 2012; Rutter, 1985), decreased self-regulation skills (McEvoy et al., 2005; Serrata, 2012), not having eye contact with parents (Serrata, 2012) and lack of interest in group activities and social work (Berjis et al., 2013; Serrata, 2012), severity and complexity of behavioral problems (Rutgers et al., 2007; Hoffman et al., 2009, Reed et al., 2016, Jones et al., 2013, Phetrasuwan and Shandor Miles, 2009, Pedersen, 2012, Pruitt et al., 2016), nutrition and behavioral problems at the time of eating such as eating only certain foods, annoying behaviors at the time of eating, eating in certain situations and choosing certain foods (Thullen and Bonsall, 2017; Aali, 2015) and sleep problems (Burrell et al. al., 2017, Serrata, 2012, Weitlauf et al., 2014, Phetrasuwan and Shandor Miles, 2009, Levin and Scher, 2016) were among the behavioral factors mentioned in the literature that can affect the quality of care and the concept of parenting.

Causes related to parents :Parents' psychological problems such as stress, anxiety and depression (Hockenberry et al., 2016; Hoffman et al., 2009, Reed et al., 2016, Serrata, 2012, Hock et al., 2012, Burrell et al., 2017), lack of social support (McEvoy et al., 2005; Pottie et al., 2009; Serrata, 2012; Sim et al., 2017), job-related problems such as limited job opportunities, job loss and constant fear related to not finding suitable work and financial problems, high costs of child treatment and family income level (McNeill, 2004; Harden, 2005; Hock et al., 2012), parental personality traits such as inflexibility, sensitivity to criticism, lack of personal resilience, lack of self-confidence (Mohammadi and Zarafshan, 2014; Davis and Carter, 2008; Hock et al., 2012), poor family cohesion, dissatisfaction with marital relationships, disputes with spouse and family, interpersonal problems (McEvoy et al., 2005; McNeill, 2004; Mohammadi and Zarafshan, 2014), low knowledge and information about child care (Dardas and Ahmad, 2015), negative parental feelings and emotions about caring for a child with autism, such as feelings of disappointment, grief and heartache (McStay et al., 2014; Parsi and Elster, 2012; Hock et al., 2012) are also parent-related causes that affect the attributes of the concept.

Consequences :A phenomenon that is expected to follow the occurrence of a concept is called a consequence (Hansen et al., 2015). After reviewing the related studies and following the concept of parenting of children with autism, both positive and negative consequences manifested.

Positive consequences :Parental adjustment for care, joining strong social networks, contacting other parents with children with autism, adaptive behaviors, participation in religious programs (Hock et al., 2012, Rodgers, 2000, Dardas and Ahmad, 2015, Serrata, 2012), protecting the child from the harsh judgments of others (Parsi and Elster, 2012), increasing parental involvement, spending more time at home and more life enjoyment and satisfaction (Hill-Chapman et al., 2013, Desai, 2012), constant efforts to protect the child and the feeling of love in child care (Parsi and Elster, 2012), feelings of pride (Parsi and Elster, 2012), better communication and respect for the spouse (Parsi and Elster, 2012), increasing parental self-efficacy (Hutchison et al., 2016), high satisfaction with parental role (Hill-Chapman et al., 2013), giving thanks to God (Hock et al., 2012; Heydari et al., 2015), parental unity, respect for the spouse, strong intimacy and commitment between the couples (Hill-Chapman et al., 2013; Hock et al., 2012), personality development and a sense of life satisfaction, and changing attitudes toward the world (Heydari et al., 2015, Boonen et al., 2015, Parsi and Elster, 2012; Cashin, 2004; Phetrasuwan and Shandor Miles, 2009) are among the positive outcomes of parenting children with autism in the literature.

Negative consequences: Social isolation, stigmatization by society, feelings of imprisonment (Burrell et al., 2017; Hock et al., 2012; Berg - Nielsen and Holen, 2003; Harden, 2005), stress and anxiety, depression and mental disorders, feelings of anger (Stewart et al., 2017; Burrell et al., 2017, McStay et al., 2014, Thullen and Bonsall, 2017, Hill-Chapman et al., 2013, Hayes and Watson, 2013, van Steijn et al., 2013 , Serrata, 2012, Pruitt et al., 2016), choosing a rigid and inflexible parenting style (Hock et al., 2012, Dieleman et al., 2016, Pruitt et al., 2016), reduced well-being and physical and mental health of the parents, heart disease in parents, lack of sleep, physical and emotional fatigue (Rodgers, 2000, Pruitt et al., 2016, Estes et al., 2009, Reed et al., 2016, Hill-Chapman et al., 2013, Hock et al., 2012, McNeill, 2004, Hamner and Turner, 1985, Serrata, 2012, Foody et al., 2015), decreased family performance and self-regulatory skills (McEvoy et al., 2005, Hayes and Watson , 2013, Burrell et al., 2017), lack of self-efficacy, feeling of less parental competence and decreased parenting quality, increased care burden and reduced parental quality of life (Burrell et al., 2017; McNeill, 2004; Serrata, 2012; Weitlauf et al., 2014; McEvoy et al., 2005; Dardas and Ahmad, 2015; Wyness, 1997; Burkett et al., 2016), financial pressure and job problems (Serrata, 2012; Hock et al., 2012; McNeill, 2004; Dardas and Ahmad, 2015; Harden, 2005), family instability, reduced marital quality, dispute with spouse and increased likelihood of divorce (Hayes and Watson, 2013; McNeill, 2004; Brobst et al., 2009; Hill-Chapman et al., 2013; McEvoy et al., 2005; Serrata, 2012; Sim et al., 2017) are also among the negative consequences of parenting of children with autism.

The attributes, antecedents and consequences of the concept are depicted in a theoretical model (Figure.1).



Figure 1: The theoretical model of the concept of parenting of children with autism.

Surrogate terms and related concepts : Related concepts include part of the relationships of the main concept but do not share all the attributes of the concept under study (Hansen et al., 2015). In the present study, the term that was most related to the concept of parenting of children with autism was “parenthood” which means becoming a parent through the birth process and is only part of parenting and not the whole of it.

Parenting is a more comprehensive and broader concept than parenthood and includes the activities and responsibilities of raising a child. Parenting is also related to the word caregiver, but it is different from it. A caregiver is a person who, along with parents, can lovingly care for and guide a child; such a person can be a grandmother, grandfather, uncle, or aunt that have a family relationship with the child, or have a non-familial relationship like child nurses, teachers, and health care providers. Surrogate terms mean expressing the concept with words and expressions other than the selected concept in the study (Hansen et al., 2015). After reviewing and analyzing the related articles, the words “mothering”, “upbringing”, and “caretaking” were manifested as the terms which could be used instead of the word parenting.

Interpretation and Implications of the Concept :The results of data analysis showed that the concept of parenting of children with autism in the field of nursing has a definition which is different from the concept of parenting in the fields of social sciences, medicine and psychology. Regarding the nursing perspective that believes the human truth and its related phenomena are constantly changing; the concepts are related to each other, and can be merely interpreted in a set of contextual factors, the definition of this concept is different from other disciplines. The review

of the studies and the combination of the subjective and objective experiences of the parents of children with autism showed that a clear and uniform definition of parenting cannot be given for all the parents of children with autism. In some instances, parenting had occurred with negative consequences mentioned earlier, and in some texts, the positive aspects of parenting and its positive consequences were mentioned for the child and the parents; there was not a thorough description of parenting of children with autism as a specific group in society in the literature of different disciplines; also there was no agreement on its attributes, antecedents and consequences.

In the present study and from a nursing perspective, considering the antecedents that affect the occurrence of the concept of parenting in children with autism and its related consequences, a very complex, multifaceted and evolving definition was provided. Findings of the present study consider the concept of parenting of children with autism as having a process nature which includes the following four characteristics:

- Demanding and challenging care
- Unique and multifaceted care (guidance, education and socialization of children)
- Reciprocal and dynamic interaction between the parents and the child
- Personality growth and spiritual journey

According to the present study, the concept of parenting of children with autism is a very unique concept that its manifestations varies from person to person. It is very pervasive and potentially affects every aspect of a person's life and is identified as its psychological, social, cognitive, behavioral, spiritual, and emotional effects.

Based on the above features, the present study defines the concept of parenting of children with autism as "a demanding, challenging, unique and multifaceted process of care, guidance, support and education for the child's socialization and comprehensive development, and the child's physical and mental well-being based on a dynamic interaction between the parents and child and parents with each other, and a spiritual journey with the growth of personality and change in oneself".

Altogether, according to the findings of this study, it can be concluded that paying attention to the attributes, antecedents and consequences in the present study contributes more to the clarity of the concept of parenting of children with autism and attentiveness to this concept can lead to the importance of paying attention to children with autism and their parents in the nursing profession.

CONCLUSION

Generally, definition of the concept of parenting of children with autism has added to the basic knowledge to nursing. This concept analysis is the basis for further research to explain the meaning of parenting in a particular group of children and develops measurable features for the programs of parenting of children with autism. Altogether, this concept analysis provides a basis for developing tools for measuring parenting skills and different aspects of parenting of children with autism. Development of instruments to measure various constructs of parenting children with autism include care, guidance, education and socialization of children, the parent-child relationship and the parents' view of life. It should be noted that one of the limitations of this study was the lack of access to the full text of some related articles and also the lack of use of articles in non-English languages (except Persian).

In the present study, it was also found that religious beliefs and values of individuals as antecedents are effective in the occurrence of parenting and the definition of this concept is influenced by culture. Therefore, future studies are recommended to analyze the concept in the cultural context of Iran and other countries using a hybrid model in order to achieve a more accurate definition of this concept in the field of nursing.

REFERENCES

1. American Psychiatric Association. 2013. Diagnostic and Statistical Manual of Mental Disorders (DSM-5®). American Psychiatric Pub
2. aali, S., Amin Yazdi, A., Abde Khodaei, Ms., Ghenaie, A. And Moharri, F. 2015. Development work families with children with autism spectrum disorders compared to Families with children healthy. Medical Journal of Mashhad.
3. Berg-Nielsen, T. S. & Holen, A. 2003. From clinical towards research interview: Parenting problems with troubled adolescents. Scandinavian journal of psychology, 44, 319-329.
4. Berjis, M., Hakim, J. M., Taher, M., Gh, L. M. & Hossein, K. A. 2013. A comparison of the amount of worry, hope and meaning of life in the mothers of deaf children, children with autism, and children with learning disability.
5. BLake Snider, J., Clements, A. & Vazsonyi, A. T. 2004. Late adolescent perceptions of parent religiosity and parenting processes. Family Process, 43, 489-502.
6. Blumberg, S. J., Bramlett, M. D., Kogan, M. D., Schieve, L. A., Jones, J. R. & Lu, M. C. 2013. Changes in prevalence of parent-reported autism spectrum disorder in school-aged US children: 2007 to 2011–2012. National health statistics reports, 65, 1-7.
7. Boonen, H., Van Esch, L., Lambrechts, G., Maljaars, J., Zink, I., Van Leeuwen, K. & Noens, I. 2015. Mothers' parenting behaviors in families of school-aged children with autism spectrum disorder: an observational and questionnaire study. Journal of autism and developmental disorders, 45, 3580-3593.
8. Brobst, J. B., Clopton, J. R. & Hendrick, S. S. 2009. Parenting children with autism spectrum disorders: The couple's relationship. Focus on Autism and Other Developmental Disabilities, 24, 38-49.
9. Burkett, K., Morris, E., Anthony, J., Shambley-Ebron, D. & Manning-Courtney, P. 2016. Parenting African American Children With Autism The Influence of Respect and Faith in Mother, Father, Single-, and Two-Parent Care. Journal of Transcultural Nursing, 1.043659616662316
10. Burrell, A., Ives, J. & Unwin, G. 2017. The Experiences of Fathers Who Have Offspring with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 47, 1135-1147.
11. CASHIN, A. Painting the vortex: The existential structure of the experience of parenting a child with autism. International Forum of Psychoanalysis, 2004. Taylor & Francis, 164-174.
12. Cantwell, J.; Muldoon, O.T.; Gallagher, S. 2014. Social support and mastery influence the association between stress and poor physical health in parents caring for children with developmental disabilities. Res. Dev. Disabil. 35, 2215–2223
13. Cooke Emma *, Valerie Smith, Maria Brenner. 2020. Parents' experiences of accessing respite care for children with Autism Spectrum Disorder (ASD) at the acute and primary care interface: a systematic review. BMC Pediatrics, 20:244
14. Chan, K.K.S.; Lam, C.B.; Law, N.C.W.; Cheung, R.Y.M. 2018. From child autistic symptoms to parental affective symptoms: A family process model. Res. Dev. Disabil, 75, 22–31
15. Dardas, L. A. & Ahmad, M. M. 2015. For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and quality of life? Research in developmental disabilities, 36, 620-629.
16. Davis, N. O. & Carter, A. S. 2008. Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. Journal of autism and developmental disorders, 38, 1278-1291.
17. Desai, M. U. 2012. Caring In Context: Parenting A Child With An Autism Spectrum Disorder In India. Fordham University.
18. Dieleman, L. M., De Pauw, S. S., Soenens, B., Beyers, W. & Prinzie, P. 2016. Examining bidirectional relationships between parenting and child maladjustment in youth with autism spectrum disorder: A 9-year longitudinal study. Development and psychopathology, 1-15.
19. Duchene, M. S. 2015. Maternal Experiences of Parenting Children with Autism Spectrum Disorder: A Qualitative Analysis.
20. Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.-H. & Abbott, R. 2009. Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Autism, 13, 375-387.
21. Emerson, E.; Hatton, C.; Llewellyn, G.; Blacker, J.; Graham, H. 2006. Socio-economic position, household composition, health status and indicators of the well-being of mothers of

- children with and without intellectual disabilities. *J. Intellect. Disabil*, 50, 862–873.
22. Fletcher PC, Markoulakis R, Bryden PJ. 2012. The costs of caring for a child with an autism spectrum disorder. *Issues Compr Pediatr Nurs*. 35(1):45–69.
 23. Foody, C., James, J. E. & Leader, G. 2015. Parenting stress, salivary biomarkers, and ambulatory blood pressure: a comparison between mothers and fathers of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 45, 1084-1095.
 24. Hall, H. R. & Graff, J. C. 2010. Parenting challenges in families of children with autism: A pilot study. *Issues in comprehensive pediatric nursing*, 33, 187-204.
 25. Hamner, T. J. & Turner, P. H. 1985. Parenting in contemporary society, Prentice-Hall .Hansen, S. N., Schendel, D. E. & Parner, E. T. 201 .5Explaining the increase in the prevalence of autism spectrum disorders: the proportion attributable to changes in reporting practices. *JAMA pediatrics*, 169, 56-62.
 26. Harden, J. 2005. Parenting a young person with mental health problems: Temporal disruption and reconstruction. *Sociology of Health & Illness*, 27, 351-371.
 27. Hayes, S. A. & Watson, S. L. 2013. The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of autism and developmental disorders*, 43, 629-642.
 28. Helseth, S. & Ulfset, N. 2005. Parenting experiences during cancer. *Journal of advanced nursing*, 52, 38-46.
 29. Heydari, A., Shahidi, L. H. & Mohammadpour, A. 2015. Spiritual Journey in Mothers' Lived Experiences of Caring for Children With Autism Spectrum Disorders. *Global journal of health science*, 7, 79.
 30. Hill-Chapman, C. R., Herzog, T. K. & Maduro, R. S. 2013. Aligning over the child: Parenting alliance mediates the association of autism spectrum disorder atypicality with parenting stress. *Research in developmental disabilities*, 34, 1498-1504.
 31. Hock, R. M., Timm, T. M. & Ramisch, J. L. 2012. Parenting children with autism spectrum disorders: A crucible for couple relationships. *Child & Family Social Work*, 17, 406-415.
 32. Hockenberry, M. J., Wilson, D. & Rodgers, C. C. 2016. *Wong's essentials of pediatric nursing*, Elsevier Health Sciences.
 33. Hoffman, C. D., Sweeney, D. P., Hodge, D., Lopez-Wagner, M. C. & Looney, L. 2009. Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 24, 178-187.
 34. Hutchison, L., Feder, M., Abar, B. & Winsler, A. 2016. Relations between Parenting Stress, Parenting Style, and Child Executive Functioning for Children with ADHD or Autism. *Journal of Child and Family Studies*, 25, 3644-3656.
 35. Jones, L., Totsika, V., Hastings, R. P. & Petalas, M. A. 2013. Gender differences when parenting children with autism spectrum disorders: A multilevel modeling approach. *Journal of Autism and Developmental Disorders*, 43, 2.2098-090
 36. Landa, R. J., Holman, K. C. & Garrett-Mayer, E. 2007. Social and communication development in toddlers with early and later diagnosis of autism spectrum disorders. *Archives of general psychiatry*, 64, 853-864.
 37. Lee, A. R., Hong, S. W., Kim, J. S & .Ju, S. J. 2010. Life transition of mothers of children with autism. *Journal of Korean Academy of Nursing*, 40, 808-819.
 38. Lee, J. 2013. Maternal stress, well-being, and impaired sleep in mothers of children with developmental disabilities: A literature review. *Res. Dev. Disabil*, 34, 4255–4273.
 39. Levin, A. & Scher, A. 2016. Sleep Problems in Young Children with Autism Spectrum Disorders: A Study of Parenting Stress, Mothers' Sleep-Related Cognitions, and Bedtime Behaviors. *CNS Neuroscience & Therapeutics*, 22, 921-927.
 40. Mayor, M. 2009. Longman dictionary of contemporary English, Pearson Education India Myers BJ, Mackintosh VH, Goin-Kochel RP. 2009. "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Res Autism Spectr Disord*.3(3):670–684.
 41. Mcevoy, M., Lee, C., O'Neill, A., Groisman, A., Roberts-Butelman, K., Dinghra ,K. & Porder, K. 2005. Are there universal parenting concepts among culturally diverse families in an inner-city pediatric clinic? *Journal of Pediatric Health Care*, 19, 142-150.
 42. McNeill, T. 2004. Fathers' experience of parenting a child with juvenile rheumatoid arthritis. *Qualitative Health Research*, 14, 526-545.
 43. Mcstay, R. L., Dissanayake, C., Scheeren, A., Koot, H. M. & Begeer, S. 2014. Parenting stress and autism: The role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism*, 18, 502-510.
 44. Mohammadi, M. & Zarafshan, H. 2014. Family function, parenting style and broader autism phenotype as predicting factors of psychological adjustment in typically developing siblings of children with autism spectrum disorders. *Iranian journal of psychiatry*, 9, 55.
 45. Mugno, D.; Ruta, L.; D'Arrigo, V.G.; Mazzone, L. 2007. Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health Qual. Life Outcomes*, 5, 22.
 46. Naumanen-Tuomela, P. 2001. Concept analysis of expertise of occupational health nurses applying Rodgers's evolutionary model. *International journal of nursing practice*, 7, 257-265.
 47. O'connor, T. G. & Scott, S. 2007. Parenting and outcomes for children, Joseph Rowntree Foundation .Ooi Khim Lynn, Ong Yin Sin, Jacob Sabrina Anne, Khan Tahir Mehmood. 2016. Meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment J*, 12: 745–762
 48. Parsi, K. & Elster, N. 2012. Growing Up With Autism: challenges and opportunities of parenting young adult children with autism spectrum disorders. *narrative inquiry in bioethics*, 2, 207-211.
 49. Pedersen, D. E. 2012. The good mother, the good father, and the good parent: Gendered definitions of parenting. *Journal of Feminist Family Therapy*, 24, 230-246.
 50. Phetrasuwan, S. & Shandor Miles, M. 2009. Parenting stress in mothers of children with autism spectrum disorders. *Journal for specialists in pediatric nursing*, 14, 157-165.
 51. Pottie, C. G., Cohen, J. & Ingram, K. M. 2009. Parenting a child with autism: Contextual factors associated with enhanced daily parental mood. *Journal of Pediatric Psychology*, 34, 419-429.
 52. Pruitt, M. M., Willis, K., Timmons, L. & Ekas, N. V. 2016. The impact of maternal, child, and family characteristics on the daily well-being and parenting experiences of mothers of children with autism spectrum disorder. *Autism-973* ,20 , .985
 53. Reed, P., Howse, J., Ho, B. & Osborne, L. A. 2016. Relationship between perceived limit-setting abilities, autism spectrum disorder severity, behaviour problems and parenting stress in mothers of children with autism spectrum disorder. *Autism*, 1362361316658775.

54. Rodgers, B. L. 2000. Concept analysis: an evolutionary view. *Concept development in nursing: Foundations, techniques, and applications*, 2, 77-102.
55. Rutgers, A. H., Van Ijzendoorn, M. H., Bakermans-Kranenburg, M. J., Swinkels, S. H., Van Daalen, E., Dietz, C., Naber, F. B., Buitelaar, J. K. & Van ENGELAND, H. 2007. Autism, attachment and parenting: A comparison of children with autism spectrum disorder, mental retardation, language disorder, and non-clinical children. *Journal of abnormal child psychology*, 35, 859-870.
56. Rutter, M. 1985. Family and school influences on cognitive development. *Journal of child psychology and psychiatry*, 26, 683-704.
57. Seay, A., Freysteinson, W. M. & Mcfarlane, J. Positive parenting. *Nursing forum*, 2014. Wiley Online Library, 200-208 .Serrata, C. A. 2012. Psychosocial aspects of parenting a child with autism. *Journal of Applied Rehabilitation Counseling*, 43, 29.
58. Sim, A., Cordier, R., Vaz, S., Netto, J. & Falkmer, T. 2017. Factors associated with negative co-parenting experiences in families of a child with autism spectrum disorder. *Developmental neurorehabilitation*, 20, 83-91.
59. Seymour, M.; Giallo, R.; Wood, C.E. 2017. The psychological and physical health of fathers of children with Autism Spectrum Disorder compared to fathers of children with long-term disabilities and fathers of children without disabilities. *Res. Dev. Disabil.* 69, 8–17
60. Singh, J. S. 2016. Parenting work and autism trajectories of care. *Sociology of health & illness*, 38, 1106-1120.
61. Stewart, M., McGillivray, J. A., Forbes, D. & Austin, D. W. 2017. Parenting a child with an autism spectrum disorder: a review of parent mental health and its relationship to a trauma-based conceptualisation. *Advances in Mental Health*, 15, 4-14.
62. Shenaar-Golan, V. 2017. Hope and subjective well-being among parents of children with special needs. *Child Fam. Soc. Work*, 22, 306–316
63. Thullen, M. & Bonsall, A. 2017. Co-Parenting Quality, Parenting Stress, and Feeding Challenges in Families with a Child Diagnosed with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 1-9.
64. Van Ijzendoorn, M. H., Rutgers, A. H., Bakermans-Kranenburg, M. J., Swinkels, S. H., Van Daalen, E., Dietz, C., Naber, F., Buitelaar, J. K. & Van ENGELAND, H. 2007. Parental sensitivity and attachment in children with autism spectrum disorder: Comparison with children with mental retardation, with language delays, and with typical development. *Child development*, 78, 597-608.
65. Van Steijn, D. J., Oerlemans, A. M., De Ruiter, S. W., Van Aken, M. A., Buitelaar, J. K. & Rommelse, N. N. 2013. Are parental autism spectrum disorder and/or attention-deficit/Hyperactivity disorder symptoms related to parenting styles in families with ASD (+ ADHD) affected children? *European child & adolescent psychiatry*, 22, 671-681.
66. Saovakon Virasiri, D. 2011. Parenting: what are the critical attributes? *J Med Assoc Thai*, 94, 1109-16.
67. Weitlauf, A. S., Vehorn, A. C., Taylor, J. L. & Warren, Z. E. 2014. Relationship satisfaction, parenting stress, and depression in mothers of children with autism. *Autism*, 18, 194-198.
68. Wyness, M. G. 1997. Parental responsibilities, social policy and the maintenance of boundaries. *The Sociological Review*, 45, 304-324.
69. Zhou, T. & Yi, C. 2014. Parenting styles and parents' perspectives on how their own emotions affect the functioning of children with autism spectrum disorders. *Family process*, 53, 67-79.