



Parenting Stress in Parents Raising Children with Autism Spectrum Disorder (ASD): A Concept Analysis

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Abstract

Research Background: Literature in the autism spectrum disorder (ASD) field provides evidence that parents of children with ASD experienced high levels of parenting stress, with 56% of them reaching clinically significant levels. However, in the literature about ASD, there is no evidence to support the attributes of parenting stress among parents having children with ASD. **Purpose/Aim:** This study aims to undertake a concept analysis of parenting stress among parents having children with ASD. **Methods:** Walker and Avant's approach to concept analysis was used. **Results:** The main attributes of parenting stress among parents raising children with ASD are 1) intense mental, emotional, and physical distress, 2) negative mood (anger, frustration, resentment, and anxiety), 3) worries (uncertainty about child future), 4) low satisfaction with the parenting role, and 5) low perception of competence in the parenting role. These attributes are influenced by antecedent factors like parental characteristics, child characteristics, environmental factors, coping, and self-compassion. Consequently, parenting stress adversely affects parents' well-being, their mental health status, parent-child relationship, family functioning, and parents and children's quality of life (QoL). **Conclusions:** Parenting stress is essential to be examined in the autism field intense distress, negative mood, worries and low satisfaction with parenting roles are important attributes of parenting stress. The findings of this concept analysis can facilitate both researchers in the autism field and healthcare providers in clinical settings to develop culturally appropriate psychosocial interventions to reduce parenting stress and enhance resilience. Nurses working with children having ASD and their families may find this concept analysis to have significant implications for them. Overall, it may provide healthcare providers with insights into how to reduce parenting stress and enhance parents' resilience.

Subject Areas

Health Sciences

Keywords

Parenting, Parenting Stress, Autism Spectrum Disorders, Concept Analysis

1. Introduction

The intersection of parenthood and stress is a complex area, particularly due to the demanding nature of the parental role [1]-[3]. Parenting stress, a role-specific form of stress, can be distinguished from general stress through careful examination and measurement [4]. Substantial scholarly consensus exists regarding the conceptualization of parenting stress, as evidenced by the works of Belsky (1984), Webster-Stratton (1990), Abidin (1992), Deater-Deckard (1998), and Morgan *et al.* (2002). For example, Abidin (1990) defined parenting stress as the relationship between a parent and the environment in which the demands of parenthood exceed one's resources, leading the parent to feel incapable of fulfilling their role.

On the other hand, Deater-Deckard defined parenting stress as a set of processes resulting in aversive psychological and physiological reactions arising from the demands of parenting. Parenting stress has been studied in various contexts, particularly among parents of children with exceptional healthcare needs, such as diabetes, cerebral palsy, and neurodevelopmental disorders. Despite this, limited research has been conducted on parenting stress within the field of autism.

Parenting stress related to raising children with autism spectrum disorder (ASD) presents a unique and distinct form of stress, commonly known as autism-specific parenting stress. This experience is pervasive and exceptionally demanding. Research indicates that parents of children with ASD face higher levels of parenting stress compared to parents of children with intellectual disabilities or typically developing children [5]. Despite its prevalence, there has been limited exploration of this phenomenon within the context of raising children with ASD.

To address this gap, this article employs a concept analysis approach to gain a deeper understanding of parenting stress experienced by parents of children with ASD. Utilizing Walker and Avant's approach to concept analysis, the study aims to identify the defining attributes, antecedents, consequences, and empirical referents associated with the concept of parenting stress. The findings of this analysis will contribute to the formulation of a comprehensive definition of parenting stress within this specific context.

2. Methods

2.1. Concept Analysis Methods

A formal concept analysis was undertaken to explore the concept of parenting stress among parents of children with ASD and to examine how it has been con-

ceptualized in the literature. This study employs a well-established concept analysis approach (Avant and Walker, 2011), which is widely recognized, particularly in health-related fields. The analysis involved the following steps: 1) selecting the concept of parenting stress, 2) establishing the objectives of the analysis, 3) identifying all possible applications of the parenting stress concept, 4) identifying the defining attributes of the parenting stress concept, 5) creating a model case, a borderline case, and a contrary case of parenting stress, 6) defining the antecedents and consequences of this concept within the literature, and 7) identifying empirical referents of parenting stress (Figure 1).

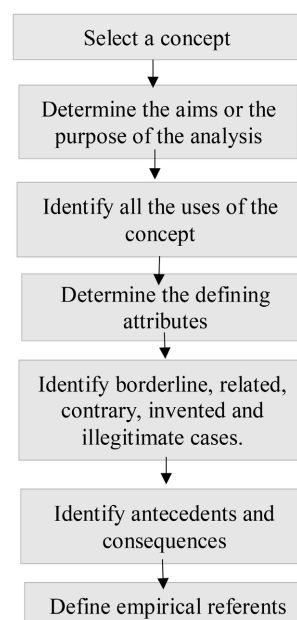


Figure 1. Avant and Walker's concept analysis approach.

2.2. Sources of Data

A literature search on parenting stress using the following databases: PubMed, Web of Science, EMBASE, Cochrane Library, and EBSCOhost databases: CINAHL PsycINFO, Academic Search Complete was conducted to identify the use of the parenting stress concept in diverse disciplines. The keywords are “parenting stress”, “autism spectrum disorder”, and “children”. Human studies from 2012 to 2022 were included in the search. The resulting literature was screened for relevance upon reviewing titles and abstracts, and selected articles were thoroughly examined. The data on parenting stress was also gathered from qualitative studies that explored the experiences of parents of children with ASD. Our search did not include articles from the gray literature, conference abstracts, and government documents. Inclusion criteria included qualitative or quantitative studies published in English that explored or examined the parenting stress of parents caring for children with an autism spectrum disorder. The article is excluded if it does not explicitly use the term “parenting stress” and uses other

terms such as parenting strain, stress-related care, stressors, perceived stress, distress, and caregiver stress. Articles are also excluded if they are for adolescent and adult individuals with ASD (Figure 2). One illustrates the number of identified, screened, and included papers using the PRISMA flow diagram. From each study that met the inclusion criteria, the author independently extracted data into a data extraction form with information regarding the study's purpose, publication year, year of study, and if it is about the antecedents, attributes, or consequences of the parenting stress concept.

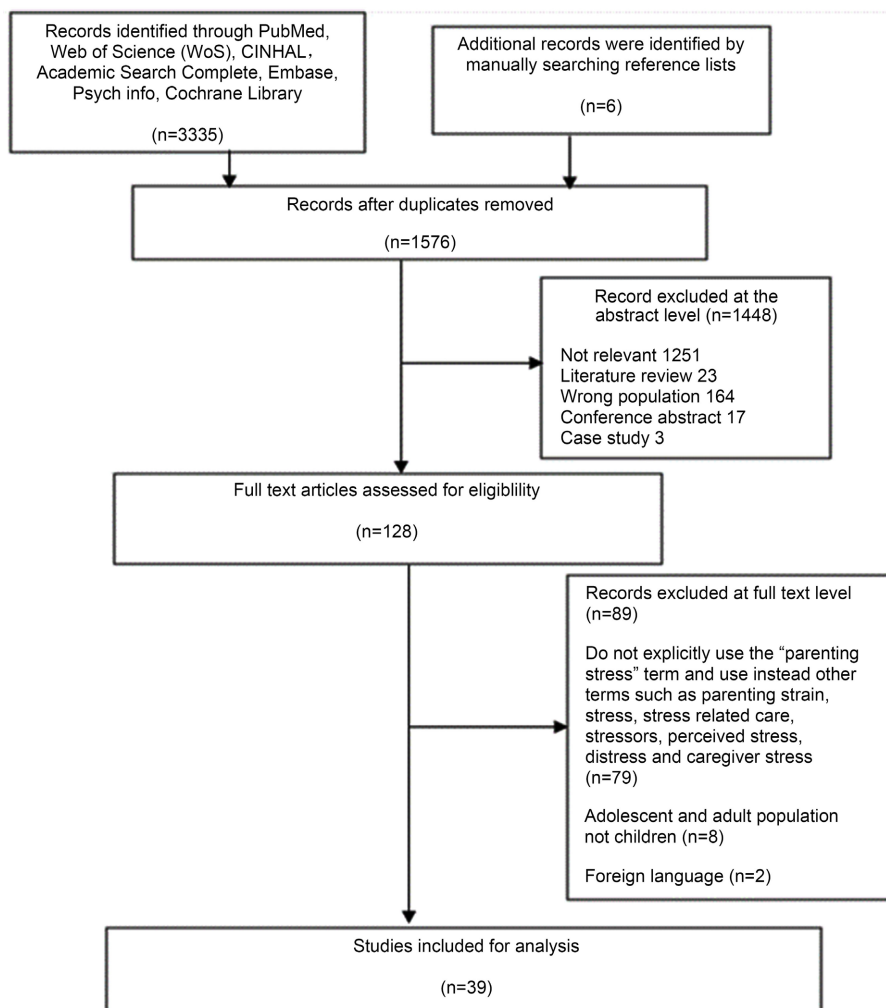


Figure 2. Search strategy for studies included in the analysis.

3. Results

3.1. Identifying the Use of the Concept

“Parenting stress” does not appear in any dictionary as one term. However, “parenting” and “stress” have been clearly defined separately. “parenting” is defined by the Collins English Dictionary & Thesaurus as 1) the activity of bringing up and looking after your child.; 2) the work or skill of a parent in raising a child; 3) the methods, techniques, etc., used or required in the rearing of children; and 4) of or

concerned with the rearing of children: 5) a state of being a parent. The New Oxford American Dictionary also defines “parenting” as the process of caring for your child or children. The Cambridge Dictionary of American English defines “parenting” as the raising of children and all responsibilities and activities that are involved in it. Thus, “parenting” can be defined as the process of raising a child from birth to independent adulthood with all activities and responsibilities involved. The word “stress”, on the other hand, is commonly used and has several definitions. In the Collins English Dictionary & Thesaurus, stress is 1) strong physical pressure applied to an object; 2) the act of emphasizing a word or action, 3) mental, emotional, or physical strain or tension. According to The New Oxford American Dictionary, “stress” is pressure or worry caused by problems in someone’s life.

According to the American Psychological Association, parenting practices share three primary goals: ensuring children’s health and safety, preparing children for life as productive adults, and transmitting cultural values. Theoretically, Belsky [6] (1984) proposed that parenting is a process influenced by the interaction between characteristics of the parent, child, and context. Stress, on the other hand, is defined as a “response of the body to any demand, whether it is caused by, or results in, pleasant or unpleasant conditions” [7]. However, current theories such as the theory of daily hassles deem that parenting stress is a normative part of the parenting role [8]. However, researchers believe that it becomes clinically important when manifested to the extent that it negatively impacts parenting practices and the parent-child relationship [9]-[13].

A core feature of parenting stress theory is the idea of balancing between parents’ perception of the demands of this role and the access to available resources to meet these demands [14]. Abidin [9] (1990), for instance, proposes a stress model within the parenting context, in which parenting stress is created by a disparity between the perceived demands of parenting and the available social and personal resources to address these demands. He postulates that a higher level of parents’ distress, perceived child difficulty, and parent-child dysfunctional interaction can lead to an increase in negative parenting, which, in turn, has an adverse impact on children’s behaviors and adjustment (Parent-Child-Relationship Theory). Abidin (1990) defined parenting stress as “a relationship between the parent and the environment in which the parent appraises the demands of being a parent as exceeding one’s resources, leaving the parent to feel she or he has difficulty filling the role of parent”.

Likewise, Webster-Stratton’s theory (1990) [15] proposed that extrafamilial stressors (e.g., unemployment and low socioeconomic status), interpersonal stressors (marital distress and divorce), and child stressors (e.g., behavior problems) affect parenting attitudes, parent-child interaction and may significantly increase parental stress. In support of Abidin and Webster-Stratton, Deater-Deckard posited that parental stress arises when parents’ expectations of resources to meet parenting role demands exceed the available resources (Deater-Deckard, 2004). According to Deater-Deckard (2008) [16], parental stress arises from the interaction between parents’ characteristics (those aspects of parenting stress that arises

from parents, e.g., level of education, gender, mental health, socioeconomic status, personality, social support, resources), child characteristics (e.g., those aspects of parenting stress that arises from the child, e.g., behavior problems), and the degree of conflict in the parent-child relationship. He suggests that this interaction may strongly influence the amount of stress experienced by parents. Deater-Deckard defines parenting stress as “a set of processes that lead to an aversive psychological and physiological reactions that arises from the attempt to adapt to the demands of parenting” [17]. Alternative terms that describe parenting stress in the literature are: “parental stress”, “parent stress”, “parenting-related stress”, the stress of the parent having children with ASD.

3.2. Attributes

In order to clearly define the parenting stress concept, it is imperative that its critical attributes be identified. The literature indicates that the key attributes associated with parental stress are severe mental, emotional, and physical distress, negative mood, worry (uncertainty about the child’s future), low satisfaction with a parenting role, low self-efficacy, low competence in the parenting role, ineffective parenting behaviors (such as decreasing expressions of warmth and affection), ineffective discipline methods (harsh, punitive), and withdrawal from parenting roles [18].

To illustrate, the literature shows that parents who report increased parenting stress report more mental, social, and physical distress generated from the daily childrearing activities of a parenting a child with ASD [19] [20]. Literature has also demonstrated that parents of children with ASD spend more time meeting their child’s care demands, constantly supervising the child, and doing household chores [21]. This child-centered life often leads to sleep disruption and physical and psychological exhaustion, reflecting physical, emotional, and social distress [22] [23]. Headache, backache, heartburn, and insomnia are examples of physical distress that may be encountered by parent raising children with ASD. Furthermore, the literature demonstrates that the social life of parents raising children with ASD is affected [23] [24]. Parents cannot have the same social life; instead, they adjust their routine and social life to accommodate this adversity, leaving less time for social life, leisure, and self-care activities (**Figure 3**).

These people are also more likely to experience negative moods (anger, fear, resentment, frustration, and anxiety) and emotional distress [25] [26]. Many parents report fear of the unknown and uncertainty about their child’s future [27]. A sense of worry about the future of their children was expressed consistently by parents according to literature. An overwhelming sense of apprehension was caused by uncertainty about a child’s living arrangements, employment opportunities, and ability to adjust to adulthood. All parents, regardless of their child’s age, felt worried about the transition to young adulthood. Parents reported increased parenting stress, also reporting that they are frustrated about their inability to understand how to help their child and anxious about dealing with autism symptomologies such as social and communication deficits. Parents

who show a high level of parenting stress also show resentment and anger due to feeling tired, dealing with daily responsibilities and demands, and attending to the enormous needs and the daunting challenges of a child with ASD [28]. Negative parental mood and parenting stress are bidirectionally related [29] [30]. That is, parenting stress can increase negative parental mood, yet negative mood can also increase perceptions of parenting stress.

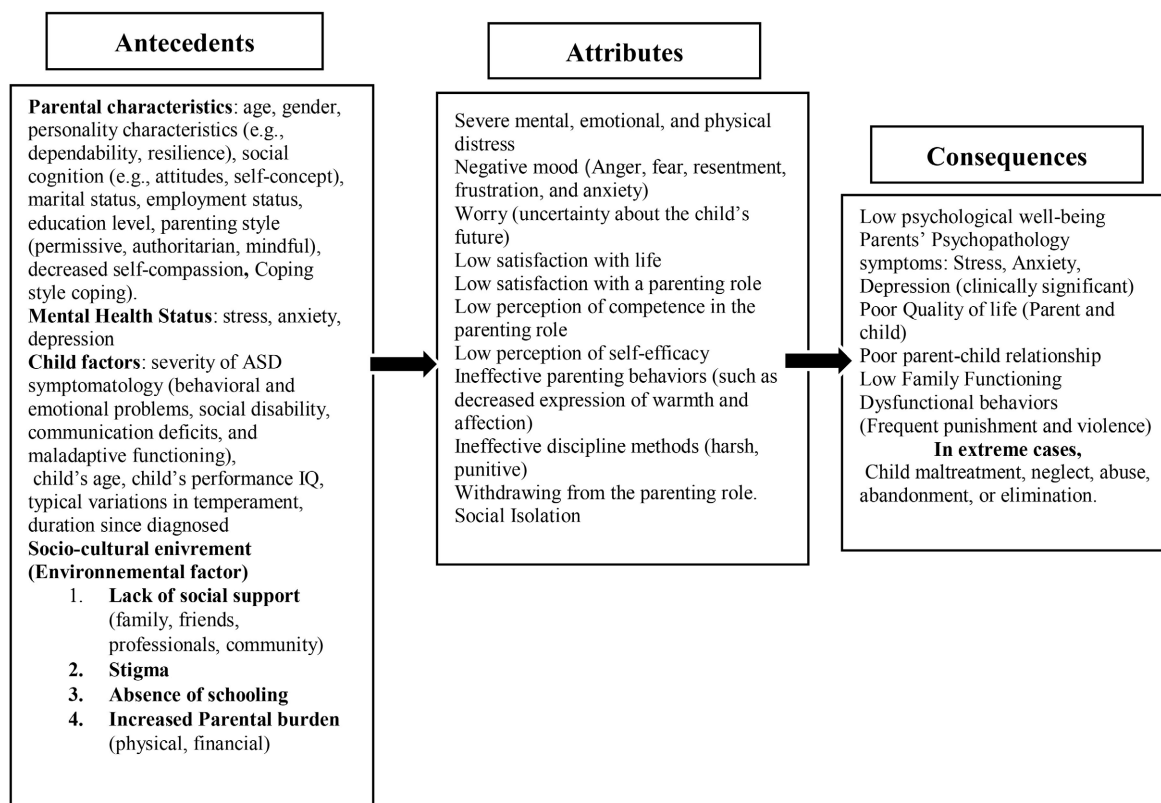


Figure 3. Antecedents, attributes and consequences of parenting stress among parenting a child/children with ASD.

Similarly, parents raising children with ASD are less satisfied with their parenting roles due to their children's unique needs [31]. There is also ample evidence to suggest that parents who report increased parenting stress feel incompetent about their ability to perform specific parent-related tasks, such as teaching their child with ASD how to perform daily activities [32]. In contrast, they believe that their children's challenging behaviors prevent them from enjoying their time together. Furthermore, parents suffering from stress tend to experience less pleasure and enjoyment in their children and leave less time for leisure and self-care activities [33]. Predictably, parents also report lower self-efficacy in their ability to perform the parenting role [34]. In the parenting context, self-efficacy refers to the perception or judgment of accomplishing a specific goal related to parenting practices.

Parenting stress is also associated with dissatisfaction with life due to parents' belief that having a child with ASD interferes with achieving their goals in life [35]. Many parents feel deeply lost when they have to abandon previously held dreams and expectations about the future and develop a new one that meets the

needs of their child with an autism spectrum disorder. The revised plan will require a great deal of sacrifice, both personally and professionally. Furthermore, having ineffective parenting behaviors (such as expressing less warmth and affection) and employing ineffective discipline methods (harsh, punitive) may indicate that parents are experiencing parenting stress [36]. When parents experience severe parenting stress, they may finally decide to withdraw from the role and isolate themselves socially [37].

3.3. Demonstration of Cases

The table below (Table 1) presents the model, borderline and contrary cases of parenting stress associated with ASD.

Table 1. Demonstration of cases.

Model case	Borderline case	Contrary case
<p>Camila and Kamal, a married couple for eight years, are the parents of Noah. Noah was diagnosed with ASD at the age of three. In the years since then, Camila and Kamal's lives have changed drastically. Noah's untypical and inconsistent development raises worries, frustration, resentment, and anxiety. Attending to Noah's unique needs, such as continuous supervision and guidance, keeping him away from danger, limiting his problematic behaviors, taking him to the autism Center for rehabilitation, and sometimes teaching him specific skills, caused Camila to quit her job. Trapped in a cycle of Noah's unique needs and daily care activities, Camila always feels drained, dull, constantly tired, and out of energy. On most days, she worries about her son's future, fears unknown, and is angry that she cannot have a child and that she can enjoy parenting just like her sister and two other brothers. She is mentally distressed and cries most nights. Camila and Kamal feel they live in a world of their own, isolated from their family, friends, and the world. Especially in regard to daily activities, they think they have to manage them alone. As Noah cried constantly and they did not know what to do to calm him down, they doubted themselves as parents and thought they were incompetent. Camila and Kamal also believe Noah prevents them from fulfilling their life goals. Kamal declines a promotion because he will have to move to another location that is not conducive to rehabilitating and raising Noah. Therefore, Kamal has a low expression of warmth to Noah and believes that harsh parenting may yield better results. In regard to parenting, Kamal prefers to withdraw, which impacts the couple's relationship. There is always disagreement between them about Noah and life in general. They are experiencing a marriage that is falling apart.</p>	<p>Nathan and Joel have two children, Daniel, three, and Gabriel, six. Daniel was diagnosed with an autism spectrum disorder. Joel is anxious, worried, and frustrated about not knowing what autism is and how to deal with it. Her husband, son, and family supported her in caring for Daniel. Joel sometimes feels that Daniel's problematic behavior in public is a source of emotional distress for them. However, she believes that she and her husband are competent parents who can survive this and nurture their son to his full potential, no matter what. As Joel and Nathan's lives revolve around Daniel, they sometimes miss their "normal" lives. Nevertheless, they do not hesitate to always show Daniel their affection toward him regardless of his negative moods and challenging behaviors.</p>	<p>Rachelle and Richard are a parent of Kyla, a 10-year-old girl. Rachelle and Richard feel so blessed to have Kyla. They both accepted her as she is, and they both adapted their lives and their routine to fulfill Kyla's unique needs, also; they were successful in teaching her to depend on herself to a certain limit. This strategy gives them some release from daily activities. Richard feels grateful for the effort and time Rachelle put into training their children to grow and flourish and thinks that she is a competent mother, so Rachelle thinks that Richard is a competent father. As opposed to punitive discipline, they show unconditional affection to their child in order to help her achieve her full potential. The couple goes to a counselor to cope with their frustrations and anger and enjoy parenting Kayla simultaneously. They believe Kayla gives meaning to their lives and makes them feel satisfied with their lives. They do not negatively internalize public hostile gestures and comments about their children's attitude in public. Instead, they think that their child is different, but she has the full right to be understood and accepted by the public as she is. Every opportunity they get, they use to educate the public about their children and raise awareness about autism. They also participate in social activities and gatherings with their families and friends to integrate her into their environment. It is also vital that their family members understand their child and how to deal with her.</p>

3.4. Antecedents and Consequences

Literature in the field of ASD shows that parental characteristics, parent psychopathology, symptoms, child's factors, lack of social support, increased parental burden, stigma, coping styles, and parent self-compassion level contribute to, and are influenced by, the level of parenting stress [38]. Studies indicate that parental characteristics, including age, gender, personality characteristics (e.g., dependability, resilience), social cognition (e.g., attitudes, self-concept), marital status, employment status, education level, and parenting style, influence the level of parenting stress experienced by parents with children with autism spectrum disorders [39].

Moreover, parents' mental health status, such as their readiness to experience stress, anxiety, or depression, may lead to higher levels of parenting stress [40]. The level of parenting stress among parents with a child with ASD may also be affected by the cumulative daily hassles of childrearing (parental physical burden) and financial costs associated with rehabilitating a child with ASD (parental financial burden) [41]. It also can be attributed to child factors, including the severity of ASD symptoms, the child's age, the child's severity and frequency of challenging behaviors (maladaptive behaviors), social disability, maladaptive function, communication deficits, and typical differences in temperament [42]. Environmental factors (socio-cultural context) such as low social support, stigma, poor quality of interaction within the extended family, and the absence of schooling, can increase parenting stress to clinically significant levels, as suggested by the literature [43]. Eventually, poor coping skills and self-compassion were associated with a higher level of parenting stress among parents raising children with autism spectrum disorder [44].

Due to the interaction between parenting stress attributes and contributing factors, parents may report low psychological well-being, increased anxiety and depression, Poor Quality of life (Parents and child), Poor parent-child relationship, Dysfunctional behaviors (Frequent punishment and violence) [45]. In extreme cases, a child may be subjected to maltreatment, neglect, abuse, abandonment, or elimination [46]. Considering abandoning or eliminating the child with ASD by parents may indicate clinically significant and severe parenting stress (Figure 3).

3.5. Empirical Referents

Parental Stress Scale (PSS; Berry & Jones, 1995) is used to assess the stress of parents caring for children having ASD and those caring for TD children [47]. This valid questionnaire is an 18-item scale that describes the parent's feelings toward the relationship with their child [48]. PSS represents positive themes like emotional benefits, self-enrichment, and personal development. It shows also negative themes such as demands on resources, opportunity costs, and restrictions. The Likert scale will be used to know the agreement among respondents. The total stress score can range from 18 to 90, with higher scores indicating

higher stress levels. The PSS has been used in other studies measuring parental stress in families who have children with ASD [49]. This instrument has been validated, and its high reliability has been approved by Berry [50]. This 18-item subscale was found to have high internal consistency, and Cronbach's α was 0.89 for this sample. A parental stress scale was selected rather than the Parenting Stress Index (PSI; Abidin, 1995) [51] [52], which has been used by many researchers because it is brief. In addition, PSS has been suggested as an alternative to PSI as PSS concentrates specifically on the stress generated by the parenting role [53]. Sample items are "Caring for my child(ren) sometimes takes more time and energy than I have to give". and "The behavior of my child(ren) is often embarrassing or stressful to me". "I am happy in my role as a parent". **Figure 4** represents the parenting stress model in the autism context based on the concept analysis discussed in this paper.

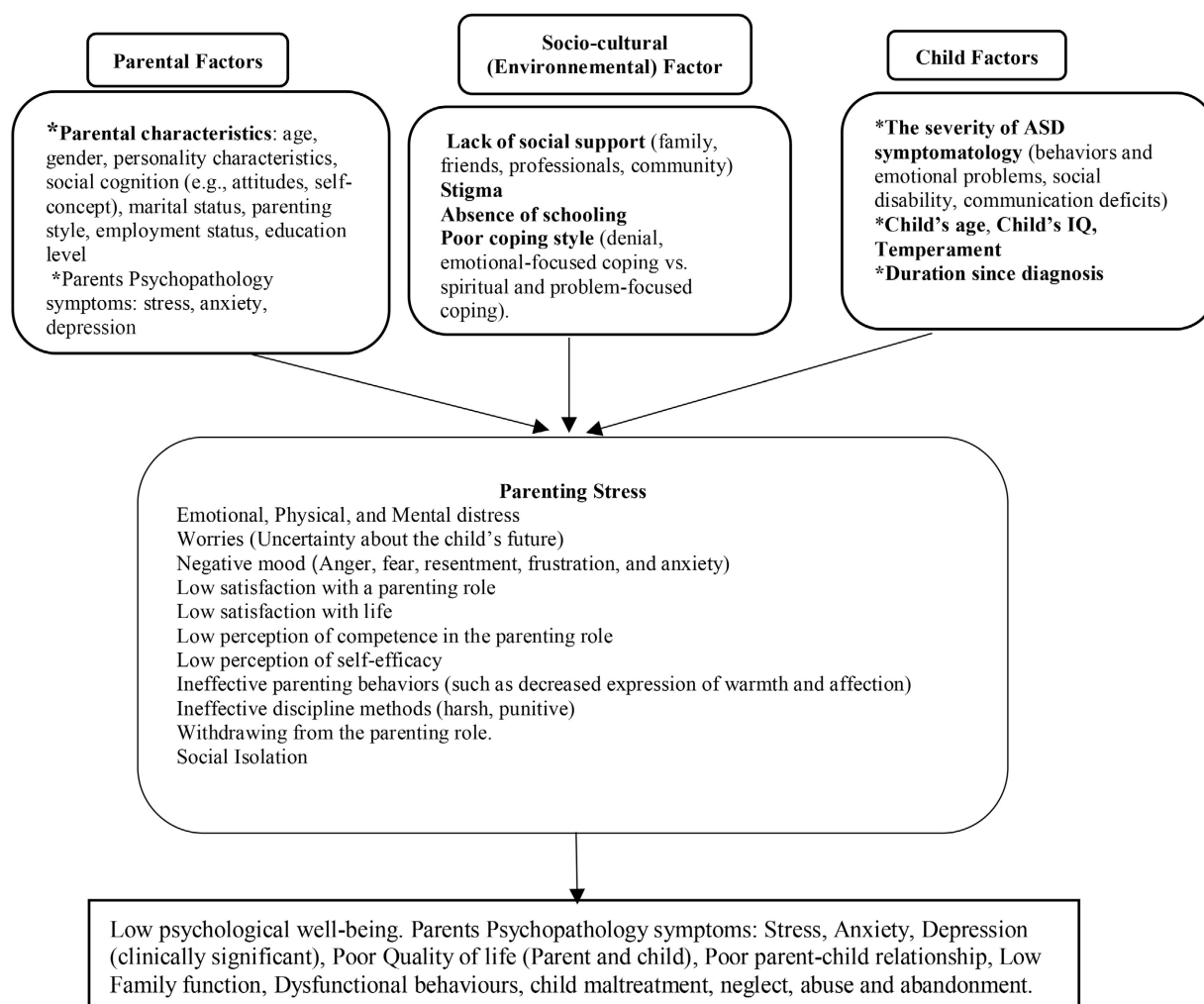


Figure 4. Conceptual model of autism-specific parenting stress.

3.6. Deriving the Definition of Parenting Stress

It is worth noting that there is a relatively complete consensus among research-

ers regarding the definition of parenting stress [54]. Yet, even with the commonly agreed upon conceptualization, there is still not a universal definition that all researchers employ. However, parenting stress in the autism context has distinctive characteristics that distinguish it from the general parenting stress endured by parents of a typically developed child. The three characteristics are intensity, chronicity, and uncertainty. A parent with a child with chronic and life-long conditions like autism knows that this stress is chronic. Autism-specific stress among parents is significant due to the chronicity of the challenges of daily activities and care of a child with ASD. Moreover, parents of children with autism often feel uncertain of how to help their children cope with the condition [55]. It is also a dynamic and subjective experience due to the interaction between parent factors, child factors, and environmental factors (see **Figure 3**: the conceptual model). Parenting stress among parents raising a child with ASD is defined by the author as “a state of intense mental, emotional, and physical distress and negative mood resulting from the constant enduring of challenges that arise when parenting a child or child with an autism spectrum disorder”.

4. Discussion and Nursing Implications

While there is extensive knowledge about the importance of supporting parents of children with chronic conditions and disabilities, the examination of parenting stress in parents raising children with ASD underscores the crucial need for effective dissemination of information on coping with autism. This is essential not only for the well-being of children with autism but also for the mental health of their parents. It also underscores the significance of a comprehensive approach to caring for children with ASD and their parents. While the healthcare system aims to provide children with ASD the necessary support to thrive to their fullest potential, it's essential to recognize that these children and their parents form a single unit. Therefore, it is vital to regularly assess parenting stress among parents raising children with ASD in order to enhance a child's quality of life. Additionally, there is a need to develop effective interventions aimed at alleviating the burden on parents of children with autism.

Furthermore, this analysis indicates that society's attitude toward these parents shapes how they experience parenting stress. Parents reported that their children with ASD were treated differently by society because of their problematic behaviors in public [56]. These challenging behaviors are also attributed by the public to parenting styles, ineffective or poor parenting, discipline needs, or the inability of parents to control their children, but not to developmental concerns. This often results in feelings of shame and rejection and increases parenting stress among parents [56]. Raising public awareness of ASD can benefit not just individuals with autism but also make lives easier for their families and caregivers. Accepting our differences enriches our society as well. The pertinent analysis underscores the crucial role of supporting parents raising children with autism spectrum disorder (ASD). It is imperative to effectively impart knowledge

on coping with autism not only to aid in the care of children with ASD but also to bolster the mental well-being of their parents. This underscores the necessity of embracing a comprehensive approach to caregiving for children with ASD and their parents. While the overarching objective of the healthcare system is to provide optimal support for children with ASD, it is essential to acknowledge the inseparable nature of these children and their parents. Regular assessment of parenting stress among parents raising children with ASD is fundamental to enhancing the quality of life for these children. Furthermore, the design of targeted interventions aimed at alleviating the challenges faced by parents of children with autism is paramount.

Moreover, the analysis elucidates the impact of societal attitudes on the experience of parenting stress among parents of children with ASD. Parents frequently report differential treatment of their children in public settings due to their challenging behaviors, resulting in feelings of shame and rejection and contributing to heightened parenting stress. Heightened public awareness of ASD holds the potential to not only benefit individuals with autism but also ease the burden on their families and caregivers. Embracing diversity serves to enrich our society.

Nurses play a crucial role in reshaping the societal perception of autism spectrum disorder (ASD) through their efforts to raise public awareness. Additionally, nurses are well-positioned to identify instances of high parenting stress among caregivers and can intervene by providing education, support, and guidance to families, community members, and other healthcare professionals. By equipping themselves with the necessary knowledge and skills, nurses across various settings can effectively alleviate parenting stress, develop coping strategies, and offer timely support and referrals to parents of children with ASD. It's essential for pediatric and psychiatric nurses to deliver comprehensive care and counseling to families of children with autism, but some evidence suggests a lack of understanding about autism and parenting stress among nurses. Therefore, ongoing education on childhood autism, including its impact on parenting stress and coping mechanisms, should be integrated into nurses' training and continuing professional development programs. Lastly, this emphasizes the significance of addressing parenting stress as a crucial factor in caring for families impacted by autism.

Conflicts of Interest

The author declares no conflicts of interest.

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