## **BUKTI KORESPONDENSI**

# ARTIKEL JURNAL NASIONAL TERAKREDITASI SINTA 2

Judul artikel	:	Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder (ASD)
Jurnal	:	Jurnal Komunikasi Indonesia, 2020, Vol 9 (2), 89-97
Penulis	:	Andria Saptyasari

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Dear Redaktur Jurnal Komunikasi Indonesia

Bersama ini saya lampirkan artikel berjudul Communication between Husband and Wife in Negotiating a

**Parenting Role for their Child with Autism Spectrum Disorder (ASD).** Saya sangat berharap artikel yang saya kirimkan ini dapat dimuat di Jurnal Komunikasi Indonesia.

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Salam, Andria Saptyasari Staf Pengajar Departemen Ilmu Komunikasi FISIP- Universitas Airlangga

Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder--andria saptyasari.docx 50K

# Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder (ASD)

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#### Abstrak/Abstract

Keluarga dengan anak ASD (Autism Spectrum Disorder) rentan akan kondisi finansial, emosional, tenaga dan waktu yang dapat memicu ketegangan antara suami dan istri sebagai orang tua dalam merawat anak ASD mereka. Studi ini bertujuan mengelaborasi komunikasi yang digunakan oleh pasangan heteroseksual yang sudah menikah dalam menegosiasikan peran merawat anak ASD terkait finansial, emosional, tenaga dan waktu dengan menggunakan teori dialektika hubungan. Metode pengumpulan data menggunakan wawancara. Cara mendapatkan tiga pasangan partisipan yang memiliki anak ASD dengan umur yang berbeda adalah dengan teknik snowball. Hasil menunjukkan ada perubahan yang dinamis terkait peran antar pasangan dalam memenuhi kebutuhan finansial, emosional, tenaga, dan waktu untuk anak ASD mereka yang memiliki kesulitan dalam komunikasi sosial. Setiap pasangan suami istri ini berusaha melakukan perubahan peran bila dibutuhkan dengan rasa tanggung jawab dan saling menghargai satu sama lain. Mereka mengakomodasi perubahan secara kolektif dan melalui kesepakatan. Sehingga bisa disimpulkan dalam merawat anak ASD, mereka menggunakan strategi kompromi terkait finansial, emosional, tenaga, dan waktu.

Families that have children with ASD (Autism Spectrum Disorder) were vulnerable in terms of financial, emotional, energy, and time that causes tension between husbands and wives as parents in caring for their children with ASD. The main purpose of this study is to elaborate on the communication used by married heterosexual couples in negotiating a parenting role related to financial, emotional, energy, and time problems for their child with ASD by using relational dialectical theory. The data collection method used interviews. The participants' selection used snowball. The participants consisted of three married

heterosexual couples with three different ages of children with ASD in East Java. The results showed that there are dynamic changes related to the role of married couple participants in meeting financial, emotional, time, and energy needs for their children with ASD who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does role sharing change when necessary and share tasks with respectable and responsibility. They also accommodate changes by using collective consensus. The conclusion of this study is a compromise strategy that was used by them when sharing roles related to financial, emotional, time, and energy for children with ASD.

#### Kata kunci/Keywords:

ASD, komunikasi, negosiasi, peran orangtua

ASD, communication, negotiation, parental roles

## Introduction

This research aims to elaborate communication on married heterosexual couples in negotiating their role in parenting for children with Autism Spectrum Disorder (ASD). The research is based on the increasing phenomenon of children born with ASD in Indonesia in recent years: in the year 2000 1:500, in 2010 1:300, and in 2015 134,000 children. These data are supported by the statement of Wardhani (2009), where the number stated previously (i.e., 134,000) indicates that out of 250 children born, one child is born with ASD (Wardhani, 2009).

Autism spectrum disorder (ASD) is a neurodevelopmental disorder associated with the presence of social-communication deficits and restricted and repetitive behaviors (Reynold and Kamphaus, 2013; Memari et al, 2015; Irawan, 2015). American Psychiatric Association (in Diagnostic & Statistical Manual of Mental Disorder 5<sup>th</sup> ed., 2013) divided autism spectrum disorder (ASD) into three severity levels, namely: (1) level 1 "requiring support" marked by difficulty initiating social interaction, unsuccessful responses to overtures of others, able to engage in conversation but to-and-fro with others in terms of social communication and by difficulty switching between activities in terms of restricted and repetitive behaviors; (2) level 2 "requiring substantial support" marked by a deficit in verbal and nonverbal communication, limited initiation of social interaction, speaks simple sentences, their interaction is limited to a narrow special interest in terms of social communication and by difficulty coping with change in terms of restricted and repetitive behaviors; (3) level 3 "requiring very substantial support" marked by severe deficits in verbal and nonverbal communication, very limited initiation of social interaction, minimal response to overtures from others in terms of social communication and by extreme difficulty coping with change, repetitive behaviors in all spheres in terms of restricted and repetitive behaviors.

In the Puterakembara (the community of parents of children with ASD in Indonesia), a majority of parents told how shocked they were when they found out their children were an ASD for the first time. Some of them told that in dealing with ASD children who have difficulties in speech and managing behavior, sometimes they lose temper, energy, and time for themselves or their partners (Marijani, 2003). Some of them blame themselves and others blame their partners due to their inability to overcome this condition (Apostelina,n.d). Another study showed that parents of children with ASD were faced with financial problems, hectic therapeutic schedules, and difficult-to-manage behavior of their children. The inability to overcome this situation potentially increased the risk for divorce or separation (Freedman et al; 2012). In Indonesia, pediatrician Sutadi, a leading consultant for children with autism, conducted research on 406 families with autistic children from 2000 to 2004. He found that 23.5% of families in Indonesia care for a child with autism, and one out of five families that care for a child with autism often divorce (Sutadi, 2011).

They need to dialogue with each other in negotiating their role in providing financial, emotional, energy, and time support for their ASD child to adapt to this situation and eliminate the risk for divorce or separation in married heterosexual couples. By implementing the dialectical relational theory, the researcher aims to elaborate on the communication used by couples in negotiating their roles in the process of caring for their child with ASD.

## Literature review

Interpersonal communication between husband and wife is a part of the study of communication within the context of family communication. Family is the smallest unit in society, wherein there is an interaction between family members: mother-child, father-child, husband-wife, or between siblings. The role of a family member is often associated with the contentment of resources. According to the resource theory by Stafford (2008), there are two types of resources: concrete and abstract. DeVito (2004), Galvin (2012), and Guerrero (2007) state that concrete resources consist of financially related resources, whereas abstract resources consist of emotion, time, and energy. The aforementioned explanation shows that the interaction between roles within a family is an exchange of attention, financial support, emotion, energy, and time from one member of the family to the other. This implies that the study of family communication is always interconnected with the theory of interactional perspective, focusing on the interaction and relationship between individuals within a family.

The characteristics of family as a system consist of the following: (1) interdependence (apparent connection and the relationship between units), (2) dynamic (ever-changing and appearing to exhibit a process of adaptation in relation to changes), and (3) dialectical tension (apparent dialectical tension in the cycle of the family's life, and thus an attempt to negotiate the tension is ever-present) (Sprey, 1999). The three mentioned characteristics show that family communication is a relational-based communication between two individuals with an interactional perspective as a part of unity. The aforementioned explanation asserts that the lack of financial, emotion, energy, and time within heterosexual marital relationships for caring for their child with ASD definitely causes dialectical tension in their relationships. However, the family system also comprises a characteristic known as dynamic, and thus they will automatically try to adapt to apparent changes by negotiating and communicating the dialectical tension. The aforementioned issue on family communication can be analyzed through relational dialectics theory.

Relational dialectics theory was proposed and developed by Mikhail Bakhtin, who observed that in an interaction between two individuals, there is always dialog. The dialog is open in nature in order to develop a relationship between the said individuals; however, there is always a chance that tension will ensue (dialectics) (Baxter, 2004). Tension (dialectics) is defined as anything that comprises itself of three major elements: contradiction, motion, and praxis (Turner & West, 2006): (1) Contradiction is an opposing condition between personal interest and expectation (private sphere) with collective interest and expectation (public sphere); (2) Motion is an element of change within a relationship or the change of proximity in a period of time, where an individual is certain to experience changes in relationship and proximity with another individual in a certain span of time, which will contribute to the increase in contradiction; (3) Praxis is an element which shows that when an individual is faced with a contradiction, he/she will never possess a decisive decision-making ability because of the limitations and norms conjured by his/her surrounding sociocultural setting.

Contradiction, motion, and praxis mentioned by Rawlins (1992) made interaction between one individual and another lead to the possibility of tension between the two, a sort of dualism of issues between the individual wanting to be open-close (openness-closedness), free-connected (autonomy-connection), and stable-dynamic (predictability-novelty) (Baxter, 2004). The aforementioned explanation asserts that relational dialectics theory is more focused on the effort to balance (balancing) the two contradicting sides, which in this research is depicted by the contradiction between togetherness and separation in two-way communication. The concept of togetherness-separation is a cultural context that sees each individual bounded to the values, rules, roles, and norms where they live. Togetherness refers to the ability that drives an individual to uphold a high level of morality and responsibility in accordance with the legitimized norms and it leads to the creation of unity or harmony with another individual. The separation refers to the ability that drives an individual to act in an egotistical manner and irresponsibly, where the promotion of his/her own needs is put above others' that leads toward disharmony within a relationship.

According to Baxter (2009) and Krueger & Funder (2004), in dialectical relational theory, the important element studied is the utterance chain. The utterance chain is an interconnected utterance within individual backgrounds and value contexts. In this research, the contradiction between togetherness and separation can be seen through husbands' and wive' utterance dealing with a role in providing financial, emotional, energy, and time support for their ASD child. The aforementioned explanation asserts that: (1) the utterances of togetherness can be seen verbally that indicate proclaim fondness, acceptance, collectiveness, supportiveness, and other related to any actions that lead toward positive results; (2) the utterances of separation include proclaim dislike, unaccepting, egotistical, demands the support, and any action that leads toward negative results. In this research, the utterance chain should explain how cohesion and adaptability are highly effective in the effort to balance both togetherness and separation.

In terms of balancing the contradiction between togetherness and separation in relational dialectics theory, Wood et al. (in Turner and West, 2006) stated that there are four

strategies in the management of dialectical tension dealing with how to negotiate their role. The four strategies namely are: (1) cyclic alternation (spiraling alternation) is a strategy to choose one side out of two depending on time; (2) segmentation is a strategy to choose one side out of two depending on the individual's domain or setting; (3) selection is a strategy to choose a particular side disregarding time and domain; and (4) integration is a strategy that tries to find a solution for both parties. The integration strategy has four kinds of function, they are: (a) neutralizing (balancing), that is, both sides try to compromise; (b) reframing (recalibration), that is, both sides try to lessen the tension; (c) disqualifying, that is, choosing one side to stand for a general issue; however, this does not apply for specific or private issues; and (d) reaffirmation, that is, both sides choose differing pathways but still consider the other's decision.

This theory will be briefly used to explore the role of husband and wife related to financial, emotional, energy, and time problems, and to explore their cohesion, adaptation, and strategy in negotiating a parenting role for their child with ASD in order to eliminate the tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation.

## **Research methodology**

This study used an interpretative phenomenological analysis (IPA) approach. According to Smith, this approach concerns exploring the part of an individual's experiences (Smith, Flowers, & Larkin, 2009). The aforementioned explanation asserts to do phenomenology, this study used interviews to collect participants' utterances about caring experience towards their child with ASD related to financial, emotional, energy, and time problems. All data were noted because all participants objected interview process by audio recording. After all, data were collected, scripted, and coded, then data would be analyzed and interpreted comprehensively by using a dual interpretation process: (1) analyze and interpret utterances from each participant either the husband or the wife to get both perspectives about their feelings dealing with financial, emotional, energy, and time problems to care for their child with ASD; (2) analyze and interpret how they adapt and work out these problems as a couple to describe their dialectic tension related to togetherness and separation. These two processes would describe their negotiation strategy related to financial, emotional, energy, and time problems to care for their child with ASD

The number of participants was three heterosexual married couples that have a child with ASD. All participants were biological mothers and fathers of children with ASD. The participants' recruitment process used snowball by asking close people who may have acquaintances who are married and have a child with ASD. One couple of participants was a friend of the researcher's acquaintance. Starting from the first couple of participants, the researcher got two other couple names. Three couple of participants is a small number, but IPA approach usually have a small number of participant and the aim is to reveal something of the experience of each those individuals (Smith and Osborn, 2006). The study may explore in detail the similarities and differences between each case dealing with different ages and the position of the child with ASD to their sibling. The small number of participants is a limitation of this study, but this study would be a pilot project for further study.

The first participant couple was a housewife with an initial of Mrs. A (50 years old) and a working father with an initial of Mr. A (50 years old). They have been married for 22 years. Their child with ASD (with an initial U) is the youngest of two and is 18 years old; he has gone through speech and occupational therapy for 11 years and is currently completing his second-year junior high school education in an inclusive school. In some countries, 18-year-olds no longer refer to children, but in Indonesia according to article 330 of The Civil Law, the age limit of children are those who are not yet 21 years old and are not yet married.

Article 98 paragraph 1 Compilation of Islamic Law also states that the age limit of children is those who are not yet 21 years old, are not physically or mentally disabled, and are not yet married. Law No. 4 of 1979 concerning Child Welfare in article 1 paragraph 2 states the age limit of children is those who are not yet 21 years old and are not yet married. The aforementioned explanation asserts that this family could be chosen as a participant, although their child with ASD is 18 years old.

The second participant couple was a housewife with an initial of Mrs. W (30 years) and a working father with an initial of Mr. W (30 years old). When they learned that their child was a child with ASD, Mrs. W decided to stop working so that she could focus on taking care of her child with ASD (with an initial L, 4 years old). They have been married for 5 years. L (4 years old) is the eldest of two, has been in speech and occupational therapies for 2 years, and is currently enrolled in an inclusive preschool.

The third participant couple was a housewife with an initial of Mrs. M (42 years old) and a father with an initial of Mr. M (44 years old). Both have been married for 12 years. Their child with ASD (with an initial A) is 7 years old and is the second child of three, currently in first grade in an inclusive elementary school, and has been in speech and occupational therapy for three years.

#### **Results and Discussion**

# Analysis of utterances between husband and wife on financial, emotional, energy, and time support during their role in parenting for their child with ASD

In the first couple of married participants, their child was a severe deficit in verbal and nonverbal communication, very limited initiation of social and minimal response to overtures others in terms of social communication. That would be seen when his teacher asked him, he repeated the teacher's question and took a long time for answering one word to his teacher. In terms of behavior, he was extreme difficulty coping with change. That would be seen when his parents changed the direction to go to other places different from the first plan, he got very mad at their parents.

Mr. A told that his son with ASD (U) more frequently bites, pinches, and hits to Mrs. A, but when Mrs. A cried, U stopped being mad and then hugged Mrs. A. Mr. A explained that emotionally his son with ASD was closer to Mrs. A rather than to Mr. A. In here, Mr. A felt sorry for his wife, because he could imagine how exhausted she was to care for U. This implies that Mrs. A was likely close emotionally to their child with ASD.

Financial support from Mr. A toward U (child with autism, 18 years old) is affirmed by Mrs. A: "... My husband is highly supportive in terms of funding the therapy, school, and doctor visit... U has been in therapy for quite a while, around 11 years since he was 6–7 years old." Mrs. A's statement shows that all the financing for the needs' their child with ASD is fulfilled by her husband because Mrs. A herself is a full-time housewife. Mr. and Mrs. A told that all the needs' their child with ASD was not cheap and they had to downsize for other needs including the needs of the oldest son.

In terms of energy and time support for U, Mr. and Mrs. A were doing their complementary and reciprocal role. The complementary role could be seen through Mrs. A's explanation when Mr. A went to work, she had the responsibility to carried out her child with ASD to go to school or for getting therapy. If Mr. A was on leave then he carried out U to go to school or go for therapy. Their reciprocal role could be seen from the couple participants' statements that Mr. and Mrs. A switch roles, for example, when Mrs. A is helping her eldest with schoolwork, Mr. A takes U for a walk and vice versa. When U accompanies his mother to cook, then Mr. A helps his eldest with the computer. They did this way because they did not want their son with ASD to ruin the eldest's project or schoolwork like before.

In the second couple of married participants, their child was a deficit in verbal and nonverbal communication, limited initiation of social interaction and speaks simple sentences in terms of social communication. As could be seen from Mrs. W's explanation that L (4 years old) could comprehend and pointed to the objects' or body parts' but he could not mention and speak clearly the objects' or body parts' name. He also gave short answered when asked, but he could not ask or request verbally when he needs something. In terms of behavior, L could not cope with noisy sounds and crowds. This is affirmed by Mr. W stating that "L likes to play with L's younger sister. They get along well, but when his little sibling cried or noisy, L can be mad because L hates noisy".

Mr. W's financial support toward L can be derived from his statement, "I only sleep for four hours every night and that happens every night. I wake up early and go straight to taking care of business ... this is because our business is still in its early days." Mr. W's statement shows that he is willing to work hard to fulfill the needs of L. His needs are, for example, therapy, piano lessons, swimming lessons, tuition, lab checks, routine check-ups to the doctor every 6 months, and a shadow (a caretaker at school). Moreover, Mrs. W is now a housewife who has stopped working after knowing L was diagnosed with ASD.

Mrs. W states: "L cannot eat chocolate or ice cream, after eating it he becomes temperamental. L also cannot drink beverages that often find in the groceries ... Last time when he lashed out, he screamed for two hours..., but we let him be. It's hard for him to control his emotion, he claws and pinches, as you can see here (showing her hands that were clawed by L)." From the aforementioned statement, Mrs. W controls the emotion of her child by regulating the food that he consumes so that he does not throw a tantrum. According to Erickson, 60% of children with ASD have a poor digestive system. Foods such as those containing animal milk cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by

the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function. Impaired brain functions are cognitive functions, receptive communication, concentration, and behavior (Erickson et al, 2005). Erickson's statement asserts that chocolate and ice cream are containing animal milk that presumably affects L's behavior.

In relation to the time and energy support that they give for L, Mr. and Mrs. W do the task together. They often take L and his younger sister to play together; they go on a recreation trip outside town or on short outings to the malls for dinner even Mrs. W has to accompany L so he does not panic in the crowd at the mall. This is done in order to build a sense of togetherness between L and his younger sister so that there will be no feelings of envy in the future.

In the third couple of married participants, their child (with an initial A) has a limited interaction to the narrow special interest and speaks simple sentences only if he needs something in terms of social communication. This would be seen from Mrs. M's affirmation that A was very passive, he rarely asked to parents or someone, he asked to someone only if he needs something. In terms of behavior, A has difficulty coping with change and has repetitive behaviors towards narrow special interest. This would be seen from Mr. M's explanation that A was easily bored when he played with his eldest and younger brother, he only lasted in 5 minutes playing with them. He prefers to play alone.

Mr. M's financial support for his child with ASD (A, 7 years old) can be seen from Mrs. M's statement: "A Nikolin injection for A costs around 250 thousand per pack, this can be administered 10 times. A requires around  $60 \times$  so we need six packs costing us around 1.5 million. The cost for therapy is about 300 thousand per month; it is scheduled twice a week for two hours." This indicates that Mr. M works hard to support the needs of his child with ASD. Mr. and Mrs. M told that for making ends meet all the needs' their child with ASD, they had to downsize for other needs including the needs of the eldest and youngest son.

Mrs. M supervises her child's emotions by regulating his intake of gluten and commonly packaged beverages. She said, "I limit his gluten consumption. For example, he asks for Indomie (the brand of instant noodles) because he sees his brothers eating it. I make a half portion for him but for seasoning, I only give soy sauce and salt, I do not include the seasoning that comes with it. If he asks for a snack with extra seasoning, I only put a little of it." It can be inferred from Mrs. M's statement that in order to control her child with ASD's behavior, she regulates the foods consumed by him. Mr. M also supports Mrs. M's regulation by not buying food containing gluten ingredients for his son with ASD. As mentioned before that some children with ASD have a poor digestive system. Foods such as wheat flour cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function. Impaired brain functions are cognitive functions, receptive communication, concentration, and behavior (Erickson et al, 2005). Erickson's statement asserts that noodles containing wheat flour that probably affects A's behavior.

Concerning the time and energy support for their child with ASD, Mrs. M frequently accompanies her son with ASD at school or home compared to Mr. M because Mr. M has not been able to fully supervise him. Mr. M preferred to accompany two other children so that they could not disturb Mrs. M dealing to care A (her child with ASD).

From the aforementioned utterances of three married couple participants, the following conclusion can be drawn: there are dynamic changes related to the role of married couple participants in meeting financial, emotional, time, and energy needs for their ASD

children who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does share tasks with respectable and responsibility. As mentioned before, the utterances of togetherness can be seen through utterances that indicate proclaim acceptance, collectiveness, supportiveness, and others related to any actions that lead toward positive results. Each participant does a complementary and reciprocal role to support his/her couple caring for their child with ASD. The study results found that each participant tries hard to create togetherness as couples handling their child with ASD even though it was not easy. All participants have a similarity of optimistic feelings that could be seen in their quotation saying every difficulty, there must be ease. Their optimistic feeling was powerful to create togetherness as a unity.

According to Koerner and Fitzpatrick, in a family, there is a degree of cohesion and adaptability among members (Koerner & Fitzpatrick, 2002). That two degrees would be useful for exploring the ability of all participants toward changes and dealing with tensions in order to balance their relationships. All about cohesion and adaptability would be explained as follows

Analysis of utterances between husband and wife about cohesion and adaptability in relation to describe the couples' role negotiate strategy in parenting for their child with ASD

After discussed the utterances of togetherness as earlier, this section would analyze participants' ability to adapt and to foster cohesion in sharing their roles during parenting for their children with ASD. The ability to adapt, according to Olson (1999) and Poire (2006), is the ability to maintain stability and to regulate changes in a relationship. The ability to adapt is divided into four different levels: (1) rigid, where a certain rigidity is shown toward

accepting changes due to authoritarian leadership and stringent rules becoming a benchmark in life; (2) structured, where moderate leadership can accommodate changes based on limited collective decisions, leading to a more stable relationship; (3) flexible, where quick and prompt attitudes are shown toward changes, and often decisions are made based on collective consensus; (4) chaotic, where tension and instability are high due to a lack of leadership, which leads to a dissimilar perception between the two when faced with changes. Olson's level of adaptation can be simplified through a matrix (see Table 1).

Table 1. Adaptability				
	Rigid	Structured	Flexible	Chaotic
Roles	Roles seldom change	Roles stable	Role sharing change	Dramatic role shift
Change	Too little change	Change when demanded	Change when necessary	Too much change
Leadership	Authoritarian leadership	Leadership sometimes shared	Share leadership	Lack of leadership

Source: Olson, 1999

According to Olson (1999) and Poire (2006), cohesion is defined as an emotional bond between members within a relationship. This bond is divided into four different levels: (1) enmeshed—in this level, members' proximity, loyalty, and dependence over each other are extremely high, leaving no space for individuality; (2) cohesive—in this level, members attempt to maintain emotional closeness, loyalty, and cohesion by emphasizing a certain degree of individuality; (3) connected—in this level, members are mostly independent, but still, involve other members to perform the group's function; (4) disengaged—in this level, members are extremely independent and thus possess a high degree of individuality, which

places emphasis on him/herself over other members. Olson's level of cohesion can be simplified through a matrix (see Table 2).

	Table 2. Cohesion	l	
Enmeshed	Cohesive	Connected	Disengaged
Little closeness	Little-Moderate closeness	Middle-High closeness	Very high closeness
High independence	Interdependent	Interdependent	High dependence
Ι	I-We	I-We	We
Little loyal	Some loyalty	High loyalty	Very high loyalty
	Little closeness High independence I	EnmeshedCohesiveLittle closenessLittle-Moderate closenessHigh independenceInterdependentII-We	Little closenessLittle-Moderate closenessMiddle-High closenessHigh independenceInterdependentInterdependentII-WeI-We

Source: Olson, 1999

Table 3 explains that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are all positive conditions, stable and conducive. In terms of adaptation, structured and flexible are two of the conditions that are able to accept and deal with changes positively compared with rigid (tends to reject changes) and chaotic (often changes attitudes toward the change). In terms of cohesion, cohesive, and connectedness are two of the most conducive conditions that are able to maintain emotional closeness, loyalty, and cohesion while still being able to give a degree of independence for other members to perform their function according to their domain. The aforementioned explanation shows that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are conditions that lead toward togetherness, symbolized by the ability to adapt (+) and to maintain cohesion (+) as can be seen as follows:

	Table 3. Adaptability and Cohesion				
Cohesion	Adaptability				
	Rigid	Structured	Flexible	Chaotic	
Enmeshed	_	_	_	_	
Cohesive	-	+	+	_	
Connected	_	+	+	_	
Disengaged	_	_	_	_	

Source: Researcher's analysis

The utterances of all three participants in terms of adaptability related to financial, emotional, time, and energy show that they tend to do role sharing change and change when necessary for caring for their children with ASD, as could be explained as follow: (1) they try work hard and reduce the unnecessary expenses to be able to make ends meet the needs of their children with ASD; (2) when wives support emotional by reducing the intake of gluten and animal milk, husbands support by not buying food containing those ingredients for their children with ASD; (3) time and energy, wives support time and energy by accompanying their children with ASD at school, place of therapy, and home daily, husbands support time and energy for their son with ASD only when husbands on leave. They do a complementary role and a reciprocal role. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level structured-flexible in terms of adaptability. A more structured and flexible level of adaptation allows the three couples to adapt to changes. It could be seen from the way they accommodate changes based on collective decisions and consensus.

The utterances of all participants related to financial, emotional, time, and energy for their sons with ASD show that the emotional bonding toward one another is cohesive and connected. All three couples actively try to maintain emotional closeness, loyalty, and interdependence with one another face-up financial, emotional, time, and energy problems for their sons' with ASD as follow: (1) in doing every task for caring for their sons' with ASD, they do together for one intention for making better the condition of their sons' with ASD; (2) they are trying actively to complement each other's role for their sons' with ASD. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level of cohesive-connected.

From the aforementioned explanation about cohesion and adaptability, this described how participants manage and balance their roles towards their son with ASD by the negotiating strategies. All three couples implement a compromise strategy for caring for their children with ASD. They interchange roles and collectively participate in devoting financial, emotional, time, and energy for them.

## Conclusion

In conclusion, the three couples participants used a compromise strategy to negotiate their roles related to financial, emotional, time, and energy for their children with ASD. They accommodate changes based on collective decisions and consensus. They also collectively interchange and participate in devoting financial, emotional, time, and energy for their children with ASD. These findings indicate that there are still married couples who have children with ASD who remain share tasks together in caring for their children with ASD. Although difficult, they have the optimism that after difficulties there is ease. The same optimism feeling would make easy to create good cohesion and adaptability.

This research attempts to help to understand and capturing the complexity of the marital, family system, and tension or stress in the health area using relational dialectic theory, family system approach, and Olson's circumplex model. The small number of participants is a limitation of this study, but this study would be a pilot project for further study. The implication of this study is to eliminate the tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation. For future work, it is

necessary to conduct research on how to balance the communication in another tension context in a family using more participants.

## Acknowledgement

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## **BUKTI KORESPONDENSI**

# ARTIKEL JURNAL NASIONAL TERAKREDITASI SINTA 2

Judul artikel	:	Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder (ASD)
Jurnal	:	Jurnal Komunikasi Indonesia, 2020, Vol 9 (2), 89-97
Penulis	:	Andria Saptyasari

No.	Perihal	Tanggal
2.	Bukti konfirmasi review dan hasil review pertama	11 November 2020



Andria Saptyasari <andria.saptyasari@fisip.unair.ac.id>

## [JKI] Editor Decision

2 pesan

jurnal jurnal komunikasi indonesia <jurnal.kom.indonesia@gmail.com> Kepada: andria.saptyasari@fisip.unair.ac.id 11 November 2020 14.05

Andria Saptyasari,

We have reached a decision regarding your submission to Jurnal Komunikasi Indonesia "Communication between

Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder (ASD)"

Our decision is: Revision Required

Please check the form below and revise by November 18, 2020 the latest.

Thank you.

## 2 lampiran

Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder.docx 46K

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21	The conclusions follow from the design, methods, and results	4
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Artikel sudah sangat kompherensif, hanya perlu ditambahkan sedikit tambahan data terbaru dalam latar belakang serta penjelasan mengenai urgensi dan kebaruan penelitian. Penjelasan partisipan/informan, selain bentuk narasi, jika dimungkinkan dibuat dalam tabel. Penyajian tabel, sebaiknya tidak terpotong/terputus

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Introduction	<ol> <li>Perlu ditambahkan data terbaru (lima tahun terakhir) agar terlihat (aktualitas) perkembangan masalah yang ingin dianalisis.</li> <li>Perlu ditambahkan penjelasan singkat urgensi dan kebaruan, agar nampak celah apa yang diiisi oleh riset ini, khususnya pengembangan di bidang ilmu komunikasi.</li> </ol>	
Review literature	1. Sudah bagus	
	2.	
Research Methods	<ol> <li>Jika dimungkinkan, penjelasan mengenai partisipan/informan, selain dalam narasi, dibuat juga dalam bentuk tabel untuk memudahkan identifikasi.</li> <li>2.</li> </ol>	
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Results	1. Sudah bagus	
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Discussion	1. Sudah bagus	
	2.	

## Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder (ASD)

#### Abstrak/Abstract

Keluarga dengan anak ASD (Autism Spectrum Disorder) rentan akan kondisi finansial, emosional, tenaga dan waktu yang dapat memicu ketegangan antara suami dan istri sebagai orang tua dalam merawat anak ASD mereka. Studi ini bertujuan mengelaborasi komunikasi yang digunakan oleh pasangan heteroseksual yang sudah menikah dalam menegosiasikan peran merawat anak ASD terkait finansial, emosional, tenaga dan waktu dengan menggunakan teori dialektika hubungan. Metode pengumpulan data menggunakan wawancara. Cara mendapatkan tiga pasangan partisipan yang memiliki anak ASD dengan umur yang berbeda adalah dengan teknik snowball. Hasil menunjukkan ada perubahan yang dinamis terkait peran antar pasangan dalam memenuhi kebutuhan finansial, emosional, tenaga, dan waktu untuk anak ASD mereka yang memiliki kesulitan dalam komunikasi sosial. Setiap pasangan suami istri ini berusaha melakukan perubahan peran bila dibutuhkan dengan rasa tanggung jawab dan saling menghargai satu sama lain. Mereka mengakomodasi perubahan secara kolektif dan melalui kesepakatan. Sehingga bisa disimpulkan dalam merawat anak ASD, mereka menggunakan strategi kompromi terkait finansial, emosional, tenaga, dan waktu.

Families that have children with ASD (Autism Spectrum Disorder) were vulnerable in terms of financial, emotional, energy, and time that causes tension between husbands and wives as parents in caring for their children with ASD. The main purpose of this study is to elaborate on the communication used by married heterosexual couples in negotiating a parenting role related to financial, emotional, energy, and time problems for their child with ASD by using relational dialectical theory. The data collection method used interviews. The participants' selection used snowball. The participants consisted of three married heterosexual couples with three different ages of children with ASD in East Java. The results showed that there are dynamic changes related to the role of married couple participants in meeting financial, emotional, time, and energy needs for their children with ASD who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does role sharing change when necessary and share tasks with respectable and responsibility. They also accommodate changes by using collective consensus.

The conclusion of this study is a compromise strategy that was used by them when sharing roles related to financial, emotional, time, and energy for children with ASD.

#### Kata kunci/Keywords:

ASD, komunikasi, negosiasi, peran orangtua

ASD, communication, negotiation, parental roles

#### Introduction

This research aims to elaborate communication on married heterosexual couples in negotiating their role in parenting for children with Autism Spectrum Disorder (ASD). The research is based on the increasing phenomenon of children born with ASD in Indonesia in recent years: in the year 2000 1:500, in 2010 1:300, and in 2015 134,000 children. These data are supported by the statement of Wardhani (2009), where the number stated previously (i.e., 134,000) indicates that out of 250 children born, one child is born with ASD (Wardhani, 2009).

Autism spectrum disorder (ASD) is a neurodevelopmental disorder associated with the presence of social-communication deficits and restricted and repetitive behaviors (Reynold and Kamphaus, 2013; Memari et al, 2015; Irawan, 2015). American Psychiatric Association (in Diagnostic & Statistical Manual of Mental Disorder 5<sup>th</sup> ed., 2013) divided autism spectrum disorder (ASD) into three severity levels, namely: (1) level 1 "requiring support" marked by difficulty initiating social interaction, unsuccessful responses to overtures of others, able to engage in conversation but to-and-fro with others in terms of social communication and by difficulty switching between activities in terms of restricted and repetitive behaviors; (2) level 2 "requiring substantial support" marked by a deficit in verbal and nonverbal communication, limited initiation of social interaction, speaks simple sentences, their interaction is limited to a narrow special interest in terms of social communication and by difficulty coping with change in terms of restricted and repetitive behaviors; (3) level 3 "requiring very substantial support" marked by severe deficits in verbal and nonverbal communication, very limited initiation of social interaction, minimal response to overtures from others in terms of social communication and by extreme difficulty coping with change, repetitive behaviors in all spheres in terms of restricted and repetitive behaviors.

In the Puterakembara (the community of parents of children with ASD in Indonesia), a majority of parents told how shocked they were when they found out their children were an ASD for the first time. Some of them told that in dealing with ASD children who have difficulties in speech and managing behavior, sometimes they lose temper, energy, and time for themselves or their partners (Marijani, 2003). Some of them blame themselves and others blame their partners due to their inability to overcome this condition (Apostelina,n.d). Another study showed that parents of children with ASD were faced with financial problems, hectic therapeutic schedules, and difficult-to-manage behavior of their children. The inability to overcome this situation potentially increased the risk for divorce or separation (Freedman et al; 2012). In Indonesia, pediatrician Sutadi, a leading consultant for children with autism, conducted research on 406 families with autistic children from 2000 to 2004. He found that 23.5% of families in Indonesia care for a child with autism, and one out of five families that care for a child with autism often divorce (Sutadi, 2011).

They need to dialogue with each other in negotiating their role in providing financial, emotional, energy, and time support for their ASD child to adapt to this situation and eliminate the risk for divorce or separation in married heterosexual couples. By implementing Commented [A1]: Perlu ada data terbaru (lima tahun terakhir)

the dialectical relational theory, the researcher aims to elaborate on the communication used by couples in negotiating their roles in the process of caring for their child with ASD.

#### Literature review

Interpersonal communication between husband and wife is a part of the study of communication within the context of family communication. Family is the smallest unit in society, wherein there is an interaction between family members: mother-child, father-child, husband-wife, or between siblings. The role of a family member is often associated with the contentment of resources. According to the resource theory by Stafford (2008), there are two types of resources: concrete and abstract. DeVito (2004), Galvin (2012), and Guerrero (2007) state that concrete resources consist of financially related resources, whereas abstract resources consist of emotion, time, and energy. The aforementioned explanation shows that the interaction between roles within a family is an exchange of attention, financial support, emotion, energy, and time from one member of the family to the other. This implies that the study of family communication is always interconnected with the theory of interactional perspective, focusing on the interaction and relationship between individuals within a family.

The characteristics of family as a system consist of the following: (1) interdependence (apparent connection and the relationship between units), (2) dynamic (ever-changing and appearing to exhibit a process of adaptation in relation to changes), and (3) dialectical tension (apparent dialectical tension in the cycle of the family's life, and thus an attempt to negotiate the tension is ever-present) (Sprey, 1999). The three mentioned characteristics show that family communication is a relational-based communication between two individuals with an interactional perspective as a part of unity. The aforementioned explanation asserts that the lack of financial, emotion, energy, and time within heterosexual marital relationships for caring for their child with ASD definitely causes dialectical tension in their relationships. **Commented [A2]:** Penjelasan singkat mengenai urgensi dan kebaruan penelitian perlu ditambahkan.

However, the family system also comprises a characteristic known as dynamic, and thus they will automatically try to adapt to apparent changes by negotiating and communicating the dialectical tension. The aforementioned issue on family communication can be analyzed through relational dialectics theory.

Relational dialectics theory was proposed and developed by Mikhail Bakhtin, who observed that in an interaction between two individuals, there is always dialog. The dialog is open in nature in order to develop a relationship between the said individuals; however, there is always a chance that tension will ensue (dialectics) (Baxter, 2004). Tension (dialectics) is defined as anything that comprises itself of three major elements: contradiction, motion, and praxis (Turner & West, 2006): (1) Contradiction is an opposing condition between personal interest and expectation (private sphere) with collective interest and expectation (public sphere); (2) Motion is an element of change within a relationship or the change of proximity in a period of time, where an individual is certain to experience changes in relationship and proximity with another individual in a certain span of time, which will contribute to the increase in contradiction; (3) Praxis is an element which shows that when an individual is faced with a contradiction, he/she will never possess a decisive decision-making ability because of the limitations and norms conjured by his/her surrounding sociocultural setting.

Contradiction, motion, and praxis mentioned by Rawlins (1992) made interaction between one individual and another lead to the possibility of tension between the two, a sort of dualism of issues between the individual wanting to be open-close (openness-closedness), free-connected (autonomy-connection), and stable-dynamic (predictability-novelty) (Baxter, 2004). The aforementioned explanation asserts that relational dialectics theory is more focused on the effort to balance (balancing) the two contradicting sides, which in this research is depicted by the contradiction between togetherness and separation in two-way communication. The concept of togetherness-separation is a cultural context that sees each individual bounded to the values, rules, roles, and norms where they live. Togetherness refers to the ability that drives an individual to uphold a high level of morality and responsibility in accordance with the legitimized norms and it leads to the creation of unity or harmony with another individual. The separation refers to the ability that drives an individual to act in an egotistical manner and irresponsibly, where the promotion of his/her own needs is put above others' that leads toward disharmony within a relationship.

According to Baxter (2009) and Krueger & Funder (2004), in dialectical relational theory, the important element studied is the utterance chain. The utterance chain is an interconnected utterance within individual backgrounds and value contexts. In this research, the contradiction between togetherness and separation can be seen through husbands' and wive' utterance dealing with a role in providing financial, emotional, energy, and time support for their ASD child. The aforementioned explanation asserts that: (1) the utterances of togetherness can be seen verbally that indicate proclaim fondness, acceptance, collectiveness, supportiveness, and other related to any actions that lead toward positive results; (2) the utterances of separation include proclaim dislike, unaccepting, egotistical, demands the support, and any action that leads toward negative results. In this research, the utterance chain should explain how cohesion and adaptability are highly effective in the effort to balance both togetherness and separation.

In terms of balancing the contradiction between togetherness and separation in relational dialectics theory, Wood et al. (in Turner and West, 2006) stated that there are four strategies in the management of dialectical tension dealing with how to negotiate their role. The four strategies namely are: (1) cyclic alternation (spiraling alternation) is a strategy to choose one side out of two depending on time; (2) segmentation is a strategy to choose one side out of two depending on the individual's domain or setting; (3) selection is a strategy to choose a particular side disregarding time and domain; and (4) integration is a strategy that

tries to find a solution for both parties. The integration strategy has four kinds of function, they are: (a) neutralizing (balancing), that is, both sides try to compromise; (b) reframing (recalibration), that is, both sides try to lessen the tension; (c) disqualifying, that is, choosing one side to stand for a general issue; however, this does not apply for specific or private issues; and (d) reaffirmation, that is, both sides choose differing pathways but still consider the other's decision.

This theory will be briefly used to explore the role of husband and wife related to financial, emotional, energy, and time problems, and to explore their cohesion, adaptation, and strategy in negotiating a parenting role for their child with ASD in order to eliminate the tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation.

#### **Research methodology**

This study used an interpretative phenomenological analysis (IPA) approach. According to Smith, this approach concerns exploring the part of an individual's experiences (Smith, Flowers, & Larkin, 2009). The aforementioned explanation asserts to do phenomenology, this study used interviews to collect participants' utterances about caring experience towards their child with ASD related to financial, emotional, energy, and time problems. All data were noted because all participants objected interview process by audio recording. After all, data were collected, scripted, and coded, then data would be analyzed and interpreted comprehensively by using a dual interpretation process: (1) analyze and interpret utterances from each participant either the husband or the wife to get both perspectives about their feelings dealing with financial, emotional, energy, and time problems to care for their child with ASD; (2) analyze and interpret how they adapt and work out these problems as a couple to describe their dialectic tension related to togetherness and separation. These two processes would describe their negotiation strategy related to financial, emotional, energy, and time problems to care for their child with ASD

The number of participants was three heterosexual married couples that have a child with ASD. All participants were biological mothers and fathers of children with ASD. The participants' recruitment process used snowball by asking close people who may have acquaintances who are married and have a child with ASD. One couple of participants was a friend of the researcher's acquaintance. Starting from the first couple of participants, the researcher got two other couple names. Three couple of participants is a small number, but IPA approach usually have a small number of participant and the aim is to reveal something of the experience of each those individuals (Smith and Osborn, 2006). The study may explore in detail the similarities and differences between each case dealing with different ages and the position of the child with ASD to their sibling. The small number of participants is a limitation of this study, but this study would be a pilot project for further study.

The first participant couple was a housewife with an initial of Mrs. A (50 years old) and a working father with an initial of Mr. A (50 years old). They have been married for 22 years. Their child with ASD (with an initial U) is the youngest of two and is 18 years old; he has gone through speech and occupational therapy for 11 years and is currently completing his second-year junior high school education in an inclusive school. In some countries, 18-year-olds no longer refer to children, but in Indonesia according to article 330 of The Civil Law, the age limit of children are those who are not yet 21 years old and are not yet married. Article 98 paragraph 1 Compilation of Islamic Law also states that the age limit of children is those who are not yet 21 years old, are not physically or mentally disabled, and are not yet married. Law No. 4 of 1979 concerning Child Welfare in article 1 paragraph 2 states the age limit of children is those who are not yet 21 years old and are not yet married. The

Commented [A3]: Jika dimungkinkan, penjelasan mengenai partisipan/informan, selair dalam narasi, dibuat juga dalam bentuk tabel untuk memudahkan identifikasi. aforementioned explanation asserts that this family could be chosen as a participant, although their child with ASD is 18 years old.

The second participant couple was a housewife with an initial of Mrs. W (30 years) and a working father with an initial of Mr. W (30 years old). When they learned that their child was a child with ASD, Mrs. W decided to stop working so that she could focus on taking care of her child with ASD (with an initial L, 4 years old). They have been married for 5 years. L (4 years old) is the eldest of two, has been in speech and occupational therapies for 2 years, and is currently enrolled in an inclusive preschool.

The third participant couple was a housewife with an initial of Mrs. M (42 years old) and a father with an initial of Mr. M (44 years old). Both have been married for 12 years. Their child with ASD (with an initial A) is 7 years old and is the second child of three, currently in first grade in an inclusive elementary school, and has been in speech and occupational therapy for three years.

#### **Results and Discussion**

# Analysis of utterances between husband and wife on financial, emotional, energy, and time support during their role in parenting for their child with ASD

In the first couple of married participants, their child was a severe deficit in verbal and nonverbal communication, very limited initiation of social and minimal response to overtures others in terms of social communication. That would be seen when his teacher asked him, he repeated the teacher's question and took a long time for answering one word to his teacher. In terms of behavior, he was extreme difficulty coping with change. That would be seen when his parents changed the direction to go to other places different from the first plan, he got very mad at their parents. Mr. A told that his son with ASD (U) more frequently bites, pinches, and hits to Mrs. A, but when Mrs. A cried, U stopped being mad and then hugged Mrs. A. Mr. A explained that emotionally his son with ASD was closer to Mrs. A rather than to Mr. A. In here, Mr. A felt sorry for his wife, because he could imagine how exhausted she was to care for U. This implies that Mrs. A was likely close emotionally to their child with ASD.

Financial support from Mr. A toward U (child with autism, 18 years old) is affirmed by Mrs. A: "... My husband is highly supportive in terms of funding the therapy, school, and doctor visit... U has been in therapy for quite a while, around 11 years since he was 6–7 years old." Mrs. A's statement shows that all the financing for the needs' their child with ASD is fulfilled by her husband because Mrs. A herself is a full-time housewife. Mr. and Mrs. A told that all the needs' their child with ASD was not cheap and they had to downsize for other needs including the needs of the oldest son.

In terms of energy and time support for U, Mr. and Mrs. A were doing their complementary and reciprocal role. The complementary role could be seen through Mrs. A's explanation when Mr. A went to work, she had the responsibility to carried out her child with ASD to go to school or for getting therapy. If Mr. A was on leave then he carried out U to go to school or go for therapy. Their reciprocal role could be seen from the couple participants' statements that Mr. and Mrs. A switch roles, for example, when Mrs. A is helping her eldest with schoolwork, Mr. A takes U for a walk and vice versa. When U accompanies his mother to cook, then Mr. A helps his eldest with the computer. They did this way because they did not want their son with ASD to ruin the eldest's project or schoolwork like before.

In the second couple of married participants, their child was a deficit in verbal and nonverbal communication, limited initiation of social interaction and speaks simple sentences in terms of social communication. As could be seen from Mrs. W's explanation that L (4 years old) could comprehend and pointed to the objects' or body parts' but he could not mention and speak clearly the objects' or body parts' name. He also gave short answered when asked, but he could not ask or request verbally when he needs something. In terms of behavior, L could not cope with noisy sounds and crowds. This is affirmed by Mr. W stating that "L likes to play with L's younger sister. They get along well, but when his little sibling cried or noisy, L can be mad because L hates noisy".

Mr. W's financial support toward L can be derived from his statement, "I only sleep for four hours every night and that happens every night. I wake up early and go straight to taking care of business ... this is because our business is still in its early days." Mr. W's statement shows that he is willing to work hard to fulfill the needs of L. His needs are, for example, therapy, piano lessons, swimming lessons, tuition, lab checks, routine check-ups to the doctor every 6 months, and a shadow (a caretaker at school). Moreover, Mrs. W is now a housewife who has stopped working after knowing L was diagnosed with ASD.

Mrs. W states: "L cannot eat chocolate or ice cream, after eating it he becomes temperamental. L also cannot drink beverages that often find in the groceries ... Last time when he lashed out, he screamed for two hours..., but we let him be. It's hard for him to control his emotion, he claws and pinches, as you can see here (showing her hands that were clawed by L)." From the aforementioned statement, Mrs. W controls the emotion of her child by regulating the food that he consumes so that he does not throw a tantrum. According to Erickson, 60% of children with ASD have a poor digestive system. Foods such as those containing animal milk cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function. Impaired brain functions are cognitive functions, receptive communication, concentration, and behavior (Erickson et al, 2005). Erickson's statement asserts that chocolate and ice cream are containing animal milk that presumably affects L's behavior.

In relation to the time and energy support that they give for L, Mr. and Mrs. W do the task together. They often take L and his younger sister to play together; they go on a recreation trip outside town or on short outings to the malls for dinner even Mrs. W has to accompany L so he does not panic in the crowd at the mall. This is done in order to build a sense of togetherness between L and his younger sister so that there will be no feelings of envy in the future.

In the third couple of married participants, their child (with an initial A) has a limited interaction to the narrow special interest and speaks simple sentences only if he needs something in terms of social communication. This would be seen from Mrs. M's affirmation that A was very passive, he rarely asked to parents or someone, he asked to someone only if he needs something. In terms of behavior, A has difficulty coping with change and has repetitive behaviors towards narrow special interest. This would be seen from Mr. M's explanation that A was easily bored when he played with his eldest and younger brother, he only lasted in 5 minutes playing with them. He prefers to play alone.

Mr. M's financial support for his child with ASD (A, 7 years old) can be seen from Mrs. M's statement: "A Nikolin injection for A costs around 250 thousand per pack, this can be administered 10 times. A requires around 60× so we need six packs costing us around 1.5 million. The cost for therapy is about 300 thousand per month; it is scheduled twice a week for two hours." This indicates that Mr. M works hard to support the needs of his child with ASD. Mr. and Mrs. M told that for making ends meet all the needs' their child with ASD, they had to downsize for other needs including the needs of the eldest and youngest son.

Mrs. M supervises her child's emotions by regulating his intake of gluten and commonly packaged beverages. She said, "I limit his gluten consumption. For example, he asks for Indomie (the brand of instant noodles) because he sees his brothers eating it. I make a half portion for him but for seasoning, I only give soy sauce and salt, I do not include the seasoning that comes with it. If he asks for a snack with extra seasoning, I only put a little of it." It can be inferred from Mrs. M's statement that in order to control her child with ASD's behavior, she regulates the foods consumed by him. Mr. M also supports Mrs. M's regulation by not buying food containing gluten ingredients for his son with ASD. As mentioned before that some children with ASD have a poor digestive system. Foods such as wheat flour cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function. Impaired brain functions are cognitive functions, receptive communication, concentration, and behavior (Erickson et al, 2005). Erickson's statement asserts that noodles containing wheat flour that probably affects A's behavior.

Concerning the time and energy support for their child with ASD, Mrs. M frequently accompanies her son with ASD at school or home compared to Mr. M because Mr. M has not been able to fully supervise him. Mr. M preferred to accompany two other children so that they could not disturb Mrs. M dealing to care A (her child with ASD).

From the aforementioned utterances of three married couple participants, the following conclusion can be drawn: there are dynamic changes related to the role of married couple participants in meeting financial, emotional, time, and energy needs for their ASD children who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does share tasks with respectable and responsibility. As mentioned before, the utterances of togetherness can be seen through utterances that indicate proclaim acceptance, collectiveness, supportiveness, and others related to any actions

that lead toward positive results. Each participant does a complementary and reciprocal role to support his/her couple caring for their child with ASD. The study results found that each participant tries hard to create togetherness as couples handling their child with ASD even though it was not easy. All participants have a similarity of optimistic feelings that could be seen in their quotation saying every difficulty, there must be ease. Their optimistic feeling was powerful to create togetherness as a unity.

According to Koerner and Fitzpatrick, in a family, there is a degree of cohesion and adaptability among members (Koerner & Fitzpatrick, 2002). That two degrees would be useful for exploring the ability of all participants toward changes and dealing with tensions in order to balance their relationships. All about cohesion and adaptability would be explained as follows

Analysis of utterances between husband and wife about cohesion and adaptability in relation to describe the couples' role negotiate strategy in parenting for their child with ASD

After discussed the utterances of togetherness as earlier, this section would analyze participants' ability to adapt and to foster cohesion in sharing their roles during parenting for their children with ASD. The ability to adapt, according to Olson (1999) and Poire (2006), is the ability to maintain stability and to regulate changes in a relationship. The ability to adapt is divided into four different levels: (1) rigid, where a certain rigidity is shown toward accepting changes due to authoritarian leadership and stringent rules becoming a benchmark in life; (2) structured, where moderate leadership can accommodate changes based on limited collective decisions, leading to a more stable relationship; (3) flexible, where quick and prompt attitudes are shown toward changes, and often decisions are made based on collective

consensus; (4) chaotic, where tension and instability are high due to a lack of leadership, which leads to a dissimilar perception between the two when faced with changes. Olson's level of adaptation can be simplified through a matrix (see Table 1).

Table 1. Adaptability				
	Rigid	Structured	Flexible	Chaotic
Roles	Roles seldom change	Roles stable	Role sharing change	Dramatic role shift
Change	Too little change	Change when demanded	Change when necessary	Too much change
Leadership	Authoritarian leadership	Leadership sometimes shared	Share leadership	Lack of leadership
		C 01 100	0	

Source: Olson, 1999

According to Olson (1999) and Poire (2006), cohesion is defined as an emotional bond between members within a relationship. This bond is divided into four different levels: (1) enmeshed—in this level, members' proximity, loyalty, and dependence over each other are extremely high, leaving no space for individuality; (2) cohesive—in this level, members attempt to maintain emotional closeness, loyalty, and cohesion by emphasizing a certain degree of individuality; (3) connected—in this level, members are mostly independent, but still, involve other members to perform the group's function; (4) disengaged—in this level, members are extremely independent and thus possess a high degree of individuality, which places emphasis on him/herself over other members. Olson's level of cohesion can be simplified through a matrix (see Table 2).

Commented [A4]: Sebaiknya tabel tidak terputus

		Table 2. Cohesion	1	
	Enmeshed	Cohesive	Connected	Disengaged
Closeness	Little closeness	Little-Moderate closeness	Middle-High closeness	Very high closeness

Independence/ dependence	High independence	Interdependent	Interdependent	High dependence
I-We balance	Ι	I-We	I-We	We
Loyalty	Little loyal	Some loyalty	High loyalty	Very high loyalty

Source: Olson, 1999

Table 3 explains that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are all positive conditions, stable and conducive. In terms of adaptation, structured and flexible are two of the conditions that are able to accept and deal with changes positively compared with rigid (tends to reject changes) and chaotic (often changes attitudes toward the change). In terms of cohesion, cohesive, and connectedness are two of the most conducive conditions that are able to maintain emotional closeness, loyalty, and cohesion while still being able to give a degree of independence for other members to perform their function according to their domain. The aforementioned explanation shows that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are conditions that lead toward togetherness, symbolized by the ability to adapt (+) and to maintain cohesion (+) as can be seen as follows:

Table 3. Adaptability and Cohesion				
Cohesion	Adaptability			
	Rigid	Structured	Flexible	Chaotic
Enmeshed	_	_	_	_
Cohesive	_	+	+	_
Connected	—	+	+	_
Disengaged	—	_	_	_

Source: Researcher's analysis

The utterances of all three participants in terms of adaptability related to financial, emotional, time, and energy show that they tend to do role sharing change and change when necessary for caring for their children with ASD, as could be explained as follow: (1) they try work hard and reduce the unnecessary expenses to be able to make ends meet the needs of their children with ASD; (2) when wives support emotional by reducing the intake of gluten and animal milk, husbands support by not buying food containing those ingredients for their children with ASD; (3) time and energy, wives support time and energy by accompanying their children with ASD at school, place of therapy, and home daily, husbands support time and energy for their son with ASD only when husbands on leave. They do a complementary role and a reciprocal role. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level structured-flexible in terms of adaptability. A more structured and flexible level of adaptation allows the three couples to adapt to changes. It could be seen from the way they accommodate changes based on collective decisions and consensus.

The utterances of all participants related to financial, emotional, time, and energy for their sons with ASD show that the emotional bonding toward one another is cohesive and connected. All three couples actively try to maintain emotional closeness, loyalty, and interdependence with one another face-up financial, emotional, time, and energy problems for their sons' with ASD as follow: (1) in doing every task for caring for their sons' with ASD, they do together for one intention for making better the condition of their sons' with ASD; (2) they are trying actively to complement each other's role for their sons' with ASD. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level of cohesive-connected.

From the aforementioned explanation about cohesion and adaptability, this described how participants manage and balance their roles towards their son with ASD by the negotiating strategies. All three couples implement a compromise strategy for caring for their children with ASD. They interchange roles and collectively participate in devoting financial, emotional, time, and energy for them.

#### Conclusion

In conclusion, the three couples participants used a compromise strategy to negotiate their roles related to financial, emotional, time, and energy for their children with ASD. They accommodate changes based on collective decisions and consensus. They also collectively interchange and participate in devoting financial, emotional, time, and energy for their children with ASD. These findings indicate that there are still married couples who have children with ASD who remain share tasks together in caring for their children with ASD. Although difficult, they have the optimism that after difficulties there is ease. The same optimism feeling would make easy to create good cohesion and adaptability.

This research attempts to help to understand and capturing the complexity of the marital, family system, and tension or stress in the health area using relational dialectic theory, family system approach, and Olson's circumplex model. The small number of participants is a limitation of this study, but this study would be a pilot project for further study. The implication of this study is to eliminate the tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation. For future work, it is necessary to conduct research on how to balance the communication in another tension context in a family using more participants.

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## **BUKTI KORESPONDENSI**

# ARTIKEL JURNAL NASIONAL TERAKREDITASI SINTA 2

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Dear Redaktur Jurnal Komunikasi Indonesia,

Saya telah merevisi beberapa poin masukan dari reviewer di bagian introduction dan metodologi dan kesemuanya telah saya beri tanda warna kuning. Besar harapan saya agar artikel ini bisa dimuat di Jurnal Komunikasi Indonesia. Atas perhatiannya saya sampaikan terimakasih.

Salam, Andria Saptyasari Staf Pengajar Departemen Ilmu Komunikasi FISIP Universitas Airlangga [Kutipan teks disembunyikan]

Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder--andria saptyasari (revisi).docx 55K

# Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder (ASD)

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#### Abstrak/Abstract

Keluarga dengan anak ASD (Autism Spectrum Disorder) rentan akan kondisi finansial, emosional, tenaga dan waktu yang dapat memicu ketegangan antara suami dan istri sebagai orang tua dalam merawat anak ASD mereka. Studi ini bertujuan mengelaborasi komunikasi yang digunakan oleh pasangan heteroseksual yang sudah menikah dalam menegosiasikan peran merawat anak ASD terkait finansial, emosional, tenaga dan waktu dengan menggunakan teori dialektika hubungan. Metode pengumpulan data menggunakan wawancara. Cara mendapatkan tiga pasangan partisipan yang memiliki anak ASD dengan umur yang berbeda adalah dengan teknik snowball. Hasil menunjukkan ada perubahan yang dinamis terkait peran antar pasangan dalam memenuhi kebutuhan finansial, emosional, tenaga, dan waktu untuk anak ASD mereka yang memiliki kesulitan dalam komunikasi sosial. Setiap pasangan suami istri ini berusaha melakukan perubahan peran bila dibutuhkan dengan rasa tanggung jawab dan saling menghargai satu sama lain. Mereka mengakomodasi perubahan secara kolektif dan melalui kesepakatan. Sehingga bisa disimpulkan dalam merawat anak ASD, mereka menggunakan strategi kompromi terkait finansial, emosional, tenaga, dan waktu.

Families that have children with ASD (Autism Spectrum Disorder) were vulnerable in terms of financial, emotional, energy, and time that causes tension between husbands and wives as parents in caring for their children with ASD. The main purpose of this study is to elaborate on the communication used by married heterosexual couples in negotiating a parenting role related to financial, emotional, energy, and time problems for their child with ASD by using relational dialectical theory. The data collection method used interviews. The participants' selection used snowball. The participants consisted of three married

heterosexual couples with three different ages of children with ASD in East Java. The results showed that there are dynamic changes related to the role of married couple participants in meeting financial, emotional, time, and energy needs for their children with ASD who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does role sharing change when necessary and share tasks with respectable and responsibility. They also accommodate changes by using collective consensus. The conclusion of this study is a compromise strategy that was used by them when sharing roles related to financial, emotional, time, and energy for children with ASD.

#### Kata kunci/Keywords:

ASD, komunikasi, negosiasi, peran orangtua

ASD, communication, negotiation, parental roles

#### Introduction

This research aims to elaborate communication on married heterosexual couples in negotiating their role in parenting for children with Autism Spectrum Disorder (ASD). The research is based on the increasing phenomenon of children born with ASD in Indonesia in recent years: in the year 2000 1:500, in 2010 1:300, and in 2015 134,000 children. These data are supported by the statement of Wardhani (2009), where the number stated previously (i.e., 134,000) indicates that out of 250 children born, one child is born with ASD (Wardhani, 2009). In 2018 there are out of 59 births, one child is born with ASD (Kementrian Kesehatan RI, 2020)

Autism spectrum disorder (ASD) is a neurodevelopmental disorder associated with the presence of social-communication deficits and restricted and repetitive behaviors (Reynold and Kamphaus, 2013; Memari et al, 2015; Irawan, 2015). American Psychiatric Association (in Diagnostic & Statistical Manual of Mental Disorder 5<sup>th</sup> ed., 2013) divided autism spectrum disorder (ASD) into three severity levels, namely: (1) level 1 "requiring support" marked by difficulty initiating social interaction, unsuccessful responses to overtures of others, able to engage in conversation but to-and-fro with others in terms of social communication and by difficulty switching between activities in terms of restricted and repetitive behaviors; (2) level 2 "requiring substantial support" marked by a deficit in verbal and nonverbal communication, limited initiation of social interaction, speaks simple sentences, their interaction is limited to a narrow special interest in terms of social communication and by difficulty coping with change in terms of restricted and repetitive behaviors; (3) level 3 "requiring very substantial support" marked by severe deficits in verbal and nonverbal communication, very limited initiation of social interaction, minimal response to overtures from others in terms of social communication and by extreme difficulty coping with change, repetitive behaviors in all spheres in terms of restricted and repetitive behaviors.

In the Puterakembara (the community of parents of children with ASD in Jakarta, Indonesia), a majority of parents told how shocked they were when they found out their children were an ASD for the first time. Some of them told that in dealing with ASD children who have difficulties in speech and managing behavior, sometimes they lose temper, energy, and time for themselves or their partners (Marijani, 2003). Some of them blame themselves and others blame their partners due to their inability to overcome this condition (Apostelina,n.d). Another study showed that parents of children with ASD were faced with financial problems, hectic therapeutic schedules, and difficult-to-manage behavior of their children. The inability to overcome this situation potentially increased the risk for divorce or separation (Freedman et al; 2012). In Indonesia, pediatrician Sutadi, a leading consultant for children with ASD, conducted research on 406 families with ASD children from 2000 to

2004. He found that 23.5% of families in Indonesia care for a child with ASD, and one out of five families that care for a child with ASD often divorce (Sutadi, 2011). Aji's research (2019) also found that some parents in the Illahi community (the community of parents of children with ASD in Semarang, Indonesia) admit that their goal of joining this community is to be able to share experiences and seek support from other parents who have the same fate because they do not get support from their spouse, parents or extended family. They hope that by joining this community they will no longer be stressed by this condition.

The paragraph above shows that married couples who have children with ASD have a poor relationship. They should need to dialogue with each other in negotiating their role in providing financial, emotional, energy, and time support for their ASD child to adapt to this situation and eliminate the risk for divorce or separation in married heterosexual couples. By implementing the dialectical relational theory, the researcher aims to elaborate on the communication used by couples in negotiating their roles in the process of caring for their child with ASD. The urgency of this research is to elaborate on the relationship between husband and wife who have children with ASD through relationship dialectical theory which sees contradictions of togetherness and separation in terms of cohesiveness and contradiction of rigid and chaotic in terms of adaptability.

#### Literature review

Interpersonal communication between husband and wife is a part of the study of communication within the context of family communication. Family is the smallest unit in society, wherein there is an interaction between family members: mother-child, father-child, husband-wife, or between siblings. The role of a family member is often associated with the contentment of resources. According to the resource theory by Stafford (2008), there are two types of resources: concrete and abstract. DeVito (2004), Galvin (2012), and Guerrero (2007)

state that concrete resources consist of financially related resources, whereas abstract resources consist of emotion, time, and energy. The aforementioned explanation shows that the interaction between roles within a family is an exchange of attention, financial support, emotion, energy, and time from one member of the family to the other. This implies that the study of family communication is always interconnected with the theory of interactional perspective, focusing on the interaction and relationship between individuals within a family.

The characteristics of family as a system consist of the following: (1) interdependence (apparent connection and the relationship between units), (2) dynamic (ever-changing and appearing to exhibit a process of adaptation in relation to changes), and (3) dialectical tension (apparent dialectical tension in the cycle of the family's life, and thus an attempt to negotiate the tension is ever-present) (Sprey, 1999). The three mentioned characteristics show that family communication is a relational-based communication between two individuals with an interactional perspective as a part of unity. The aforementioned explanation asserts that the lack of financial, emotion, energy, and time within heterosexual marital relationships for caring for their child with ASD definitely causes dialectical tension in their relationships. However, the family system also comprises a characteristic known as dynamic, and thus they will automatically try to adapt to apparent changes by negotiating and communicating the dialectical tension. The aforementioned issue on family communication can be analyzed through relational dialectics theory.

Relational dialectics theory was proposed and developed by Mikhail Bakhtin, who observed that in an interaction between two individuals, there is always dialog. The dialog is open in nature in order to develop a relationship between the said individuals; however, there is always a chance that tension will ensue (dialectics) (Baxter, 2004). Tension (dialectics) is defined as anything that comprises itself of three major elements: contradiction, motion, and praxis (Turner & West, 2006): (1) Contradiction is an opposing condition between personal

interest and expectation (private sphere) with collective interest and expectation (public sphere); (2) Motion is an element of change within a relationship or the change of proximity in a period of time, where an individual is certain to experience changes in relationship and proximity with another individual in a certain span of time, which will contribute to the increase in contradiction; (3) Praxis is an element which shows that when an individual is faced with a contradiction, he/she will never possess a decisive decision-making ability because of the limitations and norms conjured by his/her surrounding sociocultural setting.

Contradiction, motion, and praxis mentioned by Rawlins (1992) made interaction between one individual and another lead to the possibility of tension between the two, a sort of dualism of issues between the individual wanting to be open–close (openness–closedness), free–connected (autonomy–connection), and stable–dynamic (predictability–novelty) (Baxter, 2004). The aforementioned explanation asserts that relational dialectics theory is more focused on the effort to balance (balancing) the two contradicting sides, which in this research is depicted by the contradiction between togetherness and separation in two-way communication. The concept of togetherness-separation is a cultural context that sees each individual bounded to the values, rules, roles, and norms where they live. Togetherness refers to the ability that drives an individual to uphold a high level of morality and responsibility in accordance with the legitimized norms and it leads to the creation of unity or harmony with another individual. The separation refers to the ability that drives an individual to act in an egotistical manner and irresponsibly, where the promotion of his/her own needs is put above others' that leads toward disharmony within a relationship.

According to Baxter (2009) and Krueger & Funder (2004), in dialectical relational theory, the important element studied is the utterance chain. The utterance chain is an interconnected utterance within individual backgrounds and value contexts. In this research, the contradiction between togetherness and separation can be seen through husbands' and

wive' utterance dealing with a role in providing financial, emotional, energy, and time support for their ASD child. The aforementioned explanation asserts that: (1) the utterances of togetherness can be seen verbally that indicate proclaim fondness, acceptance, collectiveness, supportiveness, and other related to any actions that lead toward positive results; (2) the utterances of separation include proclaim dislike, unaccepting, egotistical, demands the support, and any action that leads toward negative results. In this research, the utterance chain should explain how cohesion and adaptability are highly effective in the effort to balance both togetherness and separation.

In terms of balancing the contradiction between togetherness and separation in relational dialectics theory, Wood et al. (in Turner and West, 2006) stated that there are four strategies in the management of dialectical tension dealing with how to negotiate their role. The four strategies namely are: (1) cyclic alternation (spiraling alternation) is a strategy to choose one side out of two depending on time; (2) segmentation is a strategy to choose one side out of two depending on the individual's domain or setting; (3) selection is a strategy to choose a particular side disregarding time and domain; and (4) integration is a strategy that tries to find a solution for both parties. The integration strategy has four kinds of function, they are: (a) neutralizing (balancing), that is, both sides try to compromise; (b) reframing (recalibration), that is, both sides try to lessen the tension; (c) disqualifying, that is, choosing one side to stand for a general issue; however, this does not apply for specific or private issues; and (d) reaffirmation, that is, both sides choose differing pathways but still consider the other's decision.

This theory will be briefly used to explore the role of husband and wife related to financial, emotional, energy, and time problems, and to explore their cohesion, adaptation, and strategy in negotiating a parenting role for their child with ASD in order to eliminate the

tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation.

#### **Research methodology**

This study used an interpretative phenomenological analysis (IPA) approach. According to Smith, this approach concerns exploring the part of an individual's experiences (Smith, Flowers, & Larkin, 2009). The aforementioned explanation asserts to do phenomenology, this study used interviews to collect participants' utterances about caring experience towards their child with ASD related to financial, emotional, energy, and time problems. All data were noted because all participants objected interview process by audio recording. After all, data were collected, scripted, and coded, then data would be analyzed and interpreted comprehensively by using a dual interpretation process: (1) analyze and interpret utterances from each participant either the husband or the wife to get both perspectives about their feelings dealing with financial, emotional, energy, and time problems to care for their child with ASD; (2) analyze and interpret how they adapt and work out these problems as a couple to describe their dialectic tension related to togetherness and separation. These two processes would describe their negotiation strategy related to financial, emotional, energy, and time problems to care for their child with ASD

The number of participants was three heterosexual married couples that have a child with ASD. All participants were biological mothers and fathers of children with ASD. The participants' recruitment process used snowball by asking close people who may have acquaintances who are married and have a child with ASD. One couple of participants was a friend of the researcher's acquaintance. Starting from the first couple of participants, the researcher got two other couple names. Three couple of participants is a small number, but IPA approach usually have a small number of participant and the aim is to reveal something of the experience of each those individuals (Smith and Osborn, 2006). The study may explore in detail the similarities and differences between each case dealing with different ages and the position of the child with ASD to their sibling. The small number of participants is a limitation of this study, but this study would be a pilot project for further study.

The first participant couple was a housewife with an initial of Mrs. A (50 years old) and a working father with an initial of Mr. A (50 years old). They have been married for 22 years. Their child with ASD (with an initial U) is the youngest of two and is 18 years old; he has gone through speech and occupational therapy for 11 years and is currently completing his second-year junior high school education in an inclusive school. In some countries, 18-year-olds no longer refer to children, but in Indonesia according to article 330 of The Civil Law, the age limit of children are those who are not yet 21 years old and are not yet married. Article 98 paragraph 1 Compilation of Islamic Law also states that the age limit of children is those who are not physically or mentally disabled, and are not yet married. Law No. 4 of 1979 concerning Child Welfare in article 1 paragraph 2 states the age limit of children is those who are not yet 21 years old and are not yet married. The aforementioned explanation asserts that this family could be chosen as a participant, although their child with ASD is 18 years old.

The second participant couple was a housewife with an initial of Mrs. W (30 years) and a working father with an initial of Mr. W (30 years old). When they learned that their child was a child with ASD, Mrs. W decided to stop working so that she could focus on taking care of her child with ASD (with an initial L, 4 years old). They have been married for 5 years. L (4 years old) is the eldest of two, has been in speech and occupational therapies for 2 years, and is currently enrolled in an inclusive preschool.

The third participant couple was a housewife with an initial of Mrs. M (42 years old) and a father with an initial of Mr. M (44 years old). Both have been married for 12 years.

Their child with ASD (with an initial A) is 7 years old and is the second child of three, currently in first grade in an inclusive elementary school, and has been in speech and occupational therapy for three years.

r.	Fable 1. Participant	Couples' Backgrou	und
	First	Second	<b>Third</b>
	<mark>Participant</mark>	Participant	Participant
	Couple	Couple Couple	Couple
<mark>Age</mark>	<mark>Mr. and Mrs. A</mark>	Mr. and Mrs. W	Mr. M (44 years
	(50 years old)	(40 years old)	old) and Mrs. M
			(42 years old
Child with ASD	Boy (18 years	Boy (4 years	Boy (7 years
	old)	old)	old)
Therapy <b>Content</b>	speech and	speech and	speech and
	occupational	occupational	occupational
	therapies for 11	therapies for 2	therapies for
	years	years	three years
Sibling	Boy (21 years	Girl (2 years	Two boys (12
	old)	old)	and 5 years old)
	Source: Rese	archer's analysis	

All information about participants can be drawn as follows:

#### **Results and Discussion**

# Analysis of utterances between husband and wife on financial, emotional, energy, and time support during their role in parenting for their child with ASD

In the first couple of married participants, their child was a severe deficit in verbal and nonverbal communication, very limited initiation of social and minimal response to overtures others in terms of social communication. That would be seen when his teacher asked him, he repeated the teacher's question and took a long time for answering one word to his teacher. In terms of behavior, he was extreme difficulty coping with change. That would be seen when his parents changed the direction to go to other places different from the first plan, he got very mad at their parents. Mr. A told that his son with ASD (U) more frequently bites, pinches, and hits to Mrs. A, but when Mrs. A cried, U stopped being mad and then hugged Mrs. A. Mr. A explained that emotionally his son with ASD was closer to Mrs. A rather than to Mr. A. In here, Mr. A felt sorry for his wife, because he could imagine how exhausted she was to care for U. This implies that Mrs. A was likely close emotionally to their child with ASD.

Financial support from Mr. A toward U (child with autism, 18 years old) is affirmed by Mrs. A: "... My husband is highly supportive in terms of funding the therapy, school, and doctor visit... U has been in therapy for quite a while, around 11 years since he was 6–7 years old." Mrs. A's statement shows that all the financing for the needs' their child with ASD is fulfilled by her husband because Mrs. A herself is a full-time housewife. Mr. and Mrs. A told that all the needs' their child with ASD was not cheap and they had to downsize for other needs including the needs of the oldest son.

In terms of energy and time support for U, Mr. and Mrs. A were doing their complementary and reciprocal role. The complementary role could be seen through Mrs. A's explanation when Mr. A went to work, she had the responsibility to carried out her child with ASD to go to school or for getting therapy. If Mr. A was on leave then he carried out U to go to school or go for therapy. Their reciprocal role could be seen from the couple participants' statements that Mr. and Mrs. A switch roles, for example, when Mrs. A is helping her eldest with schoolwork, Mr. A takes U for a walk and vice versa. When U accompanies his mother to cook, then Mr. A helps his eldest with the computer. They did this way because they did not want their son with ASD to ruin the eldest's project or schoolwork like before.

In the second couple of married participants, their child was a deficit in verbal and nonverbal communication, limited initiation of social interaction and speaks simple sentences in terms of social communication. As could be seen from Mrs. W's explanation that L (4 years old) could comprehend and pointed to the objects' or body parts' but he could not mention and speak clearly the objects' or body parts' name. He also gave short answered when asked, but he could not ask or request verbally when he needs something. In terms of behavior, L could not cope with noisy sounds and crowds. This is affirmed by Mr. W stating that "L likes to play with L's younger sister. They get along well, but when his little sibling cried or noisy, L can be mad because L hates noisy".

Mr. W's financial support toward L can be derived from his statement, "I only sleep for four hours every night and that happens every night. I wake up early and go straight to taking care of business ... this is because our business is still in its early days." Mr. W's statement shows that he is willing to work hard to fulfill the needs of L. His needs are, for example, therapy, piano lessons, swimming lessons, tuition, lab checks, routine check-ups to the doctor every 6 months, and a shadow (a caretaker at school). Moreover, Mrs. W is now a housewife who has stopped working after knowing L was diagnosed with ASD.

Mrs. W states: "L cannot eat chocolate or ice cream, after eating it he becomes temperamental. L also cannot drink beverages that often find in the groceries ... Last time when he lashed out, he screamed for two hours..., but we let him be. It's hard for him to control his emotion, he claws and pinches, as you can see here (showing her hands that were clawed by L)." From the aforementioned statement, Mrs. W controls the emotion of her child by regulating the food that he consumes so that he does not throw a tantrum. According to Erickson, 60% of children with ASD have a poor digestive system. Foods such as those containing animal milk cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function.

and behavior (Erickson et al, 2005). Erickson's statement asserts that chocolate and ice cream are containing animal milk that presumably affects L's behavior.

In relation to the time and energy support that they give for L, Mr. and Mrs. W do the task together. They often take L and his younger sister to play together; they go on a recreation trip outside town or on short outings to the malls for dinner even Mrs. W has to accompany L so he does not panic in the crowd at the mall. This is done in order to build a sense of togetherness between L and his younger sister so that there will be no feelings of envy in the future.

In the third couple of married participants, their child (with an initial A) has a limited interaction to the narrow special interest and speaks simple sentences only if he needs something in terms of social communication. This would be seen from Mrs. M's affirmation that A was very passive, he rarely asked to parents or someone, he asked to someone only if he needs something. In terms of behavior, A has difficulty coping with change and has repetitive behaviors towards narrow special interest. This would be seen from Mr. M's explanation that A was easily bored when he played with his eldest and younger brother, he only lasted in 5 minutes playing with them. He prefers to play alone.

Mr. M's financial support for his child with ASD (A, 7 years old) can be seen from Mrs. M's statement: "A Nikolin injection for A costs around 250 thousand per pack, this can be administered 10 times. A requires around  $60 \times$  so we need six packs costing us around 1.5 million. The cost for therapy is about 300 thousand per month; it is scheduled twice a week for two hours." This indicates that Mr. M works hard to support the needs of his child with ASD. Mr. and Mrs. M told that for making ends meet all the needs' their child with ASD, they had to downsize for other needs including the needs of the eldest and youngest son.

Mrs. M supervises her child's emotions by regulating his intake of gluten and commonly packaged beverages. She said, "I limit his gluten consumption. For example, he asks for Indomie (the brand of instant noodles) because he sees his brothers eating it. I make a half portion for him but for seasoning, I only give soy sauce and salt, I do not include the seasoning that comes with it. If he asks for a snack with extra seasoning, I only put a little of it." It can be inferred from Mrs. M's statement that in order to control her child with ASD's behavior, she regulates the foods consumed by him. Mr. M also supports Mrs. M's regulation by not buying food containing gluten ingredients for his son with ASD. As mentioned before that some children with ASD have a poor digestive system. Foods such as wheat flour cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function. Impaired brain functions are cognitive functions, receptive communication, concentration, and behavior (Erickson et al, 2005). Erickson's statement asserts that noodles containing wheat flour that probably affects A's behavior.

Concerning the time and energy support for their child with ASD, Mrs. M frequently accompanies her son with ASD at school or home compared to Mr. M because Mr. M has not been able to fully supervise him. Mr. M preferred to accompany two other children so that they could not disturb Mrs. M dealing to care A (her child with ASD).

From the aforementioned utterances of three married couple participants, the following conclusion can be drawn: there are dynamic changes related to the role of married couple participants in meeting financial, emotional, time, and energy needs for their ASD children who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does share tasks with respectable and responsibility. As mentioned before, the utterances of togetherness can be seen through utterances that indicate proclaim acceptance, collectiveness, supportiveness, and others related to any actions

that lead toward positive results. Each participant does a complementary and reciprocal role to support his/her couple caring for their child with ASD. The study results found that each participant tries hard to create togetherness as couples handling their child with ASD even though it was not easy. All participants have a similarity of optimistic feelings that could be seen in their quotation saying every difficulty, there must be ease. Their optimistic feeling was powerful to create togetherness as a unity.

According to Koerner and Fitzpatrick, in a family, there is a degree of cohesion and adaptability among members (Koerner & Fitzpatrick, 2002). That two degrees would be useful for exploring the ability of all participants toward changes and dealing with tensions in order to balance their relationships. All about cohesion and adaptability would be explained as follows

# Analysis of utterances between husband and wife about cohesion and adaptability in relation to describe the couples' role negotiate strategy in parenting for their child with ASD

After discussed the utterances of togetherness as earlier, this section would analyze participants' ability to adapt and to foster cohesion in sharing their roles during parenting for their children with ASD. The ability to adapt, according to Olson (1999) and Poire (2006), is the ability to maintain stability and to regulate changes in a relationship. The ability to adapt is divided into four different levels: (1) rigid, where a certain rigidity is shown toward accepting changes due to authoritarian leadership and stringent rules becoming a benchmark in life; (2) structured, where moderate leadership can accommodate changes based on limited collective decisions, leading to a more stable relationship; (3) flexible, where quick and prompt attitudes are shown toward changes, and often decisions are made based on collective consensus; (4) chaotic, where tension and instability are high due to a lack of leadership,

which leads to a dissimilar perception between the two when faced with changes. Olson's level of adaptation can be simplified through a matrix (see Table 2).

		Fable 2. Adaptabil	lity	
	Rigid	Structured	Flexible	Chaotic
Roles	Roles seldom change	Roles stable	Role sharing change	Dramatic role shift
Change	Too little change	Change when demanded	Change when necessary	Too much change
Leadership	Authoritarian leadership	Leadership sometimes shared	Share leadership	Lack of leadership

Source: Olson, 1999

According to Olson (1999) and Poire (2006), cohesion is defined as an emotional bond between members within a relationship. This bond is divided into four different levels: (1) enmeshed—in this level, members' proximity, loyalty, and dependence over each other are extremely high, leaving no space for individuality; (2) cohesive—in this level, members attempt to maintain emotional closeness, loyalty, and cohesion by emphasizing a certain degree of individuality; (3) connected—in this level, members are mostly independent, but still, involve other members to perform the group's function; (4) disengaged—in this level, members are extremely independent and thus possess a high degree of individuality, which places emphasis on him/herself over other members. Olson's level of cohesion can be simplified through a matrix (see Table 3).

		Table 3. Cohesion	l	
	Enmeshed	Cohesive	Connected	Disengaged
Closeness	Little closeness	Little-Moderate closeness	Middle-High closeness	Very high closeness
Independence/ dependence	High independence	Interdependent	Interdependent	High dependence
I-We balance	Ι	I-We	I-We	We
Loyalty	Little loyal	Some loyalty	High loyalty	Very high loyalty
		Source: Olson, 199	9	~ ~

Table 4 explains that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are all positive conditions, stable and conducive. In terms of adaptation, structured and flexible are two of the conditions that are able to accept and deal with changes positively compared with rigid (tends to reject changes) and chaotic (often changes attitudes toward the change). In terms of cohesion, cohesive, and connectedness are two of the most conducive conditions that are able to maintain emotional closeness, loyalty, and cohesion while still being able to give a degree of independence for other members to perform their function according to their domain. The aforementioned explanation shows that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are conditions that lead toward togetherness, symbolized by the ability to adapt (+) and to maintain cohesion (+) as can be seen as follows:

	Table 4.	Adaptability an	d Cohesion	
Cohesion		Adap	tability	
	Rigid	Structured	Flexible	Chaotic
Enmeshed	_	_		_
Cohesive	_	+	+	—
Connected	_	+	+	—
Disengaged	—	_	_	_

Source:	Researcher's	analysis

The utterances of all three participants in terms of adaptability related to financial, emotional, time, and energy show that they tend to do role sharing change and change when necessary for caring for their children with ASD, as could be explained as follow: (1) they try work hard and reduce the unnecessary expenses to be able to make ends meet the needs of their children with ASD; (2) when wives support emotional by reducing the intake of gluten and animal milk, husbands support by not buying food containing those ingredients for their children with ASD; (3) time and energy, wives support time and energy by accompanying their children with ASD at school, place of therapy, and home daily, husbands support time and energy for their son with ASD only when husbands on leave. They do a complementary role and a reciprocal role. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level structured-flexible in terms of adaptability. A more structured and flexible level of adaptation allows the three couples to adapt to changes. It could be seen from the way they accommodate changes based on collective decisions and consensus.

The utterances of all participants related to financial, emotional, time, and energy for their sons with ASD show that the emotional bonding toward one another is cohesive and connected. All three couples actively try to maintain emotional closeness, loyalty, and interdependence with one another face-up financial, emotional, time, and energy problems for their sons' with ASD as follow: (1) in doing every task for caring for their sons' with ASD, they do together for one intention for making better the condition of their sons' with ASD; (2) they are trying actively to complement each other's role for their sons' with ASD. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level of cohesive-connected.

From the aforementioned explanation about cohesion and adaptability, this described how participants manage and balance their roles towards their son with ASD by the negotiating strategies. All three couples implement a compromise strategy for caring for their children with ASD. They interchange roles and collectively participate in devoting financial, emotional, time, and energy for them.

#### Conclusion

In conclusion, the three couples participants used a compromise strategy to negotiate their roles related to financial, emotional, time, and energy for their children with ASD. They accommodate changes based on collective decisions and consensus. They also collectively interchange and participate in devoting financial, emotional, time, and energy for their children with ASD. These findings indicate that there are still married couples who have children with ASD who remain share tasks together in caring for their children with ASD. Although difficult, they have the optimism that after difficulties there is ease. The same optimism feeling would make easy to create good cohesion and adaptability.

This research attempts to help to understand and capturing the complexity of the marital, family system, and tension or stress in the health area using relational dialectic theory, family system approach, and Olson's circumplex model. The small number of participants is a limitation of this study, but this study would be a pilot project for further study. The implication of this study is to eliminate the tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation. For future work, it is necessary to conduct research on how to balance the communication in another tension context in a family using more participants.

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## **BUKTI KORESPONDENSI**

# ARTIKEL JURNAL NASIONAL TERAKREDITASI SINTA 2

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Yth. Andria Saptyasari,

Terima kasih atas revisi artikel yang telah dikirimkan. Setelah kami tinjau kembali, mohon untuk melengkapi kesesuaian, daftar pustaka yang belum tertulis dan memperhatikan kelengkapan komponen daftar pustaka. Berikut kami lampirkan catatan dalam proses edit teknis. Terima kasih.

Salam,

Jurnal Komunikasi Indonesia

Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder--andria saptyasari (revisi)\_edit AE.docx 55K

## Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder (ASD)

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#### Abstrak/Abstract

Keluarga dengan anak ASD (Autism Spectrum Disorder) rentan akan kondisi finansial, emosional, tenaga dan waktu yang dapat memicu ketegangan antara suami dan istri sebagai orang tua dalam merawat anak ASD mereka. Studi ini bertujuan mengelaborasi komunikasi yang digunakan oleh pasangan heteroseksual yang sudah menikah dalam menegosiasikan peran merawat anak ASD terkait finansial, emosional, tenaga dan waktu dengan menggunakan teori dialektika hubungan. Metode pengumpulan data menggunakan wawancara. Cara mendapatkan tiga pasangan partisipan yang memiliki anak ASD dengan umur yang berbeda adalah dengan teknik snowball. Hasil menunjukkan ada perubahan yang dinamis terkait peran antar pasangan dalam memenuhi kebutuhan finansial, emosional, tenaga, dan waktu untuk anak ASD mereka yang memiliki kesulitan dalam komunikasi sosial. Setiap pasangan suami istri ini berusaha melakukan perubahan peran bila dibutuhkan dengan rasa tanggung jawab dan saling menghargai satu sama lain. Mereka mengakomodasi perubahan secara kolektif dan melalui kesepakatan. Sehingga bisa disimpulkan dalam merawat anak ASD, mereka menggunakan strategi kompromi terkait finansial, emosional, tenaga, dan waktu.

Kata kunci: ASD, komunikasi, negosiasi, peran orangtua

#### <u>Abstract</u>

Families that have children with ASD (Autism Spectrum Disorder) were vulnerable in terms of financial, emotional, energy, and time that causes tension between husbands and wives as parents in caring for their children with ASD.

The main purpose of this study is to elaborate on the communication used by married heterosexual couples in negotiating a parenting role related to financial, emotional, energy, and time problems for their child with ASD by using relational dialectical theory. The data collection method used interviews. The participants' selection used snowball. The participants consisted of three married heterosexual couples with three different ages of children with ASD in East Java. The results showed that there are dynamic changes related to the role of married couple participants in meeting financial, emotional, time, and energy needs for their children with ASD who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does role sharing change when necessary and share tasks with respectable and responsibility. They also accommodate changes by using collective consensus. The conclusion of this study is a compromise strategy that was used by them when sharing roles related to financial, emotional, time, and energy for children with ASD.

#### Kata kunci/Keywords:

#### ASD, komunikasi, negosiasi, peran orangtua

ASD, communication, negotiation, parental roles

#### Introduction

This research aims to elaborate communication on married heterosexual couples in negotiating their role in parenting for children with Autism Spectrum Disorder (ASD). The research is based on the increasing phenomenon of children born with ASD in Indonesia in recent years: in the year 2000 1:500, in 2010 1:300, and in 2015 134,000 children. These data are supported by the statement of Wardhani (2009), where the number stated previously (i.e., 134,000) indicates that out of 250 children born, one child is born with ASD (Wardhani, 2009). In 2018 there are out of 59 births, one child is born with ASD (Kementrian Kesehatan RI, 2020)

Autism spectrum disorder (ASD) is a neurodevelopmental disorder associated with the presence of social-communication deficits and restricted and repetitive behaviors (Reynold and Kamphaus, 2013; Memari et al, 2015; Irawan, 2015). American Psychiatric Association (in Diagnostic & Statistical Manual of Mental Disorder 5th ed., 2013) divided autism spectrum disorder (ASD) into three severity levels, namely: (1) level 1 "requiring support" marked by difficulty initiating social interaction, unsuccessful responses to overtures of others, able to engage in conversation but to-and-fro with others in terms of social communication and by difficulty switching between activities in terms of restricted and repetitive behaviors; (2) level 2 "requiring substantial support" marked by a deficit in verbal and nonverbal communication, limited initiation of social interaction, speaks simple sentences, their interaction is limited to a narrow special interest in terms of social communication and by difficulty coping with change in terms of restricted and repetitive (3) level 3 "requiring very substantial support" marked by severe deficits in behaviors: verbal and nonverbal communication, very limited initiation of social interaction, minimal response to overtures from others in terms of social communication and by extreme difficulty coping with change, repetitive behaviors in all spheres in terms of restricted and repetitive behaviors The aforementioned explanation asserts that children with ASD have difficulty in interacting and adapting to their social environment, including difficulty in establishing a relationship with peers or family members.

In the Puterakembara (the community of parents of children with ASD in Jakarta, Indonesia), a majority of parents told how shocked they were when they found out their children were an ASD for the first time. Some of them told that in dealing with ASD children who have difficulties in speech and managing behavior, sometimes they lose temper, energy, and time for themselves or their partners (Marijani, 2003). Some of them blame themselves and others blame their partners due to their inability to overcome this condition (Apostelina, -n.d2012n.d). Another study showed that parents of children with ASD were faced with financial problems, hectic therapeutic schedules, and difficult-to-manage behavior of their children. The inability to overcome this situation potentially increased the risk for divorce or separation (Freedman et al; 2012). In Indonesia, pediatrician Sutadi, a leading consultant for children with ASD, conducted research on 406 families with ASD children from 2000 to 2004. He found that 23.5% of families in Indonesia care for a child with ASD, and one out of five families that care for a child with ASD often divorce (Sutadi, 2011). Aji's research (2019) also found that some parents in the Illahi community (the community of parents of children with ASD in Semarang, Indonesia) admit that their goal of joining this community is to be able to share experiences and seek support from other parents who have the same fate because they do not get support from their spouse, parents or extended family. They hope that by joining this community they will no longer be stressed by this condition.

The paragraph above shows that married couples who have children with ASD have a poor relationship. They should need to dialogue with each other in negotiating their role in providing financial, emotional, energy, and time support for their ASD child to adapt to this situation and eliminate the risk for divorce or separation in married heterosexual couples. By implementing the dialectical relational theory, the researcher aims to elaborate on the communication used by couples in negotiating their roles in the process of caring for their child with ASD. The urgency of this research is to elaborate on the relationship between husband and wife who have children with ASD through relationship dialectical theory which sees contradictions of togetherness and separation in terms of cohesiveness and contradiction of rigid and chaotic in terms of adaptability.

#### Literature review

Interpersonal communication between husband and wife is a part of the study of communication within the context of family communication. Family is the smallest unit in society, wherein there is an interaction between family members: mother-child, father-child, husband-wife, or between siblings. The role of a family member is often associated with the contentment of resources. According to the resource theory by Stafford (2008), there are two types of resources: concrete and abstract. DeVito (2004), Galvin (2012), and Guerrero (2007) state that concrete resources consist of financially related resources, whereas abstract resources consist of emotion, time, and energy. The aforementioned explanation shows that the interaction between roles within a family is an exchange of attention, financial support, emotion, energy, and time from one member of the family to the other. This implies that the study of family communication is always interconnected with the theory of interactional perspective, focusing on the interaction and relationship between individuals within a family.

The characteristics of family as a system consist of the following: (1) interdependence (apparent connection and the relationship between units), (2) dynamic (ever-changing and appearing to exhibit a process of adaptation in relation to changes), and (3) dialectical tension (apparent dialectical tension in the cycle of the family's life, and thus an attempt to negotiate the tension is ever-present) (Sprey, 1999). The three mentioned characteristics show that family communication is a relational-based communication between two individuals with an interactional perspective as a part of unity. The aforementioned explanation asserts that the lack of financial, emotion, energy, and time within heterosexual marital relationships for caring for their child with ASD definitely causes dialectical tension in their relationships. However, the family system also comprises a characteristic known as dynamic, and thus they will automatically try to adapt to apparent changes by negotiating and communicating the dialectical tension. The aforementioned issue on family communication can be analyzed through relational dialectics theory. Relational dialectics theory was proposed and developed by Mikhail Bakhtin, who observed that in an interaction between two individuals, there is always dialog. The dialog is open in nature in order to develop a relationship between the said individuals; however, there is always a chance that tension will ensue (dialectics) (Baxter, 2004). Tension (dialectics) is defined as anything that comprises itself of three major elements: contradiction, motion, and praxis (Turner & West, 2006): (1) Contradiction is an opposing condition between personal interest and expectation (private sphere) with collective interest and expectation (public sphere); (2) Motion is an element of change within a relationship or the change of proximity in a period of time, where an individual is certain to experience changes in relationship and proximity with another individual in a certain span of time, which will contribute to the increase in contradiction; (3) Praxis is an element which shows that when an individual is faced with a contradiction, he/she will never possess a decisive decision-making ability because of the limitations and norms conjured by his/her surrounding sociocultural setting.

Contradiction, motion, and praxis mentioned by **Rawlins (1992)** made interaction between one individual and another lead to the possibility of tension between the two, a sort of dualism of issues between the individual wanting to be open-close (openness-closedness), free-connected (autonomy-connection), and stable-dynamic (predictability-novelty) (Baxter, 2004). The aforementioned explanation asserts that relational dialectics theory is more focused on the effort to balance (balancing) the two contradicting sides, which in this research is depicted by the contradiction between togetherness and separation in two-way communication. The concept of togetherness-separation is a cultural context that sees each individual bounded to the values, rules, roles, and norms where they live. Togetherness refers to the ability that drives an individual to uphold a high level of morality and responsibility in accordance with the legitimized norms and it leads to the creation of unity or harmony with another individual. The separation refers to the ability that drives an individual to act in an

egotistical manner and irresponsibly, where the promotion of his/her own needs is put above others' that leads toward disharmony within a relationship.

According to Baxter (2009) and Krueger & Funder (2004), in dialectical relational theory, the important element studied is the utterance chain. The utterance chain is an interconnected utterance within individual backgrounds and value contexts. In this research, the contradiction between togetherness and separation can be seen through husbands' and wive' utterance dealing with a role in providing financial, emotional, energy, and time support for their ASD child. The aforementioned explanation asserts that: (1) the utterances of togetherness can be seen verbally that indicate proclaim fondness, acceptance, collectiveness, supportiveness, and other related to any actions that lead toward positive results; (2) the utterances of separation include proclaim dislike, unaccepting, egotistical, demands the support, and any action that leads toward negative results. In this research, the utterance chain should explain how cohesion and adaptability are highly effective in the effort to balance both togetherness and separation.

In terms of balancing the contradiction between togetherness and separation in relational dialectics theory, Wood et al. (in Turner and West, 2006) stated that there are four strategies in the management of dialectical tension dealing with how to negotiate their role. The four strategies namely are: (1) cyclic alternation (spiraling alternation) is a strategy to choose one side out of two depending on time; (2) segmentation is a strategy to choose one side out of two depending on the individual's domain or setting; (3) selection is a strategy to choose a particular side disregarding time and domain; and (4) integration is a strategy that tries to find a solution for both parties. The integration strategy has four kinds of function, they are: (a) neutralizing (balancing), that is, both sides try to compromise; (b) reframing (recalibration), that is, both sides try to lessen the tension; (c) disqualifying, that is, choosing one side to stand for a general issue; however, this does not apply for specific or private

issues; and (d) reaffirmation, that is, both sides choose differing pathways but still consider the other's decision.

This theory will be briefly used to explore the role of husband and wife related to financial, emotional, energy, and time problems, and to explore their cohesion, adaptation, and strategy in negotiating a parenting role for their child with ASD in order to eliminate the tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation.

#### **Research methodology**

This study used an interpretative phenomenological analysis (IPA) approach. According to Smith, this approach concerns exploring the part of an individual's experiences (Smith, Flowers, & Larkin, 2009). The aforementioned explanation asserts to do phenomenology, this study used interviews to collect participants' utterances about caring experience towards their child with ASD related to financial, emotional, energy, and time problems. All data were noted because all participants objected interview process by audio recording. After all, data were collected, scripted, and coded, then data would be analyzed and interpreted comprehensively by using a dual interpretation process: (1) analyze and interpret utterances from each participant either the husband or the wife to get both perspectives about their feelings dealing with financial, emotional, energy, and time problems to care for their child with ASD; (2) analyze and interpret how they adapt and work out these problems as a couple to describe their dialectic tension related to togetherness and separation. These two processes would describe their negotiation strategy related to financial, emotional, energy, and time problems to care for their child with ASD

The number of participants was three heterosexual married couples that have a child with ASD. All participants were biological mothers and fathers of children with ASD. The participants' recruitment process used snowball by asking close people who may have acquaintances who are married and have a child with ASD. One couple of participants was a friend of the researcher's acquaintance. Starting from the first couple of participants, the researcher got two other couple names. Three couple of participants is a small number, but IPA approach usually have a small number of participant and the aim is to reveal something of the experience of each those individuals (Smith and Osborn, 2006). The study may explore in detail the similarities and differences between each case dealing with different ages and the position of the child with ASD to their sibling. The small number of participants is a limitation of this study, but this study would be a pilot project for further study.

The first participant couple was a housewife with an initial of Mrs. A (50 years old) and a working father with an initial of Mr. A (50 years old). They have been married for 22 years. Their child with ASD (with an initial U) is the youngest of two and is 18 years old; he has gone through speech and occupational therapy for 11 years and is currently completing his second-year junior high school education in an inclusive school. In some countries, 18-year-olds no longer refer to children, but in Indonesia according to article 330 of The Civil Law, the age limit of children are those who are not yet 21 years old and are not yet married. Article 98 paragraph 1 Compilation of Islamic Law also states that the age limit of children is those who are not physically or mentally disabled, and are not yet married. Law No. 4 of 1979 concerning Child Welfare in article 1 paragraph 2 states the age limit of children is those who are not yet 21 years old and are not yet married. The aforementioned explanation asserts that this family could be chosen as a participant, although their child with ASD is 18 years old.

The second participant couple was a housewife with an initial of Mrs. W (30 years) and a working father with an initial of Mr. W (30 years old). When they learned that their child was a child with ASD, Mrs. W decided to stop working so that she could focus on

taking care of her child with ASD (with an initial L, 4 years old). They have been married for 5 years. L (4 years old) is the eldest of two, has been in speech and occupational therapies for 2 years, and is currently enrolled in an inclusive preschool.

The third participant couple was a housewife with an initial of Mrs. M (42 years old) and a father with an initial of Mr. M (44 years old). Both have been married for 12 years. Their child with ASD (with an initial A) is 7 years old and is the second child of three, currently in first grade in an inclusive elementary school, and has been in speech and occupational therapy for three years.

Table 1. Participant Couples' Background			
First Second		Third	
Participant	Participant	Participant	
Couple	Couple	Couple	
Mr. and Mrs. A (50 years old)	Mr. and Mrs. W (40 years old)	Mr. M (44 years old) and Mrs. M (42 years old	
Boy (18 years old)	Boy (4 years old)	Boy (7 years old)	
speech and occupational therapies for 11	speech and occupational therapies for 2	speech and occupational therapies for	
years	years	three years	
Boy (21 years old)	Girl (2 years old)	Two boys (12 and 5 years old)	
	First Participant CoupleMr. and Mrs. A (50 years old)Boy (18 years old)speech and occupational therapies for 11 yearsBoy (21 years	FirstSecondParticipantParticipantCoupleParticipantCoupleCoupleMr. and Mrs. A (50 years old)Mr. and Mrs. W (40 years old)Boy (18 years old)Boy (4 years old)Speech and occupational therapies for 11 	

All information about participants can be drawn as follows:

Source: Researcher's analysis

#### **Results and Discussion**

## Analysis of utterances between husband and wife on financial, emotional, energy, and time support during their role in parenting for their child with ASD

In the first couple of married participants, their child was a severe deficit in verbal and nonverbal communication, very limited initiation of social and minimal response to overtures others in terms of social communication. That would be seen when his teacher asked him, he repeated the teacher's question and took a long time for answering one word to his teacher. In terms of behavior, he was extreme difficulty coping with change. That would be seen when his parents changed the direction to go to other places different from the first plan, he got very mad at their parents.

Mr. A told that his son with ASD (U) more frequently bites, pinches, and hits to Mrs. A, but when Mrs. A cried, U stopped being mad and then hugged Mrs. A. Mr. A explained that emotionally his son with ASD was closer to Mrs. A rather than to Mr. A. In here, Mr. A felt sorry for his wife, because he could imagine how exhausted she was to care for U. This implies that Mrs. A was likely close emotionally to their child with ASD.

Financial support from Mr. A toward U (child with autism, 18 years old) is affirmed by Mrs. A: "... My husband is highly supportive in terms of funding the therapy, school, and doctor visit... U has been in therapy for quite a while, around 11 years since he was 6–7 years old." Mrs. A's statement shows that all the financing for the needs' their child with ASD\_—is fulfilled by her husband because Mrs. A herself is a full-time housewife. Mr. and Mrs. A told that all the needs' their child with ASD was not cheap and they had to downsize for other needs including the needs of the oldest son.

In terms of energy and time support for U, Mr. and Mrs. A were doing their complementary and reciprocal role. The complementary role could be seen through Mrs. A's explanation when Mr. A went to work, she had the responsibility to carried out her child with ASD to go to school or for getting therapy. If Mr. A was on leave then he carried out U to go to school or go for therapy. Their reciprocal role could be seen from the couple participants' statements that Mr. and Mrs. A switch roles, for example, when Mrs. A is helping her eldest with schoolwork, Mr. A takes U for a walk and vice versa. When U accompanies his mother

to cook, then Mr. A helps his eldest with the computer. They did this way because they did not want their son with ASD to ruin the eldest's project or schoolwork like before.

In the second couple of married participants, their child was a deficit in verbal and nonverbal communication, limited initiation of social interaction and speaks simple sentences in terms of social communication. As could be seen from Mrs. W's explanation that L (4 years old) could comprehend and pointed to the objects' or body parts' but he could not mention and speak clearly the objects' or body parts' name. He also gave short answered when asked, but he could not ask or request verbally when he needs something. In terms of behavior, L could not cope with noisy sounds and crowds. This is affirmed by Mr. W stating that "L likes to play with L's younger sister. They get along well, but when his little sibling cried or noisy, L can be mad because L hates noisy".

Mr. W's financial support toward L can be derived from his statement, "I only sleep for four hours every night and that happens every night. I wake up early and go straight to taking care of business ... this is because our business is still in its early days." Mr. W's statement shows that he is willing to work hard to fulfill the needs of L. His needs are, for example, therapy, piano lessons, swimming lessons, tuition, lab checks, routine check-ups to the doctor every 6 months, and a shadow (a caretaker at school). Moreover, Mrs. W is now a housewife who has stopped working after knowing L was diagnosed with ASD.

Mrs. W states: "L cannot eat chocolate or ice cream, after eating it he becomes temperamental. L also cannot drink beverages that often find in the groceries ... Last time when he lashed out, he screamed for two hours..., but we let him be. It's hard for him to control his emotion, he claws and pinches, as you can see here (showing her hands that were clawed by L)." From the aforementioned statement, Mrs. W controls the emotion of her child by regulating the food that he consumes so that he does not throw a tantrum. According to Erickson, 60% of children with ASD have a poor digestive system. Foods such as those

containing animal milk cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function. Impaired brain functions are cognitive functions, receptive communication, concentration, and behavior (Erickson et al, 2005). Erickson's statement asserts that chocolate and ice cream are containing animal milk that presumably affects L's behavior.

In relation to the time and energy support that they give for L, Mr. and Mrs. W do the task together. They often take L and his younger sister to play together; they go on a recreation trip outside town or on short outings to the malls for dinner even Mrs. W has to accompany L so he does not panic in the crowd at the mall. This is done in order to build a sense of togetherness between L and his younger sister so that there will be no feelings of envy in the future.

In the third couple of married participants, their child (with an initial A) has a limited interaction to the narrow special interest and speaks simple sentences only if he needs something in terms of social communication. This would be seen from Mrs. M's affirmation that A was very passive, he rarely asked to parents or someone, he asked to someone only if he needs something. In terms of behavior, A has difficulty coping with change and has repetitive behaviors towards narrow special interest. This would be seen from Mr. M's explanation that A was easily bored when he played with his eldest and younger brother, he only lasted in 5 minutes playing with them. He prefers to play alone.

Mr. M's financial support for his child with ASD (A, 7 years old) can be seen from Mrs. M's statement: "A Nikolin injection for A costs around 250 thousand per pack, this can be administered 10 times. A requires around  $60 \times$  so we need six packs costing us around 1.5 million. The cost for therapy is about 300 thousand per month; it is scheduled twice a week

for two hours." This indicates that Mr. M works hard to support the needs of his child with ASD. Mr. and Mrs. M told that for making ends meet all the needs' their child with ASD, they had to downsize for other needs including the needs of the eldest and youngest son.

Mrs. M supervises her child's emotions by regulating his intake of gluten and commonly packaged beverages. She said, "I limit his gluten consumption. For example, he asks for Indomie (the brand of instant noodles) because he sees his brothers eating it. I make a half portion for him but for seasoning, I only give soy sauce and salt, I do not include the seasoning that comes with it. If he asks for a snack with extra seasoning, I only put a little of it." It can be inferred from Mrs. M's statement that in order to control her child with ASD's behavior, she regulates the foods consumed by him. Mr. M also supports Mrs. M's regulation by not buying food containing gluten ingredients for his son with ASD. As mentioned before that some children with ASD have a poor digestive system. Foods such as wheat flour cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function. Impaired brain functions are cognitive functions, receptive communication, concentration, and behavior (Erickson et al, 2005). Erickson's statement asserts that noodles containing wheat flour that probably affects A's behavior.

Concerning the time and energy support for their child with ASD, Mrs. M frequently accompanies her son with ASD at school or home compared to Mr. M because Mr. M has not been able to fully supervise him. Mr. M preferred to accompany two other children so that they could not disturb Mrs. M dealing to care A (her child with ASD).

From the aforementioned utterances of three married couple participants, the following conclusion can be drawn: there are dynamic changes related to the role of married

couple participants in meeting financial, emotional, time, and energy needs for their ASD children who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does share tasks with respectable and responsibility. As mentioned before, the utterances of togetherness can be seen through utterances that indicate proclaim acceptance, collectiveness, supportiveness, and others related to any actions that lead toward positive results. Each participant does a complementary and reciprocal role to support his/her couple caring for their child with ASD. The study results found that each participant tries hard to create togetherness as couples handling their child with ASD even though it was not easy. All participants have a similarity of optimistic feelings that could be seen in their quotation saying every difficulty, there must be ease. Their optimistic feeling was powerful to create togetherness as a unity.

According to Koerner and Fitzpatrick, in a family, there is a degree of cohesion and adaptability among members (Koerner & Fitzpatrick, 2002). That two degrees would be useful for exploring the ability of all participants toward changes and dealing with tensions in order to balance their relationships. All about cohesion and adaptability would be explained as follows

# Analysis of utterances between husband and wife about cohesion and adaptability in relation to describe the couples' role negotiate strategy in parenting for their child with ASD

After discussed the utterances of togetherness as earlier, this section would analyze participants' ability to adapt and to foster cohesion in sharing their roles during parenting for their children with ASD. The ability to adapt, according to Olson (1999) and Poire (2006), is the ability to maintain stability and to regulate changes in a relationship. The ability to adapt is divided into four different levels: (1) rigid, where a certain rigidity is shown toward

accepting changes due to authoritarian leadership and stringent rules becoming a benchmark in life; (2) structured, where moderate leadership can accommodate changes based on limited collective decisions, leading to a more stable relationship; (3) flexible, where quick and prompt attitudes are shown toward changes, and often decisions are made based on collective consensus; (4) chaotic, where tension and instability are high due to a lack of leadership, which leads to a dissimilar perception between the two when faced with changes. Olson's level of adaptation can be simplified through a matrix (see Table 2).

Table 2. Adaptability				
	Rigid	Structured	Flexible	Chaotic
Roles	Roles seldom change	Roles stable	Role sharing change	Dramatic role shift
Change	Too little change	Change when demanded	Change when necessary	Too much change
Leadership	Authoritarian leadership	Leadership sometimes shared	Share leadership	Lack of leadership

Source: Olson, 1999

According to Olson (1999) and Poire\_-(2006), cohesion is defined as an emotional bond between members within a relationship. This bond is divided into four different levels: (1) enmeshed—in this level, members' proximity, loyalty, and dependence over each other are extremely high, leaving no space for individuality; (2) cohesive—in this level, members attempt to maintain emotional closeness, loyalty, and cohesion by emphasizing a certain degree of individuality; (3) connected—in this level, members are mostly independent, but still, involve other members to perform the group's function; (4) disengaged—in this level, members are extremely independent and thus possess a high degree of individuality, which

places emphasis on him/herself over other members. Olson's level of cohesion can be simplified through a matrix (see Table 3).

		Table 3. Cohesion	l	
	<b>Enmeshed</b>	<b>Cohesive</b>	<b>Connected</b>	<b>Disengaged</b>
Closeness	Little closeness	Little-Moderate closeness	Middle-High closeness	Very high closeness
Independence/ dependence	High independence	Interdependent	Interdependent	High dependence
I-We balance	Ι	I-We	I-We	We
Loyalty	Little loyal	Some loyalty	High loyalty	Very high loyalty
		Source: Olson, 199	9	<i></i>

Table 4 explains that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are all positive conditions, stable and conducive. In terms of adaptation, structured and flexible are two of the conditions that are able to accept and deal with changes positively compared with rigid (tends to reject changes) and chaotic (often changes attitudes toward the change). In terms of cohesion, cohesive, and connectedness are two of the most conducive conditions that are able to maintain emotional closeness, loyalty, and cohesion while still being able to give a degree of independence for other members to perform their function according to their domain. The aforementioned explanation shows that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are conditions that lead toward togetherness, symbolized by the ability to adapt (+) and to maintain cohesion (+) as can be seen as follows:

Table 4. Adaptability and Cohesion				
Cohesion	Adaptability			
	Rigid	Structured	Flexible	Chaotic
Enmeshed	-	—	—	—
Cohesive	-	+	+	—
Connected	-	+	+	—
Disengage	_	—	—	—
d				

Source: Researcher's analysis

The utterances of all three participants in terms of adaptability related to financial, emotional, time, and energy show that they tend to do role sharing change and change when necessary for caring for their children with ASD, as could be explained as follow: (1) they try work hard and reduce the unnecessary expenses to be able to make ends meet the needs of their children with ASD; (2) when wives support emotional by reducing the intake of gluten and animal milk, husbands support by not buying food containing those ingredients for their children with ASD; (3) time and energy, wives support time and energy by accompanying their children with ASD at school, place of therapy, and home daily, husbands support time and energy for their son with ASD only when husbands on leave. They do a complementary role and a reciprocal role. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level structured-flexible in terms of adaptability. A more structured and flexible level of adaptation allows the three couples to adapt to changes. It could be seen from the way they accommodate changes based on collective decisions and consensus.

The utterances of all participants related to financial, emotional, time, and energy for their sons with ASD show that the emotional bonding toward one another is cohesive and connected. All three couples actively try to maintain emotional closeness, loyalty, and interdependence with one another face-up financial, emotional, time, and energy problems for their sons' with ASD as follow: (1) in doing every task for caring for their sons' with ASD, they do together for one intention for making better the condition of their sons' with ASD; (2) they are trying actively to complement each other's role for their sons' with ASD. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level of cohesive-connected.

From the aforementioned explanation about cohesion and adaptability, this described how participants manage and balance their roles towards their son with ASD by the negotiating strategies. All three couples implement a compromise strategy for caring for their children with ASD. They interchange roles and collectively participate in devoting financial, emotional, time, and energy for them.

#### Conclusion

In conclusion, the three couples participants used a compromise strategy to negotiate their roles related to financial, emotional, time, and energy for their children with ASD. They accommodate changes based on collective decisions and consensus. They also collectively interchange and participate in devoting financial, emotional, time, and energy for their children with ASD. These findings indicate that there are still married couples who have children with ASD who remain share tasks together in caring for their children with ASD. Although difficult, they have the optimism that after difficulties there is ease. The same optimism feeling would make easy to create good cohesion and adaptability.

This research attempts to help to understand and capturing the complexity of the marital, family system, and tension or stress in the health area using relational dialectic theory, family system approach, and Olson's circumplex model. The small number of participants is a limitation of this study, but this study would be a pilot project for further study. The implication of this study is to eliminate the tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation. For future work, it is

necessary to conduct research on how to balance the communication in another tension context in a family using more participants.

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### **BUKTI KORESPONDENSI**

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> 2B-Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder--andria saptyasari (revisi)\_edit AE.docx 65K

## Communication between Husband and Wife in Negotiating a Parenting Role for their Child with Autism Spectrum Disorder (ASD)

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#### Abstrak

Keluarga dengan anak ASD (Autism Spectrum Disorder) rentan akan kondisi finansial, emosional, tenaga dan waktu yang dapat memicu ketegangan antara suami dan istri sebagai orang tua dalam merawat anak ASD mereka. Studi ini bertujuan mengelaborasi komunikasi yang digunakan oleh pasangan heteroseksual yang sudah menikah dalam menegosiasikan peran merawat anak ASD terkait finansial, emosional, tenaga dan waktu dengan menggunakan teori dialektika hubungan. Metode pengumpulan data menggunakan wawancara. Cara mendapatkan tiga pasangan partisipan yang memiliki anak ASD dengan umur yang berbeda adalah dengan teknik snowball. Hasil menunjukkan ada perubahan yang dinamis terkait peran antar pasangan dalam memenuhi kebutuhan finansial, emosional, tenaga, dan waktu untuk anak ASD mereka yang memiliki kesulitan dalam komunikasi sosial. Setiap pasangan suami istri ini berusaha melakukan perubahan peran bila dibutuhkan dengan rasa tanggung jawab dan saling menghargai satu sama lain. Mereka mengakomodasi perubahan secara kolektif dan melalui kesepakatan. Sehingga bisa disimpulkan dalam merawat anak ASD, mereka menggunakan strategi kompromi terkait finansial, emosional, tenaga, dan waktu.

Kata kunci: ASD, komunikasi, negosiasi, peran orangtua

#### Abstract

Families that have children with ASD (Autism Spectrum Disorder) were vulnerable in terms of financial, emotional, energy, and time that causes tension between husbands and wives as parents in caring for their children with ASD. The main purpose of this study is to elaborate on the communication used by married heterosexual couples in negotiating a parenting role related to financial,

emotional, energy, and time problems for their child with ASD by using relational dialectical theory. The data collection method used interviews. The participants' selection used snowball. The participants consisted of three married heterosexual couples with three different ages of children with ASD in East Java. The results showed that there are dynamic changes related to the role of married couple participants in meeting financial, emotional, time, and energy needs for their children with ASD who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does role sharing change when necessary and share tasks with respect and responsibility. They also accommodate changes by using collective consensus. The conclusion of this study is a compromise strategy that was used by them when sharing roles related to financial, emotional, time, and energy for children with ASD.

#### **Keywords:**

ASD, communication, negotiation, parental roles

#### Introduction

This research aims to elaborate communication on married heterosexual couples in negotiating their role in parenting for children with Autism Spectrum Disorder (ASD). The research is based on the increasing phenomenon of children born with ASD in Indonesia in recent years: in the year 2000 1:500, in 2010 1:300, and in 2015 134,000 children. These data are supported by the statement of Wardhani (2009), where the number stated previously (i.e., 134,000) indicates that out of 250 children born, one child is born with ASD (Wardhani, 2009). In 2018 there are out of 59 births, one child is born with ASD (Kementrian Kesehatan RI, 2020)

Autism spectrum disorder (ASD) is a neurodevelopmental disorder associated with the presence of social-communication deficits and restricted and repetitive behaviors (Kamphaus and Reynolds, 2007; Memari et al, 2015; Irawan, 2015). American Psychiatric Association (in Diagnostic & Statistical Manual of Mental Disorder 5<sup>th</sup> ed., 2013) divided autism spectrum disorder (ASD) into three severity levels, namely: (1) level 1 "requiring support" marked by difficulty initiating social interaction, unsuccessful responses to overtures of others, able to engage in conversation but to-and-fro with others in terms of social communication and by difficulty switching between activities in terms of restricted and repetitive behaviors; (2) level 2 "requiring substantial support" marked by a deficit in verbal and nonverbal communication, limited initiation of social interaction, speaks simple sentences, their interaction is limited to a narrow special interest in terms of social communication and by difficulty coping with change in terms of restricted and repetitive behaviors: (3) level 3 "requiring very substantial support" marked by severe deficits in verbal and nonverbal communication, very limited initiation of social interaction, minimal response to overtures from others in terms of social communication and by extreme difficulty coping with change, repetitive behaviors in all spheres in terms of restricted and repetitive behaviors The aforementioned explanation asserts that children with ASD have difficulty in interacting and adapting to their social environment, including difficulty in establishing a relationship with peers or family members.

In the Puterakembara (the community of parents of children with ASD in Jakarta, Indonesia), a majority of parents told how shocked they were when they found out their children were an ASD for the first time. Some of them told that in dealing with ASD children who have difficulties in speech and managing behavior, sometimes they lose temper, energy, and time for themselves or their partners (Marijani, 2003). Some of them blame themselves and others blame their partners due to their inability to overcome this condition (Apostelina, 2012). Another study showed that parents of children with ASD were faced with financial problems, hectic therapeutic schedules, and difficult-to-manage behavior of their children. The inability to overcome this situation potentially increased the risk for divorce or separation (Freedman et al; 2012). In Indonesia, pediatrician Sutadi, a leading consultant for children with ASD, conducted research on 406 families with ASD children from 2000 to 2004. He found that 23.5% of families in Indonesia care for a child with ASD, and one out of five families that care for a child with ASD often divorce (Sutadi, 2011). Aji's research (2019) also found that some parents in the Illahi community (the community of parents of children with ASD in Semarang, Indonesia) admit that their goal of joining this community is to be able to share experiences and seek support from other parents who have the same fate because they do not get support from their spouse, parents or extended family. They hope that by joining this community they will no longer be stressed by this condition.

The paragraph above shows that married couples who have children with ASD have a poor relationship. They should need to dialogue with each other in negotiating their role in providing financial, emotional, energy, and time support for their ASD child to adapt to this situation and eliminate the risk for divorce or separation in married heterosexual couples. By implementing the dialectical relational theory, the researcher aims to elaborate on the communication used by couples in negotiating their roles in the process of caring for their child with ASD. The urgency of this research is to elaborate on the relationship between husband and wife who have children with ASD through relationship dialectical theory which sees contradictions of togetherness and separation in terms of cohesiveness and contradiction of rigid and chaotic in terms of adaptability.

#### Literature review

Interpersonal communication between husband and wife is a part of the study of communication within the context of family communication. Family is the smallest unit in society, wherein there is an interaction between family members: mother-child, father-child, husband-wife, or between siblings. The role of a family member is often associated with the contentment of resources. According to the resource theory by Stafford (2008), there are two

types of resources: concrete and abstract. DeVito (2004), Galvin (2012), and Guerrero (2007) state that concrete resources consist of financially related resources, whereas abstract resources consist of emotion, time, and energy. The aforementioned explanation shows that the interaction between roles within a family is an exchange of attention, financial support, emotion, energy, and time from one member of the family to the other. This implies that the study of family communication is always interconnected with the theory of interactional perspective, focusing on the interaction and relationship between individuals within a family.

The characteristics of family as a system consist of the following: (1) interdependence (apparent connection and the relationship between units), (2) dynamic (ever-changing and appearing to exhibit a process of adaptation in relation to changes), and (3) dialectical tension (apparent dialectical tension in the cycle of the family's life, and thus an attempt to negotiate the tension is ever-present) (Sprey, 1999). The three mentioned characteristics show that family communication is a relational-based communication between two individuals with an interactional perspective as a part of unity. The aforementioned explanation asserts that the lack of financial, emotion, energy, and time within heterosexual marital relationships for caring for their child with ASD definitely causes dialectical tension in their relationships. However, the family system also comprises a characteristic known as dynamic, and thus they will automatically try to adapt to apparent changes by negotiating and communicating the dialectical tension. The aforementioned issue on family communication can be analyzed through relational dialectics theory.

Relational dialectics theory was proposed and developed by Mikhail Bakhtin, who observed that in an interaction between two individuals, there is always dialog. The dialog is open in nature in order to develop a relationship between the said individuals; however, there is always a chance that tension will ensue (dialectics) (Baxter, 2004). Tension (dialectics) is defined as anything that comprises itself of three major elements: contradiction, motion, and praxis (Turner & West, 2006): (1) Contradiction is an opposing condition between personal interest and expectation (private sphere) with collective interest and expectation (public sphere); (2) Motion is an element of change within a relationship or the change of proximity in a period of time, where an individual is certain to experience changes in relationship and proximity with another individual in a certain span of time, which will contribute to the increase in contradiction; (3) Praxis is an element which shows that when an individual is faced with a contradiction, he/she will never possess a decisive decision-making ability because of the limitations and norms conjured by his/her surrounding sociocultural setting.

Contradiction, motion, and praxis mentioned by Rawlins (1989) made interaction between one individual and another lead to the possibility of tension between the two, a sort of dualism of issues between the individual wanting to be open-close (openness-closedness), free-connected (autonomy-connection), and stable-dynamic (predictability-novelty) (Baxter, 2004). The aforementioned explanation asserts that relational dialectics theory is more focused on the effort to balance (balancing) the two contradicting sides, which in this research is depicted by the contradiction between togetherness and separation in two-way communication. The concept of togetherness-separation is a cultural context that sees each individual bounded to the values, rules, roles, and norms where they live. Togetherness refers to the ability that drives an individual to uphold a high level of morality and responsibility in accordance with the legitimized norms and it leads to the creation of unity or harmony with another individual. The separation refers to the ability that drives an individual to act in an egotistical manner and irresponsibly, where the promotion of his/her own needs is put above others' that leads toward disharmony within a relationship.

According to Baxter & Scharp (2015) and Krueger & Funder (2004), in dialectical relational theory, the important element studied is the utterance chain. The utterance chain is an interconnected utterance within individual backgrounds and value contexts. In this

research, the contradiction between togetherness and separation can be seen through husbands' and wive' utterance dealing with a role in providing financial, emotional, energy, and time support for their ASD child. The aforementioned explanation asserts that: (1) the utterances of togetherness can be seen verbally that indicate proclaim fondness, acceptance, collectiveness, supportiveness, and other related to any actions that lead toward positive results; (2) the utterances of separation include proclaim dislike, unaccepting, egotistical, demands the support, and any action that leads toward negative results. In this research, the utterance chain should explain how cohesion and adaptability are highly effective in the effort to balance both togetherness and separation.

In terms of balancing the contradiction between togetherness and separation in relational dialectics theory, Wood et al. (in Turner and West, 2006) stated that there are four strategies in the management of dialectical tension dealing with how to negotiate their role. The four strategies namely are: (1) cyclic alternation (spiraling alternation) is a strategy to choose one side out of two depending on time; (2) segmentation is a strategy to choose one side out of two depending on the individual's domain or setting; (3) selection is a strategy to choose a particular side disregarding time and domain; and (4) integration is a strategy that tries to find a solution for both parties. The integration strategy has four kinds of function, they are: (a) neutralizing (balancing), that is, both sides try to compromise; (b) reframing (recalibration), that is, both sides try to lessen the tension; (c) disqualifying, that is, choosing one side to stand for a general issue; however, this does not apply for specific or private issues; and (d) reaffirmation, that is, both sides choose differing pathways but still consider the other's decision.

This theory will be briefly used to explore the role of husband and wife related to financial, emotional, energy, and time problems, and to explore their cohesion, adaptation, and strategy in negotiating a parenting role for their child with ASD in order to eliminate the

tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation.

#### **Research methodology**

This study used an interpretative phenomenological analysis (IPA) approach. According to Smith, this approach concerns exploring the part of an individual's experiences (Smith, Flowers, & Larkin, 2009). The aforementioned explanation asserts to do phenomenology, this study used interviews to collect participants' utterances about caring experience towards their child with ASD related to financial, emotional, energy, and time problems. All data were noted because all participants objected interview process by audio recording. After all, data were collected, scripted, and coded, then data would be analyzed and interpreted comprehensively by using a dual interpretation process: (1) analyze and interpret utterances from each participant either the husband or the wife to get both perspectives about their feelings dealing with financial, emotional, energy, and time problems to care for their child with ASD; (2) analyze and interpret how they adapt and work out these problems as a couple to describe their dialectic tension related to togetherness and separation. These two processes would describe their negotiation strategy related to financial, emotional, energy, and time problems to care for their child with ASD

The number of participants was three heterosexual married couples that have a child with ASD. All participants were biological mothers and fathers of children with ASD. The participants' recruitment process used snowball by asking close people who may have acquaintances who are married and have a child with ASD. One couple of participants was a friend of the researcher's acquaintance. Starting from the first couple of participants, the researcher got two other couple names. Three couple of participants is a small number, but IPA approach usually have a small number of participant and the aim is to reveal something of the experience of each those individuals (Smith and Osborn, 2006). The study may explore in detail the similarities and differences between each case dealing with different ages and the position of the child with ASD to their sibling. The small number of participants is a limitation of this study, but this study would be a pilot project for further study.

The first participant couple was a housewife with an initial of Mrs. A (50 years old) and a working father with an initial of Mr. A (50 years old). They have been married for 22 years. Their child with ASD (with an initial U) is the youngest of two and is 18 years old; he has gone through speech and occupational therapy for 11 years and is currently completing his second-year junior high school education in an inclusive school. In some countries, 18-year-olds no longer refer to children, but in Indonesia according to article 330 of The Civil Law, the age limit of children are those who are not yet 21 years old and are not yet married. Article 98 paragraph 1 Compilation of Islamic Law also states that the age limit of children is those who are not physically or mentally disabled, and are not yet married. Law No. 4 of 1979 concerning Child Welfare in article 1 paragraph 2 states the age limit of children is those who are not yet 21 years old and are not yet married. The aforementioned explanation asserts that this family could be chosen as a participant, although their child with ASD is 18 years old.

The second participant couple was a housewife with an initial of Mrs. W (30 years) and a working father with an initial of Mr. W (30 years old). When they learned that their child was a child with ASD, Mrs. W decided to stop working so that she could focus on taking care of her child with ASD (with an initial L, 4 years old). They have been married for 5 years. L (4 years old) is the eldest of two, has been in speech and occupational therapies for 2 years, and is currently enrolled in an inclusive preschool.

The third participant couple was a housewife with an initial of Mrs. M (42 years old) and a father with an initial of Mr. M (44 years old). Both have been married for 12 years.

Their child with ASD (with an initial A) is 7 years old and is the second child of three, currently in first grade in an inclusive elementary school, and has been in speech and occupational therapy for three years.

	First Second		Third	
	Participant	Participant	Participant	
	Couple	Couple	Couple	
Age	Mr. and Mrs. A (50 years old)	Mr. and Mrs. W (40 years old)	Mr. M (44 years old) and Mrs. M (42 years old	
Child with ASD	Boy (18 years old)	Boy (4 years old)	Boy (7 years old)	
Therapy	speech and occupational therapies for 11 years	speech and occupational therapies for 2 years	speech and occupational therapies for three years	
Sibling	Boy (21 years old)	Girl (2 years old)	Two boys (12 and 5 years old)	

All information about participants can be drawn as follows:

Source: Researcher's analysis

#### **Results and Discussion**

# Analysis of utterances between husband and wife on financial, emotional, energy, and time support during their role in parenting for their child with ASD

In the first couple of married participants, their child was a severe deficit in verbal and nonverbal communication, very limited initiation of social and minimal response to overtures others in terms of social communication. That would be seen when his teacher asked him, he repeated the teacher's question and took a long time for answering one word to his teacher. In terms of behavior, he was extreme difficulty coping with change. That would be seen when his parents changed the direction to go to other places different from the first plan, he got very mad at their parents.

Mr. A told that his son with ASD (U) more frequently bites, pinches, and hits to Mrs. A, but when Mrs. A cried, U stopped being mad and then hugged Mrs. A. Mr. A explained that emotionally his son with ASD was closer to Mrs. A rather than to Mr. A. In here, Mr. A felt sorry for his wife, because he could imagine how exhausted she was to care for U. This implies that Mrs. A was likely close emotionally to their child with ASD.

Financial support from Mr. A toward U (child with autism, 18 years old) is affirmed by Mrs. A: "... My husband is highly supportive in terms of funding the therapy, school, and doctor visit... U has been in therapy for quite a while, around 11 years since he was 6–7 years old." Mrs. A's statement shows that all the financing for the needs' their child with ASD is fulfilled by her husband because Mrs. A herself is a full-time housewife. Mr. and Mrs. A told that all the needs' their child with ASD was not cheap and they had to downsize for other needs including the needs of the oldest son.

In terms of energy and time support for U, Mr. and Mrs. A were doing their complementary and reciprocal role. The complementary role could be seen through Mrs. A's explanation when Mr. A went to work, she had the responsibility to carried out her child with ASD to go to school or for getting therapy. If Mr. A was on leave then he carried out U to go to school or go for therapy. Their reciprocal role could be seen from the couple participants' statements that Mr. and Mrs. A switch roles, for example, when Mrs. A is helping her eldest with schoolwork, Mr. A takes U for a walk and vice versa. When U accompanies his mother to cook, then Mr. A helps his eldest with the computer. They did this way because they did not want their son with ASD to ruin the eldest's project or schoolwork like before.

In the second couple of married participants, their child was a deficit in verbal and nonverbal communication, limited initiation of social interaction and speaks simple sentences in terms of social communication. As could be seen from Mrs. W's explanation that L (4 years old) could comprehend and pointed to the objects' or body parts' but he could not mention and speak clearly the objects' or body parts' name. He also gave short answered when asked, but he could not ask or request verbally when he needs something. In terms of behavior, L could not cope with noisy sounds and crowds. This is affirmed by Mr. W stating that "L likes to play with L's younger sister. They get along well, but when his little sibling cried or noisy, L can be mad because L hates noisy".

Mr. W's financial support toward L can be derived from his statement, "I only sleep for four hours every night and that happens every night. I wake up early and go straight to taking care of business ... this is because our business is still in its early days." Mr. W's statement shows that he is willing to work hard to fulfill the needs of L. His needs are, for example, therapy, piano lessons, swimming lessons, tuition, lab checks, routine check-ups to the doctor every 6 months, and a shadow (a caretaker at school). Moreover, Mrs. W is now a housewife who has stopped working after knowing L was diagnosed with ASD.

Mrs. W states: "L cannot eat chocolate or ice cream, after eating it he becomes temperamental. L also cannot drink beverages that often find in the groceries ... Last time when he lashed out, he screamed for two hours..., but we let him be. It's hard for him to control his emotion, he claws and pinches, as you can see here (showing her hands that were clawed by L)." From the aforementioned statement, Mrs. W controls the emotion of her child by regulating the food that he consumes so that he does not throw a tantrum. According to Erickson, 60% of children with ASD have a poor digestive system. Foods such as those containing animal milk cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function.

and behavior (Erickson et al, 2005). Erickson's statement asserts that chocolate and ice cream are containing animal milk that presumably affects L's behavior.

In relation to the time and energy support that they give for L, Mr. and Mrs. W do the task together. They often take L and his younger sister to play together; they go on a recreation trip outside town or on short outings to the malls for dinner even Mrs. W has to accompany L so he does not panic in the crowd at the mall. This is done in order to build a sense of togetherness between L and his younger sister so that there will be no feelings of envy in the future.

In the third couple of married participants, their child (with an initial A) has a limited interaction to the narrow special interest and speaks simple sentences only if he needs something in terms of social communication. This would be seen from Mrs. M's affirmation that A was very passive, he rarely asked to parents or someone, he asked to someone only if he needs something. In terms of behavior, A has difficulty coping with change and has repetitive behaviors towards narrow special interest. This would be seen from Mr. M's explanation that A was easily bored when he played with his eldest and younger brother, he only lasted in 5 minutes playing with them. He prefers to play alone.

Mr. M's financial support for his child with ASD (A, 7 years old) can be seen from Mrs. M's statement: "A Nikolin injection for A costs around 250 thousand per pack, this can be administered 10 times. A requires around  $60 \times$  so we need six packs costing us around 1.5 million. The cost for therapy is about 300 thousand per month; it is scheduled twice a week for two hours." This indicates that Mr. M works hard to support the needs of his child with ASD. Mr. and Mrs. M told that for making ends meet all the needs' their child with ASD, they had to downsize for other needs including the needs of the eldest and youngest son.

Mrs. M supervises her child's emotions by regulating his intake of gluten and commonly packaged beverages. She said, "I limit his gluten consumption. For example, he asks for Indomie (the brand of instant noodles) because he sees his brothers eating it. I make a half portion for him but for seasoning, I only give soy sauce and salt, I do not include the seasoning that comes with it. If he asks for a snack with extra seasoning, I only put a little of it." It can be inferred from Mrs. M's statement that in order to control her child with ASD's behavior, she regulates the foods consumed by him. Mr. M also supports Mrs. M's regulation by not buying food containing gluten ingredients for his son with ASD. As mentioned before that some children with ASD have a poor digestive system. Foods such as wheat flour cannot be digested properly so that the protein in these foods cannot be turned into amino acids or peptone. In children with ASD, this peptone is reabsorbed by the body, enters the bloodstream, is passed on to the brain, and converted to morphine, casomorphin, and gliadrophine which damage brain cells and cause impaired brain function. Impaired brain functions are cognitive functions, receptive communication, concentration, and behavior (Erickson et al, 2005). Erickson's statement asserts that noodles containing wheat flour that probably affects A's behavior.

Concerning the time and energy support for their child with ASD, Mrs. M frequently accompanies her son with ASD at school or home compared to Mr. M because Mr. M has not been able to fully supervise him. Mr. M preferred to accompany two other children so that they could not disturb Mrs. M dealing to care A (her child with ASD).

From the aforementioned utterances of three married couple participants, the following conclusion can be drawn: there are dynamic changes related to the role of married couple participants in meeting financial, emotional, time, and energy needs for their ASD children who have difficulties in social communication and repetitive, restricted behavior. In meeting all those needs, each participant does share tasks with respect and responsibility. As mentioned before, the utterances of togetherness can be seen through utterances that indicate proclaim acceptance, collectiveness, supportiveness, and others related to any actions that

lead toward positive results. Each participant does a complementary and reciprocal role to support his/her couple caring for their child with ASD. The study results found that each participant tries hard to create togetherness as couples handling their child with ASD even though it was not easy. All participants have a similarity of optimistic feelings that could be seen in their quotation saying every difficulty, there must be ease. Their optimistic feeling was powerful to create togetherness as a unity.

According to Koerner and Fitzpatrick, in a family, there is a degree of cohesion and adaptability among members (Koerner & Fitzpatrick, 2002). That two degrees would be useful for exploring the ability of all participants toward changes and dealing with tensions in order to balance their relationships. All about cohesion and adaptability would be explained as follows

# Analysis of utterances between husband and wife about cohesion and adaptability in relation to describe the couples' role negotiate strategy in parenting for their child with ASD

After discussed the utterances of togetherness as earlier, this section would analyze participants' ability to adapt and to foster cohesion in sharing their roles during parenting for their children with ASD. The ability to adapt, according to Olson (1996) and Poire (2006), is the ability to maintain stability and to regulate changes in a relationship. The ability to adapt is divided into four different levels: (1) rigid, where a certain rigidity is shown toward accepting changes due to authoritarian leadership and stringent rules becoming a benchmark in life; (2) structured, where moderate leadership can accommodate changes based on limited collective decisions, leading to a more stable relationship; (3) flexible, where quick and prompt attitudes are shown toward changes, and often decisions are made based on collective consensus; (4) chaotic, where tension and instability are high due to a lack of leadership,

which leads to a dissimilar perception between the two when faced with changes. Olson's level of adaptation can be simplified through a matrix (see Table 2).

		Fable 2. Adaptabil	lity	
	Rigid	Structured	Flexible	Chaotic
Roles	Roles seldom change	Roles stable	Role sharing change	Dramatic role shift
Change	Too little change	Change when demanded	Change when necessary	Too much change
Leadership	Authoritarian leadership	Leadership sometimes shared	Share leadership	Lack of leadership

Source: Olson, 1996

According to Olson (1996) and Poire (2006), cohesion is defined as an emotional bond between members within a relationship. This bond is divided into four different levels: (1) enmeshed—in this level, members' proximity, loyalty, and dependence over each other are extremely high, leaving no space for individuality; (2) cohesive—in this level, members attempt to maintain emotional closeness, loyalty, and cohesion by emphasizing a certain degree of individuality; (3) connected—in this level, members are mostly independent, but still, involve other members to perform the group's function; (4) disengaged—in this level, members are extremely independent and thus possess a high degree of individuality, which places emphasis on him/herself over other members. Olson's level of cohesion can be simplified through a matrix (see Table 3).

		Table 3. Cohesion	1		
	Disengaged	Cohesive	Connected	Enmeshed	
Closeness	Little closeness	Little-Moderate closeness	Middle-High closeness	Very high closeness	
Independence/ dependence	High independence	Interdependent	Interdependent	High dependence	
I-We balance	Ι	I-We	I-We	We	
Loyalty	Little loyal	Some loyalty	High loyalty	Very high loyalty	
Source: Olson, 1996					

Table 4 explains that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are all positive conditions, stable and conducive. In terms of adaptation, structured and flexible are two of the conditions that are able to accept and deal with changes positively compared with rigid (tends to reject changes) and chaotic (often changes attitudes toward the change). In terms of cohesion, cohesive, and connectedness are two of the most conducive conditions that are able to maintain emotional closeness, loyalty, and cohesion while still being able to give a degree of independence for other members to perform their function according to their domain. The aforementioned explanation shows that cohesive-structured, cohesive-flexible, connected-structured, and connected-flexible are conditions that lead toward togetherness, symbolized by the ability to adapt (+) and to maintain cohesion (+) as can be seen as follows:

Table 4. Adaptability and Cohesion					
Cohesion	Adaptability				
	Rigid	Structured	Flexible	Chaotic	
Enmeshed	-	_	_	_	
Cohesive	_	+	+	_	
Connected	_	+	+	_	
Disengaged	_	_	_	_	

Source: Researcher's analysis

The utterances of all three participants in terms of adaptability related to financial, emotional, time, and energy show that they tend to do role sharing change and change when necessary for caring for their children with ASD, as could be explained as follow: (1) they try work hard and reduce the unnecessary expenses to be able to make ends meet the needs of their children with ASD; (2) when wives support emotional by reducing the intake of gluten and animal milk, husbands support by not buying food containing those ingredients for their children with ASD; (3) time and energy, wives support time and energy by accompanying their children with ASD at school, place of therapy, and home daily, husbands support time and energy for their son with ASD only when husbands on leave. They do a complementary role and a reciprocal role. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level structured-flexible in terms of adaptability. A more structured and flexible level of adaptation allows the three couples to adapt to changes. It could be seen from the way they accommodate changes based on collective decisions and consensus.

The utterances of all participants related to financial, emotional, time, and energy for their sons with ASD show that the emotional bonding toward one another is cohesive and connected. All three couples actively try to maintain emotional closeness, loyalty, and interdependence with one another face-up financial, emotional, time, and energy problems for their sons' with ASD as follow: (1) in doing every task for caring for their sons' with ASD, they do together for one intention for making better the condition of their sons' with ASD; (2) they are trying actively to complement each other's role for their sons' with ASD. From the aforementioned explanation, the following conclusion can be drawn: three married couple participants have a level of cohesive-connected.

From the aforementioned explanation about cohesion and adaptability, this described how participants manage and balance their roles towards their son with ASD by the negotiating strategies. All three couples implement a compromise strategy for caring for their children with ASD. They interchange roles and collectively participate in devoting financial, emotional, time, and energy for them.

### Conclusion

In conclusion, the three couples participants used a compromise strategy to negotiate their roles related to financial, emotional, time, and energy for their children with ASD. They accommodate changes based on collective decisions and consensus. They also collectively interchange and participate in devoting financial, emotional, time, and energy for their children with ASD. These findings indicate that there are still married couples who have children with ASD who remain share tasks together in caring for their children with ASD. Although difficult, they have the optimism that after difficulties there is ease. The same optimism feeling would make easy to create good cohesion and adaptability.

This research attempts to help to understand and capturing the complexity of the marital, family system, and tension or stress in the health area using relational dialectic theory, family system approach, and Olson's circumplex model. The small number of participants is a limitation of this study, but this study would be a pilot project for further study. The implication of this study is to eliminate the tension of husband and wife in caring for children with ASD so as to reduce the risk of divorce or separation. For future work, it is necessary to conduct research on how to balance the communication in another tension context in a family using more participants.

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