Resilience in Families of Children with Special Needs from Sibling's Perspective

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Abstract--- Family resilience is a dynamic process in the family to make positive adaptations to the danger from outside and from within the family. The purpose of this study was to describe the family resilience in families with special needs children from the perspective of siblings. This was a qualitative research design phenomenological approach with in-depth interview method on 15 siblings of children with special needs. The population was the siblings of children with special needs who were registered at the Gresik Resource Center. Participants were teenage siblings of children with special needs who live in the same house. Data were collected by visiting the participant's home. This study used data collection with purposive sampling. The level of family resilience was strongly influenced by the relationship, level or sequence of birth positions within the brotherhood, and various responses of the siblings of the child with special needs. The positive response generated will strengthen the communication process, the division of tasks and obligations in accordance with the role in the family belief system that can produce better family resilience. It is hoped that this research could be the basis for further research and could be a model of community nursing intervention, especially families with child with special needs, such as the establishment of sibling communities of children with special needs in Indonesia by involving related institutions.

Keywords--- Family resilience, sibling, children with special needs

I. INTRODUCTION

The family can be called an extraordinary organization, where the bond of each member is very strong and able to form the background of each member bound in it. Family needs to know how they can be able to solve various stressors because, when a family faces significant stressors, it will go through certain process that allows them to survive and adapt until they can become resilient [1]. The resilience of children with special needs siblings is important because it can influence parental responses and processes in the family. The pattern of positive behavior and functional competence of each individual in the family determines the ability of the family to rise in critical and recovering conditions [2]. Family resilience is a dynamic process between risk and protective factors. Risk factors can drive negative outcomes in families, while protective factors help ease the negative outcomes. Protective factors interact with risk factors and stir family power to overcome the difficulty [3]. The increasing number of children with special needs is rapid, so it is important to increase the acceptance and support from each family member. According to the results of data collection from the Directorate of Social Rehabilitation of People with Disabilities in 2009,

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children with special needs are large in Indonesia. In 24 provinces, there were 65,727 children, consisting of 78,412 children with mild instability, 74,603 children with moderate disability and 46,148 children with severe instability. In 2014, Mais stated that, in one city in East Java, persons with disabilities included in the special needs group had 27,447 out of 1,945,597 people [2].

The influence of having a sibling with special needs is according to an individual's psychological functioning, which can be defined as their ability to achieve their goals, within themselves and their environment, including their emotional regulation, behavior, social skills and mental health. Response to having a sibling with any form of special need is likely influenced by their parents' reactions to dealing with the needs. Variation in this response may be dependent upon the age of diagnosis, severity of need and the amount of support received from family and friends. Parents should try to consider the needs of other children by providing enough information for them to understand their sibling's needs, helping them to understand the diagnosis and what it means for them and their sibling [4]. Therefore, resilience of families with special needs children is crucial and needs to be considered due to limitations of special needs children to fulfill their personal needs independently without the help of family and the surrounding compared to normal children [1]. This study aims to obtain a family understanding of family resilience with children with special needs from the sibling's perspective using qualitative research methods with phenomenology approach.

II. METHODS

The qualitative methodology used in-depth interviews with siblings   to explore the family resilience when caring for a child with special needs. The qualitative methodology allowed researchers to hear the participants from their own   perspective. The research and particular approach were chosen to identify the meaning of life experience [5]. This study used Husserl's phenomenology to explore the family resilience of siblings.

Husserl's phenomenology is transcendental because it adheres to what can be discovered through reflection on the subjective acts and their objective correlates. Sheehan [6] stated that this exegetical research first discusses Husserl's transcendental phenomenology constructs of noema, noesis, and epoche, as presented by Moustakas [7], followed by discussion of elements that affect individual decision-making [8].

Transcendental phenomenology is a scientific study of the appearance of things, of the phenomena just as we see them and as they appear to us in our consciousness. Every one of these 'phenomenon' can be a suitable starting point for reflection [9]. The bracketing process is carried out throughout the entire research process starting from the data collection and the analysis of the data using a reflective diary. Reflective is a thought process that helps the writers to identify potential things that can influence the process and results of the research [10].

The reflective diary was used in interview to write down the author's thoughts, feelings, and perceptions about parenting when conducting the research. This allowed the researchers to re-examine their position when problems arose that might affect the research process [11].

Participants are siblings of children with special needs who are members of the Technical Implementation Unit Resources Center or a student at Tlogopatut Elementary School. Participants chosen are 12-20 years old because they are considered to be able to responsibly receive information delivered during study. The researcher also believes that teenagers need guidance due to their search of identity stage. The participants included the fifteen siblings who were raising their siblings with special needs.

The interviews were scheduled at the participants' homes at a convenient date and time, involving the sibling. After a discussion regarding their approval and confidentiality, the siblings were asked brief demographic data about the child with special needs (e.g., gender and age). Then, an in-depth interview with the sibling using six open-ended questions (with additional questions if necessary) was conducted to gain information on the sibling's experience while nurturing the child with special needs.

Data Analysis

The data were analyzed and interpreted using the Colaizzi method. This method was chosen because of the advantages compared to other methods. The advantages of this method are that the data can be clarified with the participants, as well as possible changes in the results [3]. A summary of the process of data analysis using the Colaizzi method is as follows. Step 1: describe the phenomenon under study. The researchers gain the perception of family resilience by enriching the information gained through reading the results of research from books. Step 2: gather the description of the phenomenon through the participants' opinions. The researchers conducted interviews and wrote in verbatim form so that the researchers could then describe the perception of family resilience. Step 3: read the whole description given by the participants about the phenomenon being studied. The description of the participant's interview results were arranged in a verbatim script form. The verbatim script was synchronized between the sound recording and field notes, so that the verbatim script then contained the participant's statements (verbal information) as well as the various participant expressions and gestures (non-verbal information) that emerged during the interview. Step 4: separate the significant statements. This process was done by coding the participant statements that had a significant meaning as listed verbatim. Step 5: formulate the meaning of each significant statement. The researchers fully used the participants' point of view and put aside all of the knowledge, assumptions and personal experience of the researcher. Step 6: categorize each unit of meaning into a theme of meaning. Step 7: integrate each theme into a complete description. Step 8: validate the results of the analysis with the participants. The results obtained from the data analysis process were then given to the participants to be reviewed and checked with the participants' experience and feelings. Step 9: refine the analysis results with the data obtained during the validation process [5].

The author involved two of their colleagues for an external examination of the research interpretation process to validate the findings, to discuss the different perspectives, and to clarify the 'bias of researchers' that may have influenced the process of data interpretation. The research team met at three points in the research interpretation process (i.e. beginning, middle, and end) to discuss and to reach a consensus on the findings and whether the data had achieved saturation. If different perspectives arose, further discussions were conducted until a full consensus was reached [5].

Ethical Approval

The Research Ethics Committee of the Faculty of Nursing Universitas Airlangga gave the Ethical Approval for this research. The number of the Ethical Approval was 1049-KEPK. Participation was voluntary and each participant who represented by the parents signed an informed consent form before participating. The participants were given pseudonyms. All of the research documents were stored in a locked cabinet in the main author's office and all electronic copies were password protected.

III. RESULTS

The study involved 15 siblings from families of special needs children, wherein the inclusion criteria have been fulfilled for the study, and all those participants lived in one house with their brother or sister with special needs. A summary table explaining the characteristics of the participants and their siblings has been included (see Tables 1).

Table 1. The sibling as participants Characteristic of the

Characteristic	Total	%
Age		
13-20 years old	10	66,6
>20 years old	5	33,3
Gender		
Female	9	60
Male	6	40
Marital status		
Married	1	6,6
Single	14	93,6
Education		
Less than junior high school	2	13,3
Complete junior high school	4	26,6
Senior high school	5	33,3
Collage & graduate degree	4	26,6
Profession of family member		
Student	11	73,3
Non-government worker	3	20
Fulltime mother	1	6,6
Time for Caring		
<10 years	9	60
10-19 years	6	40

Qualitative Findings

Various themes the participants' answer purposes of this study. from this study resilience in families of needs from a sibling's were formed based on regarding the specific These themes produced described about children with special perspective.

Sibling Response

The role of the family cannot be separated from the role of siblings of autistic children. Siblings certainly feel the impact of having a brother or sister who has autism [12]. We concluded that there were five subthemes for siblings' responses: sad, do not believe, shy. The sad subtheme was described by participants:

"Heem .. sad" - Participants cannot speak and cry, followed by an expression "Don't have the heart with sister ... I don't have the heart to worship too ..." - P15

"Yes ... it's bad with brother, can't go anywhere ... parents are also more difficult ..." - P6

The second subtheme, feeling upset during "unbelievable" was described by participants:

"How about that, feeling ... it's not good ... sis (mentioning his sister's name) is difficult to teach and annoyed ..." - P14

"First it doesn't believe me, ... can't bear it" - P9

The third subtheme, feeling upset during "shy" was described by participants:

"In the beginning, there was a small sociologist, embarrassed ... but I was very disappointed" - P13

"I'm insecure ... not confident before" - P10

The fourth subtheme, feeling upset during "shy" was described by participants:

"Really tired. There is a sense of badness, but what else do you do ... told to take care of your little brother, they are jailed, told to understand, told to beat, even though the brother is wrong "- P7

"I'm not sad, but more upset ... usually the smallest is preferred ... or why the smallest is preferred" - P14

The fifth subtheme, feeling upset during "accept" was described by participants:

"Thankful ... initially, the first one was insecure, but now it's better ... wait patiently . .." - P10

"Yes, I will be accepted with all the shortcomings, Ms. .. always support the shortcomings that are given, surely everything is not perfect" - P11

Four forms of sibling relations intertwined in the subject of research are close and warm relationships, relationships dominated by firstborns, relationships with jealousy and conflicting or competitive relationships [13].

Family Communication Process

Communication facilitated all family functions and was important for resilience. In crisis situations, communication is essential in helping the problem solving process [14].

Strategies for family communication process include functional and dysfunctional. The subtheme of functional was described by a participant:

"Alhamdulillah ... now it's closer. Father after sister (mentioning name) was born so there were more at home, invited to walk, joked ... it was good "- P2

"I often talk to my mom and dad ... told to keep the big one tomorrow, big was ... often talking, joking" - P13

The subtheme of dysfunctional was described by a participant:

"Yes, it's hard to deal with ... right, we don't know what he wants, he's just crying. poor ... "- P3

"I never told you ... the most ordinary thing" The participant also told me that he had left home because he was annoyed with his parents "yes ... ever, ever left the house ... seemed before he never understood" - P9

Family Organization Process

Strategies for family organization process include sibling job description.

The subtheme of sibling job description was described by a participant:

"Sometimes ... asked to take care of brother, get your bed cleaned, study ..." - P14

"... yes ... and moreover I'm happy, because of his duty to learn to continue praying ..." - P14

"For the assignment ... if you make it clean, I sweep it ... the task is just divided ... there is someone who keeps the brother" - P9

The subtheme of children with special needs job description was described by a participant:

"(Mentioning special need children's name) who is more diligent in washing dishes, drying, than usually ahahaha ... after eating it cleaned, .." - P8

Connectivity or cohesion is a structural and emotional bond in family members. According to Olson and Gorel, families with strong ties tend to feel satisfied and connected with what is in the family[[14]. The form of connectedness in the family was mutual support, cooperation, commitment and respecting the differences, desires, and limitations of individuals.

Family Belief System

The family belief system was divided into three subthemes: exam, attempted, high confidence.

The subtheme "exam" was described by participants:

"... trials from Allah SWT and tests that must be faced with sincerity, spaciousness" - P11

The subtheme "attempted" was described by participants:

"Yes, I keep trying ... I'm sorry, Mom, but you can talk" - P7

"Yes ... teach prayers, but it can't yet ... Just copy it - Allahubar just like that ..." - P5 * while practicing

The subtheme "high confidence" was described by participants:

"Sure .. sis can be cured .." - P4

"... often to the mosque with me ... often pray in congregation" - P10

The form of worship carried out by the participants were prayer in congregation, went to the mosque, and things that were able to strengthen the soul to be more calm.11 The expressions of P11, P10, and P5 in the theme of the family belief system showed that, with worship, they had good habits, which were able to help them in their lives automatically.

Valuable Experience

The valuable experience was divided into four subthemes: difficult experience, proud feeling, hope, and concern.

The subtheme "difficult experience" was described by participants:

"Yes, like taking care of a younger sibling (mentioning the name), missing ... playing ... if it is lost, look for it ... the neighbor will come looking for it" - P7

The subtheme "proud feeling" was described by participants:

"... Proud of its development ... can already understand ... strong" - P3

"Feel more valuable family, of course ... not everyone can accept" -P5

This study showed that if the sibling process went well, it would produce a good response as well.

The subtheme "hope" was described by participants:

"... the expectation is only normal ..." - P14

The subtheme "concern" was described by participants:

"Yes, if the sister (mentions the name), it is important not to be down. If down, the returns like a baby again, so it can't do anything, so just be guarded ... just don't get sick like that ... if the therapy is exhausted, it's postponed, it's afraid, instead it drops ... "- P3

IV. DISCUSSION

The findings in the phenomenology study proved that each family with special needs children passes their respective adaptations. As in the P2 family who had many conflicts, in which the man had two wives, six children, and had a newborn in old age, P2 explained it was not easy to go through the condition. However, with good communication, then each problem was getting better and the connection among family members was increased.

This study founded many variations among families with special needs children and others. Some families had treated special needs children for a period of 19 years, 15 years, 14 years, 13 years, 12 years, 10 years, 8 years, 6 years, 5 years, and 3 years, respectively. Families who treated special needs children for more than 10 years got better adaptations. As in P1, who had a younger sibling with cerebral palsy. P1 had a closer relationship in the family and told of his experience of having a younger sibling with special needs, making him

more petrified for the parents to take care of their homes or do things independently. P1 told us that he was happy to have the opportunity to teach his sister to be able to continue to fight against limitations. Caring for siblings with limitations was not easy. P1 showed us he was grateful to be a therapist because of his experience in caring for his younger brother.

The family resilience approach utilizes concepts from individual resilience and general systems perspectives, recognizes the importance of ecosystems, and views families as one of several proximal contexts (peers, communities) that increase the vulnerability or protection of individual development, or as systems with functions, goals, and interaction patterns that regulate day-to-day life at multiple family system levels [15].

Resilience in the family is the result of collaboration among family members. Each member has an important role in the condition of family resilience. P11 was an interesting proof that, by a good understanding of the role of a child, he was able to substitute the position of his parents. Since he graduated from high school, P11 had replaced his parents in earning a living for the family. P11 revealed that he still tried to be strong with the conditions experienced by his family. He was proud of his strong sister who endured tough conditions. His younger brother could not walk normally, nor could as his father. This became reinforcement for P11's working to find blessings for his family. P11 had become a role model and had pride in the family. In contrast with P1, research conducted by Siminghalam [16] showed that children with special needs can adversely affect his/her siblings so as siblings feel ignored when their parents pay more attention to the special needs child. The research also stated that normal siblings of special needs children are 0.6-1.2 times more likely to experience emotional and behavioral problems compared to the sibling in a normal family [14]. There were many crises experienced by each family member with special needs children. By a variety of adaptation processes from each family, starting from the feeling of rejection, bargaining, anger, eventually they were able to accept and adapt well. The response from siblings who have special needs children in the family is one of the keys to family resilience in addition to communication processes, organizational processes, and family belief systems. The limitation of this study is that the social aspect of the family of children with special needs is the main obstacle of the study because the family is not willing to visit.

V. CONCLUSION

Family resilience from a sibling perspective provides a positive experience and a happy feeling. The family belief system shows that, with worship, they have good habits, which can help them in life. They take on the role as a sibling to support and help each other. The existence of family challenges that must be solved together makes them more intense in terms of communication. There is a more difficult communication process because children with special needs are owned by the crew. The condition of children with special needs requires more understanding and a different communication process, which makes the communication process in the family less good.

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