
Portrait of Acceptance by Parents of Special Needs Children with Developmental Disabilities

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ABSTRACT

The ability of parents to accept the condition of their children with special needs (ABK) positively impacts the process of handling children. This study aimed to explore the experiences of parents who have ABK with developmental disorders using the perspective of Elisabeth Kubbler Ross' theory about the stages of grief and forms of acceptance. The research subjects were selected purposively, and it was found that three parents who had ABK with developmental disorders were susceptible to age 5-7 years. This phenomenological qualitative research focused on parents' acceptance as a phenomenon. The research data was extracted using in-depth interviews and observations both directly and using online communication media. The data were processed and reduced manually by the researchers before being presented. The results showed that all subjects went through the stages of acceptance as the theory of stages of grief, but the stages experienced by the subjects were slightly different. The stage of rejecting was only passed by Subject 1 and Subject 2, the angry stage was passed by Subject 2 and Subject 3, the bargaining stage was passed by Subject 1, Subject 2, and Subject 3, and the depression stage was passed by Subject 1 and Subject 3, the receiving stage was passed by subject 1, Subject 2, Subject 3. The parents' acceptance of the condition of ABK directly affects the parenting model and fulfillment of children's rights in various ways.

Keywords: Children With Special Needs, Acceptance Of Parents, and Acceptance Stage

INTRODUCTION [Arial 10, bold]

In general, parents will find it difficult to accept that they have children with special needs (Putri & Rusli, 2023). In a study, Rahayuningsih & Andriani (2011) stated that having ABK causes parents to be depressed and causes adverse reactions in mothers when raising children. Simamora (2019) also stated that this was in line with previous research, namely the emergence of inadequate responses from parents seeing a reality that did not match their expectations.

Acceptance means being willing and ready to admit the situation experienced by the child, which is manifested through positive parenting (Faradina, 2016). Parent Acceptance is shown by the willingness to try to fulfill the rights and needs of children and loves children without caring about children's deficiencies (Rohner et al., 2008). The family environment that accepts the presence of ABK has a psychologically positive influence on ABK (Carrasco et al., 2019). Family acceptance will also directly impact how

families meet needs in child growth and development (Marlina et al., 2022). In general, parental Acceptance is also said to impact learning social skills in ABK (Pancawati, 2013). Furthermore, Dewinda & Affarhouk (2019) stated that accepting the presence of ABK can also help parents control their feelings so that, in the end, they can control the conditions they are experiencing.

Several main things can help parents in the process of receiving ABK, namely the level of understanding of the barriers to child development and also the point of view of the surrounding environment (Negara, 2020). The point of view from the environment is essential because it directly impacts obtaining social support for parents in raising children with special needs. Because, in general, social support can develop subjective well-being (Ningtyas et al., 2019). The same thing was stated in Rahayu & Ahyani's research (2017), which stated that the support provided by the family and the level of emotional intelligence possessed by parents were included in the supporting factors that helped parents accept that their child was with special needs. Detailed information about the child's condition is also one of the support so that parents can accept the child's condition (Bayrakli & Sucuoglu, 2018). Good Acceptance of children's conditions is manifested by fulfilling children's rights and needs, such as providing educational facilities and therapy and supporting children to develop their talents and interests.

On the contrary, the attitude of rejection shown by parents causes the rights and needs of children not to be met, which results in sub-optimal growth and development of children (Normasari et al., 2021). Zulfiana (2017) states that parents' rejection of children's conditions is considered to tend to be in line with the attitude of parents who do not care and ignore children. Furthermore, Zulfana (2017) also stated that rejection of a child's condition could negatively impact the psychology of parents, such as depression. Parents' rejection of a child's condition can negatively influence the child's development (Putri & Lutfianawati, 2021). In the end, refusal

will prevent ABK from getting positive parenting and directly harm ABK and ABK's parents in the long term.

Parents' unpreparedness to accept the condition of ABK, caused by the lack of support from the surrounding environment (Munisa et al., 2022), results in feelings of inferiority (Hannsen & Erina, 2022). Parents' perceptions of children also influence the way they care for children (Diana et al., 2022), such as feelings of shame and disappointment with the child's condition (Islami & Ansyah, 2020). In addition, the lack of understanding of parents about developmental disorders experienced by children is one of the reasons parents depend on high expectations for their children and focus more on their children's deficiencies (Bayrakli & Sucuoglu, 2018).

In general, parents will go through certain stages to understand and accept the child's situation (Gumilang & Irnawati, 2022). Accepting the condition of children with special needs requires a long process (Tarigan, 2022). Being able to accept a child's condition is often preceded by a feeling that it is difficult to accept the condition experienced by the child (Yasar, 2022).

As for the cases the researchers encountered, the three subjects were parents of children with special needs with developmental disorders with a vulnerability of 5-7 years. The three subjects have been able to accept the child's condition. Departing from this, researchers are interested in exploring the experiences that each subject goes through so that they can accept the conditions of children with special needs, as mentioned in Ross (2009), regarding the stages that are passed after facing a situation that causes grief or sadness including denial, anger, bargaining, depression, and also acceptance. In addition, this study will also explore further the forms of acceptance of the subjects towards the condition that they have ABK. This research focuses on describing the stages passed by the research subjects so that they can accept the child's condition. Adding to previous research findings, which describe the stages of acceptance that

parents go through, this study also further explains the phenomenon of experience in the form of acceptance for each subject in each acceptance stage.

METHODOLOGY

A qualitative approach with a type of phenomenology was chosen as the methodology of this research to explore the experiences of the research subjects regarding the stages of old acceptance of ABK. The selected subjects were three parents of children with special needs and developmental disorders aged 5-7 years. Two of them have children with speech delays, and one of them has children with special learning difficulties (dysgraphia). Data was collected directly at the subjects' residences in Malang, East Java, for four months from December 2022-March 2023. The primary data sources were three parents who were research subjects. While the secondary data sources are, observation notes and documentation in the form of photos or pictures and screen captures of WhatsApp messages. Data collection techniques include interviews, observation, and documentation.

The type of interview to gather data in this study is semi-structured with the aim that the subject can provide in-depth information regarding experiences that have been passed freely and comfortably. The interview instrument was taken from the five stages of the theory of the stages of grief Elisabeth Kubler Ross (2009). The type of observation used is non-participant, meaning that the researcher only acts as an observer without being directly involved in the life of the research subject with the aim that the atmosphere is more natural and the research subject does not feel supervised so that they can act as they are. Data collection through documentation was carried out by browsing the research subject's posts on social media, especially Instagram, Facebook, and WhatsApp, related to the data needed.

This study uses three stages of data processing, namely data reduction, data presentation, and conclusion (Creswell, 2012; Moustakas, 1994; Sugiyono, 2013). Data reduction was done using manual coding,

namely sorting and categorizing themes from the interviews. Data reduction results are in categories that are given a specific code. In presenting data, the letter S refers to the subject code, and the number after the letter S (e.g., S1) is the number for the order of the research subjects. Checking the validity of the data in this study used triangulation, namely by extending the research time to obtain more comprehensive and credible data.

RESULT AND DISCUSSION

The three research subjects went through stages of acceptance as in the theory of stages of grief by Ross (2009), which included rejection, anger, bargaining, depression, and acceptance. However, the three subjects went through slightly different stages. The following describes the five stages of acceptance of research subjects for ABK. The refusal stage was experienced by two research subjects in the form of trying to ward off the reality related to speech delay disorder in children and believing that the child was delicate (S1) and assuming that the child's inability to write was a natural thing, not included in the category of developmental disorders (S2). As explained in a study (Suheri, 2014), the first response of parents when they first discover disturbances in the growth and development of children is to deny the actual condition of the child by convincing themselves that the child's condition is good. The subject's experience at this stage is different from that described in Ross' research (2009), namely the stage of refusing to be passed by someone after receiving a doctor's diagnosis. In contrast, in this study, parents experienced rejection when they first encountered symptoms of developmental disorders in children before receiving the results of a doctor's diagnosis.

Parents of children with special needs generally go through the anger stage, namely two research subjects. Angry expressions generally appear in the form of blaming the wife for thinking she has never accompanied her child to study at home (S2) and blaming herself for feeling very confused about the right way to get her child to communicate on her own, and also blaming other people who

try to provide a solution but it does not work. (S3). In line with what was described in the research by Rahmadayanti et al. (2020), one reason for angry reactions among parents is feeling confused about how to handle and care for children. Parents also find it difficult to handle children due to a lack of understanding of how to handle children and a lack of support from those around them (Yasar, 2022). Likewise, as explained in the study of Swandi et al. (2022), some parents of ABK get angry quickly or have difficulty controlling their emotions.

Besides refusing and getting angry, the subject also goes through the bargaining stage. The three subjects experienced this stage in the form of trying to believe in destiny and not assuming the child's condition was the result of their mistakes as parents (subject 1), assuming that the obstacles experienced by children in the academic field, especially writing, had something to do with their abilities in the academic field while still at school (S2) believes that the child's condition will improve as the child's father also experienced the same thing with the child as a child. This is as explained in the research by Firmawati & Ayu (2022), which states that at the bargaining stage, parents try to cheer themselves up and focus more on the efforts that must be made in dealing with the child's condition as an effort to ward off the sadness that is felt for the child's condition. In a study by Purwaningrum et al. (2018), it was stated that mothers' rejection of the condition of children with special needs was caused by concern for the child's future due to the lack of knowledge about the child's condition.

Before accepting the child's condition, the subject had passed through the depression stage. This stage is in the form of feeling very anxious and worried about imagining the future of the child, especially in the field of education (S1), fear that the child will not be able to continue his education because he is not accepted at public schools in general (S3). A study by Cristiani et al. (2021) stated that depression tends to be caused by worry or anxiety about a child's ability to grow, develop, and meet their own needs. This anxiety leads

to fear if the child always depends on other people and is afraid that the child will not be able to survive if no one cares for him, in this case, himself as a parent. In addition, Ghaisani & Hendriani's (2022) study stated that the lack of support from those around them also causes depression because they feel a lack of support in the form of information sources that can help them deal with children. In line with what was mentioned by Vikawati et al. (2018), namely the limited ability to handle ABK is also one of the causes of depression.

At the receiving stage, it shows that the three subjects can accept the child's condition, which is manifested in the form of positive parenting, such as being open to learning and understanding the child's condition and facilitating the child for therapy (S1 & S3) understanding the child's condition and not demanding the child as desired but by remaining a facilitator for children by presenting private teachers who are assigned to guide children to practice writing outside of school hours (S2). As Sesa & Yarni (2022) mentioned, accepting the child's situation is ultimately accompanied by a positive perspective on the child so that they are more focused on providing treatment.

Acceptance of the ABK condition manifests in implementing care according to what the child needs. The positive acceptance of the subjects was shown through an open attitude towards the child's condition, such as actively seeking information regarding the condition and how to handle the child either through consulting with child growth and development doctors, learning through parenting social media accounts (S1) consulting with the child's teacher and trying to check the child's condition in order to find out detailed information about the disorders experienced by children (S2) and are willing to be open to asking people who are considered more knowledgeable about the child's condition and are willing to receive input regarding how to invite children to communicate (S3). As described in research (Boham et al., 2018), the open attitude of parents who have children with special needs

is based on parents' awareness of their role as facilitators for children, awareness that God entrusts children, and the belief that children's conditions can improve if parents provide full support in assisting the process of growth and development of children. Parents' acceptance of developmental disorders experienced by children raises awareness in parents to collaborate with other parties or experts in providing treatment according to children's needs (Zeylurt, 2020).

The subject's acceptance of the child's condition is shown by trying to fulfill the rights and needs of the child in the form of facilitating the child for therapy (S1 & S3) and facilitating education for children in the form of formal schools and private tutoring (S1, S2 & S3), giving children the freedom to socialize with other people (S1, S2 & S3) as described in the research by Dolu et al. (2014), as well as facilitating children's interests and talents (S1, S2 & S3). Several things include the rights of children with special needs, namely being protected from various things that can harm children from all aspects, not being discriminated against, not being ignored, and having their needs met in terms of education as children who do not have special needs (Husna, 2019).

Involvement of the subject in children's activities is also a form of acceptance of the child's condition, such as participating in preparing children's learning equipment when they want to go to school, reciting the Koran, or private tutoring (S1 & S3), participating in children's play activities (S1, S2 & S3), and participate in activities held by the child's school (S1 & S3) as mentioned in the research (Margijanto & Pandia, 2022) parental involvement includes at home and at school which can be done in several activities such as accompanying children in do homework (PR), invite children to tell about their experiences, play with children, and attend events organized by children's schools. Parental involvement in children's activities can positively influence efforts to provide interventions for children. Intervention is expected to follow the child's needs (Ashari, 2021). Appreciating the uniqueness of children is included in the form of positive

acceptance by parents of children's conditions, such as understanding that even though children have poor abilities in speech and academics, they have advantages in terms of activities related to physical development (S1 & S2) even though they are lacking in speech and academics. However, children have advantages in assembling lego and pouring out their imagination in playing Lego activities (S3). As explained in Riati's research (2018), one of the essential things that parents understand is the uniqueness of ABK.

The limitations of this study include: First, the subjects studied were only parents of children with special needs with developmental disabilities, two of whom were parents of children who had speech delays, and one of them had learning difficulties. Second, interview activities were only conducted with one of the child's parents, the mother or father. Third is the lack of supporting data for interviews, such as observation and documentation from one of the research subjects, S2. Fourth, researchers could not obtain data from doctors' diagnoses of child growth and development and therapy notes. Fifth, the perspective studied is limited to only the stages and forms of parental acceptance of the condition of children with special needs with developmental disorders.

CONCLUSION

All subjects went through stages of acceptance of children with special needs according to Ross' (2009) stages of grief theory, but not sequentially, and each subject did not go through the five stages of acceptance completely. The denial stage was only experienced by S1 and S2 in trying to ward off reality and convince themselves that the child was delicate the first time they encountered symptoms of speech delay in children (S1). They did not immediately realize that the child had learning difficulties (dysgraphia) because they assumed that children still in kindergarten were naturally not interested in learning to read and write (S2).

S2 and S3 passed the anger stage towards his wife because he thought the child had

never been accompanied by his mother to study at home (S2). This is done as a form of frustration because they do not know the correct pattern to apply to children (S3). The bargaining stage was passed by the three subjects in the form of assuming that the conditions experienced by the child were pure destiny that had to be faced and not mistakes made as parents in the past (S1). Realizing that when he was still in school, he had academic abilities that can be said to be lacking (S2), he believes that over time the child will be able to speak fluently as the child's father used to be when he was small (S3).

S1 and S3 experienced stages of depression (Depression) in the form of worry if the child could not grow and develop appropriately like their siblings, which would cause the child to be mentally disturbed and worried if the child would experience autism (S1) worried if the child's education was hampered (S3). All subjects have reached the acceptance stage in the form of being open with the child's condition and facilitating dealing with children (S1, S2, & S3). The form of acceptance of all subjects is manifested in the form of positive parenting, which includes facilitating children's needs such as speech and occupational therapy and private study according to children's needs, trying to be involved in children's activities, and giving children opportunities to socialize with other people.

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