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THE PROFILE OF SELF-ACCEPTANCE OF PARENTS OF CHILDREN WITH SPECIAL NEEDS AND DEVELOPMENTAL DISABILITIES

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ABSTRACT

The ability of parents to accept the condition of their children with special needs has a positive impact on the process of handling children. This study aims to explore the experiences of parents who have children with special needs and developmental disorders using Elisabeth Kübler-Ross' theoretical perspective regarding the stages of grief and forms of acceptance. This qualitative phenomenological research focuses on parents' self-acceptance as a phenomenon. The research subjects were selected using a purposive sampling technique, and three parents of children with special needs and developmental disorders aged 5-7 years were identified. Research data was collected using direct interviews, in-depth observations, and 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 according to the stages of grief theory, but the stages experienced by the subjects varied slightly. The rejection stage was experienced only by Subject 1 and Subject 2; the anger stage by Subject 2 and Subject 3; the bargaining stage by Subject 1, Subject 2, and Subject 3; the depression stage by Subject 1 and Subject 3; and the acceptance stage by all three subjects. The process of parental acceptance of children with special needs has a direct impact on the parenting model and the fulfillment of children's rights in everyday life. Therefore, good acceptance skills are crucial for parents of children with special needs, enabling them to feel comfortable and guide their children towards achieving self-actualization.

Keywords: Children with Special Needs Children, Parental Acceptance, Acceptance Stages

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INTRODUCTION

Every child with special needs has a condition that requires assistance from others, especially parents. Generally, parents find it challenging to accept that they have a child with special needs (Putri & Rusli, 2023; Hartanto et al., 2021). Children with special needs will henceforth be referred to as ABK. Rahayuningsih and Andriani (2011) stated that having ABK causes parents significant stress and leads to adverse reactions from mothers when raising their children. Simamora (2019) echoed this, noting that parents often have an inadequate response to the reality that does not match their expectations.

An accepting attitude involves being willing and ready to acknowledge the child's situation, realized through positive parenting (Faradina, 2016). Parental acceptance is demonstrated by a willingness to fulfill the child's rights and needs and to love the child regardless of their shortcomings (Rohner et al., 2008). A family environment that accepts ABK positively influences their psychological development (Carrasco et al., 2019). Family acceptance also directly impacts how the family meets the needs of the child's growth and development (Marlina et al., 2022). Furthermore, parental acceptance is said to impact the learning of social skills in ABK (Pancawati, 2013). Dewinda Affarhouk (2019) stated that accepting the presence of ABK can help parents manage their feelings and better control the conditions they are experiencing.

Several factors can help parents accept children with special needs, including their understanding of the obstacles to their child's growth and development and the perspective of the surrounding environment (State, 2020). The environmental perspective is crucial because it directly impacts obtaining social support for parents in caring for ABK, which can enhance subjective well-being (Ningtyas et al., 2019). Rahayu and Ahyani (2017) similarly found that family support and parents' emotional intelligence are key factors in helping parents accept their children as ABK. Providing detailed information about the child's condition can also support parental acceptance (Bayrakli & Sucuoglu, 2018). Acceptance is further demonstrated by fulfilling children's rights and needs, such as providing educational facilities, therapy, and support for developing their talents and interests.

Conversely, parental rejection leads to unmet needs and suboptimal growth and development (Normasari et al., 2021). Zulfiana (2017) noted that rejection often results in neglect and indifference toward the child, adversely affecting both the child's and the parents' psychological well-being. (Putri & Lutfianawati, 2021).

The lack of support from the surrounding environment can cause feelings of inferiority and impede parental acceptance (Munisa etal., 2022; Hannsen & Erina, 2022). Parents' perceptions, such as feelings of shame and disappointment, also influence how they raise their children (Diana et al., 2022; Islami & Ansyah, 2020). A lack of understanding of developmental disorders leads parents to place unrealistic expectations on their children and focus on their shortcomings (Bayrakli & Sucuoglu, 2018).

Parents typically go through stages to understand and accept their child's condition (Gumilang & Irnawati, 2022). Acceptance is a long and individualized process (Tarigan, 2022; O'Connor, 2019; Stroebe et al., 2017), often beginning with difficulty accepting the child's condition (Yasar, 2022).

Elisabeth Kübler-Ross's theory of grief, outlined in her 1969 book "On Death and Dying," describes five stages: denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 2014). Denial, or refusing the situation, is the first stage when a person has not accepted the reality that makes them sad (Kübler-Ross, 2014). Denial is a stage where loss or grief feels unreal, acting as a self-defense mechanism to minimize the pain of grief. The types and forms of denial vary for each person (O'Connor, 2019), manifesting as shock, emotional numbness, confusion, disorientation, forgetting sadness, avoiding triggers of sadness, or even sleeping longer than usual (Newman, 2004; Barath et al., 2023).

The second stage of grief is anger. In this stage, a person questions why something happened and expresses anger outwardly. Anger can be particularly challenging when the loss or grief is unpredictable or unknown. It often manifests as control-seeking behavior, where a person engages in aggression to avoid feelings of helplessness (American Psychological Association, 2023; Stroebe et al., 2017).

The third stage of grief is bargaining. This involves making deals with oneself or with God to alleviate emotional pain. Bargaining is a common stage of grief and often occurs alongside other difficult emotions such as denial and anger (Saracino et al., 2019; Corr, 2021). Bargaining in grief can be directed towards the present or the past.

The fourth stage of grief is depression. The duration, frequency, and intensity of depressive feelings and symptoms vary. Reactions to loss can include feeling sad, empty, or numb; feeling overwhelmed by daily life; experiencing despair; frequent crying; sadness triggered by reminders; thinking others will not understand one's feelings; withdrawing from others; and feeling tired and lacking energy (Kübler-Ross, 2014; O'Connor, 2019).

The final stage of grief is acceptance. In this stage, a person accepts the new reality that cannot be changed and figures out how it will impact their life, relationships, and future trajectory. Acceptance does not mean feeling happy about the sadness or loss; rather, it involves accepting the pain and loss experienced and beginning to look forward and plan for the future (Kübler-Ross, 2014; O'Connor, 2019; Stroebe et al., 2017).

This research aims to explore and describe the experiences of parents of children with developmental disorders and special needs. The focus is on examining the subjects' experiences using Kübler-Ross's (2014) five stages of grief theory. Although this theory was initially developed to address grief resulting from bereavement, it has been adapted here to understand the stages of acceptance experienced by parents of ABK. Previous studies have shown that each person's experience of sadness and its expression is unique (O'Connor, 2019; Stroebe et al., 2017), including the sadness over the disparity between the hope of having an average child and the reality of having a child with special needs. Additionally, this research also presents the various forms of acceptance demonstrated by the subjects.

METHODOLOGY

A qualitative approach with a phenomenological design was chosen to explore the experiences of parents regarding the stages of acceptance of their children with special needs. The selected subjects were three parents of children aged 5-7 years with developmental disorders. Two of the children had speech delays, and one had special learning difficulties (dysgraphia). Data was collected directly at the subjects' residences in Malang, East Java, over four months, from December 2022 to March 2023. The primary data sources were the three parents who participated as research subjects. Secondary data sources included observation notes and documentation in the form of photos, pictures, and screen captures of WhatsApp messages. Data collection techniques included interviews, observation, and documentation.

The interviews were semi-structured to allow subjects to provide in-depth and comfortable accounts of their experiences. The interview instrument was based on the five stages of grief theory by Elisabeth Kübler-Ross (2009). Non-participant observation was employed, meaning the researcher acted only as an observer without direct involvement in the subjects' lives, aiming for a more natural atmosphere where subjects did not feel supervised and could act naturally. Documentation involved browsing the subjects' posts on social media, including Instagram, Facebook, and WhatsApp, related to the data needed.

Data processing involved three stages: data reduction, data presentation, and conclusion (Creswell, 2012; Moustakas, 1994; Sugiyono, 2013). Data reduction was performed using manual coding, sorting, and categorizing themes from the interviews. The results of data reduction were placed into categories assigned specific codes. In presenting the data, the letter "S" refers to the subject code, and the number following "S" (e.g., S1) indicates the order of the research subjects. To ensure the validity of the data, triangulation was used by extending the research time to obtain more comprehensive and credible data.

RESULT AND DISCUSSION

The subjects in this study were parents of vulnerable children aged 6-7 years who experienced developmental disorders. The first subject (S1) is a parent of twins, one of whom has a speech delay accompanied by ADHD. The second subject (S2) is a parent of a child with learning disorders, commonly referred to as learning disabilities. The third subject (S3) also has a child with a speech delay.

1.1 Portrait of the Stages of Acceptance in Subject 1

S1 went through several stages of acceptance regarding their child's condition, who was diagnosed with a speech delay. The first signs of irregularities became apparent around the child's second birthday when the child could only say one or two words, unlike their twin brother, who could form simple words and phrases. S1's concern grew when the child did not respond to being called by age 2 years and three months.

Initially, S1 did not believe their child had special needs, Through prayer and treatment, S1 continuously reassured himself with thoughts like "my child is fine" and "later he will develop like his twin brother."

However, the persistent symptoms of slow development led S1 to start doubting his child's condition. These doubts grew stronger when he compared him to his twin brother. Additionally, S1 became increasingly worried that his child would be unable to socialize.

S1 admitted that worrying about his child's future led to feelings of despair. Even so, S1 never thought that the developmental disorders experienced by the child were the result of mistakes made by him and his spouse in the past. Instead, S1 believes that his child's condition is a destiny from God. S1 maintains that every human being must strive to improve their situation.

Belief in fate and the symptoms that appeared encouraged S1 to take anticipatory steps to ensure that his child's disorder received appropriate treatment. S1 started communicating seriously with his husband and gained his support. As S1 wrote in his Instagram post on June 23, 2016, "The greatest man in the world, father and husband who loves his wife and children, so proud of you #fatherbabytriplet #tripletbayias #workingmom #babyivfsiloamsby."

In addition to belief in destiny and support from her husband and family, S1's acceptance of her child's condition was also influenced by gratitude for having children. Unlike other couples who immediately had children, S1 gave birth to twins through an IVF program.

In general, the acceptance stage that S1 goes through regarding the child's condition begins with denial. Denial is characterized by trying to ignore reality when first encountering symptoms of speech delay in the child. The second stage is bargaining, where S1 considers the child's condition as fate that must be faced. The third stage is depression, characterized by S1's worry about the child's future development compared to the twin sibling. Additionally, S1 was very concerned about the possibility of the child's condition being part of autism symptoms. The fourth stage is acceptance, when S1 begins to accept the child's condition, bolstered by her husband's unwavering support. This support helped S1 to remain strong and willing to seek the appropriate treatment for the child's needs.

1.2. Portrait of the Stages of Acceptance on Subject 2

Subject 2 (S2) is the father of a child with learning difficulties. Since Kindergarten (TK), S2 frequently received information and input from various sources indicating that his child differed from peers in academic achievements. However, S2 did not believe this information until the end of the kindergarten period. S2 considered his child's interest in physical play and sports to be normal for a boy.

His awareness of the child's condition emerged when the child entered elementary school (SD). Through teachers, the school provided assessments indicating that S2's child tended to have learning difficulties and recommended special assistance or therapy. Initially, S2 attributed the responsibility for addressing the child's condition to his wife, citing her work commitments and lack of time to support the child. In addition to blaming his wife, S2 felt confused and unsure about how to improve his child's condition. He also felt incapable of supporting the child academically, even if he had the time, and admitted that he did not feel competent enough to assist with learning.

Despite his frustration with the child's condition, S2 considered the difficulties to be expected, as he had experienced similar challenges in elementary school. However, additional information showing that the child had significant potential in sports such as swimming and badminton eventually led S2 to acknowledge and accept his child's learning difficulties in academics. This realization prompted S2 to prioritize and support his child's potential in sports and cease comparing the child's academic development with that of peers.

In general, S2 experiences four stages in accepting his child's condition. Initially, S2 refused to believe the information regarding his child's condition. This denial persisted until the child entered elementary school, where assessments revealed learning difficulties. At this point, S2 expressed his anger towards his wife, marking the second stage, anger. S2's anger then led to the third stage, bargaining, during which he compared his child's condition to his own experiences as a child, considering the difficulties to be normal and similar.

The realization that his child had significant potential in sports prompted a new awareness in S2, leading him to fully accept his child's condition. This final stage, acceptance, helped S2 recognize both his child's shortcomings and strengths. It guided S2 and his wife to focus on developing the child's talents and cease comparing him with his peers.

1.3. Portrait of the Stages of Acceptance on Subject 3

When his child was three years old, S3 began to acknowledge the issues he had previously suspected. His child could not babble or speak like children of the same age; when attempting to speak, the child could only produce the beginning or end of words. S3 continued to communicate with his husband and closest family members.

With their support, S3 decided to have the child examined by a pediatric growth and development doctor, drawing on his brother's experience with a similar condition. The doctor's examination confirmed that the child had a speech delay disorder. S3 and his husband experienced mixed feelings; they felt relieved to have a diagnosis but were also worried about the child's development and future. S3 felt confused and struggled to communicate effectively with the child, especially when implementing the recommended treatments. S3 also considered that the child might need to attend a special education school (SLB).

Concurrently, S3 decided to resign from his job and start a home business to focus on caring for his child. He arranged for a therapist to visit the house periodically and sought additional medical treatment.

S3 experienced feelings of guilt, believing that the child's condition was a form of retribution for past mistakes made by him and his wife. He also thought the issue might be hereditary, as his husband had also been perceived as a late speaker in childhood. However, these feelings gradually changed as S3 gained a better understanding through consultations with doctors and information from the internet.

Support from family in the form of motivation and information eventually led S3 to accept his child's condition and continue working to improve it. S3 views the child's condition as a fate that must be faced. Information about inclusive schools helped S3 feel more at ease. Subsequently, S3 set aside worries about the child's future and focused on speech therapy.

Initially, S3 ignored the child's speech development issues, which represents the denial stage. As symptoms became more apparent at age three, S3 entered the anger stage, often expressing frustration over how to address the condition. Anger emerged as a reaction to the challenges faced. Information about his husband's similar childhood experience led S3 to the bargaining stage, where he perceived the condition as hereditary.

S3 also felt that the condition was a response to past mistakes, representing the depression stage. Ultimately, S3 reached the acceptance stage. This shift was facilitated by the doctor's diagnosis, along with support from family and other sources. S3 demonstrated acceptance by actively seeking therapy to address the child's disorders. The following table explains the stages and forms of acceptance of research subjects towards their ABK children.

Table 1.

Stages and forms of subject acceptance with ABK children

Stage	Subject 1	Subject 2	Subject 3
Denial	Call it normal or ordinary	Doesn't trust other people's information about their child	Ignore visible symptoms
	Think it's fine	Seeing his son is normal, because men like to play physically	Ignoring information from others
	Ignoring symptoms		Assuming the child will develop over time
Anger	X	Angry with wife	Angry with the condition and results of his child's assessment
	X	Blame yourself for being too busy	Annoyed by people's input regarding the care of ABK children
Begaining	Believe conditions as fate, and have nothing to do with the accumulation of previous mistakes	Assuming his child's condition is the same as his condition when he was small	Believe that conditions are destiny, and every destiny is given to the person who is able to overcome it
Depression	Doubtful about the child's future	X	Difficulty communicating with children
	Feeling hopeless	X	Feeling there is no way out

Acceptance	Starting from children aged 2 years 3 months	Starting with children aged 7 years	Starting with children aged 3 years
	Get support from your husband	Get school assessment results	Quit office work and become self-employed at home
	Take the child to the doctor	Realizing children's talents in sports	Consult a doctor
	Carrying out systematic treatment	Facilitate talent	Seek information from other sources
		Don't compare children with peers	Undertake professional therapy

DISCUSSION

The three research subjects experienced the acceptance stages as outlined by Kübler-Ross’s (2014) theory of grief: denial, anger, bargaining, depression, and acceptance. However, their experiences varied slightly.

All three subjects went through the denial stage. For Subject 1 (S1), denial manifested as a belief that the child was fine despite developmental delays. Subject 2 (S2) initially viewed the child’s academic struggles as normal and not indicative of a developmental disorder. Subject 3 (S3) ignored developmental concerns until symptoms became strikingly evident. This finding aligns with previous research (Suheri, 2014; Tarigan, 2022; Putri & Rusli, 2023), which notes that parents often deny developmental issues, convincing themselves that the child’s condition is acceptable. In contrast to Kübler-Ross’s (2014) description, where denial typically occurs after a formal diagnosis, this study found that denial occurred when the parents first noticed symptoms of developmental disorders, before receiving a medical diagnosis. This observation supports O’Connor’s (2019) finding that individuals’ expressions and sequences of grief can vary.

were related to his own experiences in school and anticipated that the child would improve over time, as S2 had. This is supported by the idea that the bargaining stage often involves parents attempting to find solace and focus on efforts to address their child’s condition as a way to mitigate their sadness (Purwaningrum et al., 2018; Putri & Rusli, 2023). Purwaningrum et al. (2018)

The next stage, anger, was experienced by two of the subjects. Subject 2 (S2) expressed anger by blaming his wife for not being more involved in the child’s education. Subject 3 (S3) felt frustrated, blaming himself for not knowing how to communicate with the child and other people for offering ineffective solutions. These findings complement previous research indicating that parents often display anger when faced with the challenges of raising children with special needs. Rahmadayanti et al. (2020) found that parental anger can stem from confusion about how to handle and care for the child. Similarly, Yasar (2022) highlighted that parents often struggle due to a lack of understanding and support from their surroundings. Swandi et al. (2022) also noted that some parents of children with special needs exhibit quick temper and difficulty managing emotions.

Apart from denial and anger, the subjects also experienced a bargaining stage. Both S1 and S3 attempted to reconcile with the condition by attributing it to fate rather than their own shortcomings as parents. In contrast, S2 believed that the child’s academic difficulties, particularly with writing, noted that mothers' initial denial of their child's condition is often driven by concerns about the child's future and a lack of knowledge about the condition.

Before reaching acceptance, the subjects went through a stage of depression. This stage involved significant anxiety and concern about their child’s future, particularly in terms of education (S1) and fears that the child might not be accepted into regular schools (S3). Cristiani et al. (2021) observed that depression in parents often arises from worries about a child's ability to grow, develop, and meet their needs, leading to fears about the child’s dependence on others and their survival without adequate care. Ghaisani Hendriani (2022) highlighted that a lack of support and information from those around them can contribute to parental depression, as parents feel unsupported in managing their child's needs. Additionally, Vikawati et al. (2018) noted that limited ability to manage the child's condition also contributes to feelings of depression.

The acceptance stage reveals that all three subjects have come to terms with their child's condition, demonstrating positive parenting practices. This is reflected in their proactive approaches: S1 and S3 actively engage in learning about and facilitating their child's therapy, while S2 adjusts expectations and provides additional support through private tutors for writing practice outside school hours. As noted by Sesa and Yarni (2022), acceptance of the child's condition is often accompanied by a positive perspective,

focusing on providing effective treatment and support. The subjects' positive acceptance is evidenced by their openness to learning about their child’s condition and how to address it. This includes seeking information from various sources, such as consultations with child development doctors, social media parenting accounts (S1), discussions with teachers, and detailed inquiries about their child's condition (S2). They are also open to receiving input and guidance from more knowledgeable individuals (S3). Research by Boham et al. (2018) suggests that the open attitude of parents with children with special needs stems from their awareness of their role as facilitators, their recognition that children are a gift, and their belief that a child’s condition can improve with full parental support throughout the growth and development process. Parental acceptance of developmental disorders fosters a collaborative approach with other experts to tailor treatment to the child's needs (Zeylurt, 2020).

The subjects' acceptance of their child's condition is demonstrated through efforts to meet the child's rights and needs. This includes facilitating therapy (S1 & S3), supporting education through formal schooling and private tutoring (S1, S2 & S3), and allowing social interactions with others (S1, S2 & S3), as well as nurturing the child's interests and talents (S1, S2 & S3). According to Dolu et al. (2014), such efforts align with the rights of children with special needs, which include protection from harm, non-discrimination, and meeting their educational needs in a manner similar to children without special needs (Husna, 2019).

The subjects' involvement in their children's activities further reflects their acceptance. This includes preparing learning materials for school, assisting with reciting the Koran or private lessons (S1 & S3), participating in play activities (S1), and engaging in school events (S1 & S3), as noted by Margijanto & Pandia (2022). Parental involvement in activities such as homework assistance, storytelling, playing, and attending school events can positively influence efforts to provide appropriate interventions for the child (Ashari, 2021). Understanding and respecting the child's uniqueness is another aspect of positive parental acceptance. Despite challenges in speaking and academics, parents recognize their child’s strengths in physical activities (S1 & S2) or creativity with Lego (S3), as highlighted in Riati's (2018) research. Recognizing these strengths is crucial for providing supportive and individualized care.

The research indicates that parents go through different stages in accepting their child's condition. For guidance and counseling services, Acceptance and Commitment Therapy (Barida & Widyastuti, 2019) could be a useful technique.

This study has several limitations: First, the subjects were limited to parents of children with special needs and developmental disorders, with two having children with speech delays and one with learning difficulties; Second Interviews were conducted with only one parent per child, either the mother or father. Third, there was a lack of supporting interview data such as observations and documentation from one research subject, S2. Fourth, data from doctors' diagnoses and therapy notes were not obtained. Fifth, the study's perspective is limited to the stages and forms of parental acceptance of children with developmental disorders.

CONCLUSION

All subjects experienced the stages of acceptance of children with special needs according to Kübler-Ross's stages of grief theory (2014), though not sequentially, and none of the subjects went through all five stages completely. The rejection stage was experienced by S1 and S2. S1 initially tried to dismiss the reality of the situation, convincing himself that the child was just developing slowly. S2, on the other hand, did not immediately recognize that his child had learning difficulties (dysgraphia) and believed that children in kindergarten naturally have limited interest in learning to read and write.

S2 and S3 went through the anger stage, expressing frustration towards their wives. S2 was upset because he believed his child’s mother was not supporting the child’s education at home. S2 needed clarification about encouraging children to communicate and, consequently, blamed several people who suggested always inviting children to talk. This was a manifestation of frustration due to their lack of knowledge about the correct approach to apply to children (S3). The three subjects went through the bargaining stage by assuming that the child's condition was pure fate to be faced, rather than a mistake they had made as parents in the past (S1). Realizing that his own academic abilities while at school might have been inadequate (S2), he believes that over time, the child will be able to speak as fluently as the child's father did when he was little (S3).

S1 and S3 experienced the depression stage through worries about whether the child would grow and develop well like his siblings, fearing that this could lead to mental disturbance and concerns about autism (S1) or hinder the child's education (S3). All subjects have reached the acceptance stage by being open to the child's condition and facilitating appropriate handling of the child (S1, S2, & S3). The acceptance of all subjects is realized through positive parenting, which includes addressing the child's needs with speech and occupational therapy, private study tailored to the child's requirements, involvement in the child's activities, and providing opportunities for socialization with others.

S2 and S3 initially experienced anger towards their wives because they believed the child was not receiving adequate study support from their mother at home (S2). This anger stemmed from frustration due to their lack of knowledge about the correct approach to take with the child (S3). The three subjects navigated the bargaining stage by viewing the child's condition as pure destiny to be faced rather than mistakes made as parents in the past (S1). Realizing that his own academic abilities while in school might have been lacking (S2), he believes that over time the child will develop the fluency in speech that the child's father had when he was young (S3).

S1 and S3 went through the depression stage, worrying about whether the child would grow and develop appropriately like their siblings, fearing mental disturbance and concerns about autism (S1), and worrying about potential hindrances to the child's education (S3). Ultimately, all subjects have reached the acceptance stage by being open to the child's condition and facilitating appropriate handling of the child (S1, S2, & S3). The acceptance of all subjects is manifested through positive parenting, which includes addressing children's needs with speech and occupational therapy, providing private study tailored to their requirements, being involved in their activities, and offering opportunities for socialization with others..

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