

Total Blind Resilience of Parents Who Have Total Blind Children with Blindness

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Abstract

Being a parent of a blind child requires various abilities, one of which is resilience. Resilience is a universal capacity that enables individuals, groups, or communities to prevent, minimize, or resist damaging influences when faced with disaster or adversity. According to Grotberg (1995), resilience is the human ability to face, overcome and become strong when facing obstacles and obstacles. This research aims to describe the factors that support the resilience of parents of totally blind children at the National School for the Blind. This research uses qualitative methods with case studies. Data collection techniques involve interviews, observation, and secondary data. The subject of this research was a parent who had a totally blind child.

Keywords: *Resilience, Parents, visually impaired totally blind.*

Introduction

In the child's growth and development process, parents play a very important role, apart from that, the most important thing is the child's growth and development process. Positive support from the family has a positive impact on children's optimal growth and development, but of course every family definitely has conflicts, dynamics and other problems. As a parent who has a role that is certainly not easy, when a new family member is born it certainly raises new challenges related to several adjustments that must be made, especially when the child born has special needs such as being blind. For parents who find that their offspring is born with a child with special needs, such as a blind person, the dynamics that occur can become complex and more severe. At least the family routine is different and not as usual, the family has to spend a lot of time caring for a blind child. Having a blind child affects the mother, father and all family members in varying ways.

The eyes are a very important sense of sight in our lives, when the eyes do not function optimally it can hinder social interaction and carrying out daily activities. For example, consider an educational activity that relies largely on visual perception. Recognizing colors, paying attention to facial expressions of teachers and friends, reading and writing are visual activities. Children who have visual impairments, who cannot even be intervened with aids

such as glasses, have greater difficulties than children without impairments. Therefore, they need great help from others. However, people with vision or other sensory problems need help using their remaining vision and other senses to express who they are.

According to Mangunsong (2009), blindness is where a person experiences problems with their vision, so they cannot see clearly or cannot see at all. Very limited vision, such as not being able to distinguish colors, only being able to see the edges, blind people can be classified into two main types based on the level of vision loss, firstly Total Blind or also called blind in this condition, where a person loses the ability to see completely. They can't see anything; they can't even differentiate between dark and light. Although they may still be able to use other senses, such as hearing or touch, to help navigate and interact with their environment. Meanwhile, low vision means lack of attention, where this type of blind person has weak vision. A person is said to have low vision if they can still see a little or can differentiate between dark and light, but their ability is limited and inadequate to carry out daily activities without additional assistance, such as special glasses or other assistive devices. According to Hallahan, Kauffman, and Pullen (2009), blind people can be divided into two categories, namely total blindness and low vision. A person is considered to be totally blind (legally blind) if their vision is less than 20/200, even though they are using vision aids such as glasses, or if they have a very narrow field of view, namely no more than 20 degrees. On the other hand, a person is said to have low vision if his visual acuity ranges from 20/70 to 20/200, even though he uses glasses. Generally, people with low vision use books with large writing and magnification tools such as magnifying glasses or telescopes (Hallahan & Kauffman, in Mangunsong, 2014).

In general, motor problems, overprotective parental attitudes, interacting with peers and children with normal vision can make it difficult for blind children to adapt, making them helpless and dependent on others. Therefore, the attitudes of parents, peers and teachers are very important in shaping the self-image of blind children. Social contact with peers requires great effort, because nonverbal communication does not function effectively. Some research suggests that difficulties in social interactions are often caused by society's inappropriate response to individuals with visual impairments. This happens because individuals with visual impairments have different facial expressions from people without visual impairments, for example, they tend to have difficulty hiding their true feelings, especially negative feelings (Galati, Sini, Schmidt, & Tinti, in Kauffman & Hallahan, in Mangunsong, 2006).

Scientifically, there are several factors that cause children to become blind, both internal and external. Internal factors include conditions related to the baby's condition while in the womb, such as genetic factors (congenital characteristics), the mother's psychological condition, malnutrition, and drug poisoning. Mangunsong emphasized that various factors influence blind children, including external factors such as family support, social environment, educational services, government policies, and community awareness and attitudes.

According to Hallahan and Kauffman (in Mangunsong, 2014), blindness can have various negative impacts on people with it, including obstacles in cognitive development and conceptual abilities, motor development and mobility, and social development.

Obstacles in cognitive development and conceptual abilities can interfere with a child's learning process, such as obstacles in motor development and mobility can affect body coordination abilities, orientation towards objects and landmarks, and the ability to move in the surrounding environment. Obstacles in social development can have a negative impact on the ability to adapt and skills in establishing relationships with other people (Mangunsong, 2014).

Another impact felt by parents is disruption in daily activities, such as needing to move home to a more supportive environment or closer to a therapist, delayed household tasks, and disruption in their work. Research also shows that parents of children with disabilities often have difficulty maintaining a balance between work and child care, which can result in reducing work hours, changing jobs, or even stopping work entirely.

Resilience is an important component throughout human life, because individuals need to develop the ability to cope with stress and changes that come quickly and intensely. The ability to survive for a long time is becoming increasingly important to maintain optimal survival. People with a high level of resilience can face problems quickly and are not affected by their circumstances or environment. This is especially important for children who have to deal with physical conditions that require them to develop their own abilities. What is more important is the optimal development of their confidence, self-esteem and self-confidence.

According to Grotberg (1995), resilience is a universal capacity that allows individuals, groups and communities to prevent, minimize or resist damaging influences when they experience disaster or misfortune. Resilience is also defined as the human ability to face, overcome and become strong when facing obstacles and challenges. Everyone has the potential to become resilient and is able to learn how to overcome obstacles and challenges in life, so that they can develop to become more resilient (Grotberg, 2003). According to Grotberg (1995), achieving resilience requires an understanding of the factors to be able to identify the resilience characteristics of various cultures and different social groups. The factors include I Am (I am), I Have (I have), and I Can (I am this).

The social support factor (I Have) is: (a). having someone to look up to, (b), being able to have the drive to be independent. (c). health, education and security and welfare services, (e). trustworthy person. while the self-strength factor (I Am) has several dimensions, namely: (a). feelings of love and an attitude of belief in oneself, (b). have a sense of pride in oneself (c). be independent and responsible, (d). be able to measure one's own emotions. The social ability factor (I Can) is: (a). good communication, (b). ability to solve problems, (c). find someone you can trust.

According to Luthar and Kalil (2003), family resilience is influenced by two main factors, namely risk factors and protective factors. Risk factors are variables that can trigger problem behavior, while protective factors are "buffer" variables that interact with risk factors to change or offset the relationship between risk and possible outcomes. According to Walsh (2006), the process of forming family resilience is influenced by belief systems, family organizational patterns, and communication processes. Each of these components has subcomponents that can help families become more resilient.

According to Walsh (2012), one of the sub-components of family resilience is understanding crisis situations. The way families view the problems and crisis periods they face as shared challenges is important in building family resilience. The addition of new family members brings dynamics that require adjustment. For parents who find out that their child was born with special needs, such as visual impairment, the situation can become more complex and difficult. A family's daily life changes, and they may need to spend more time caring for a blind child. The presence of a blind child affects mothers, fathers, and the entire family in different ways, with varying emotional ranges and dynamics (Hardman et al., 2002). Parents are able to deal with their own psychological dynamics as well as various external demands. Dealing with society's reaction is also a challenge for parents of blind children. When a family faces an unexpected situation, it becomes a significant stressor, and the family must go through certain processes to survive and adapt. McCubbin et al. (2001 in Puspita et al., 2011) stated that the adaptation period is one of the central concepts in family resilience.

Based on the above phenomenon, this research aims to obtain an overview of the factors that support the fulfillment of resilience in parents who have totally blind children in Special School Part A National Level, South Tangerang.

Method

The research method used in this research is a qualitative research method. This research uses a qualitative approach with case studies. Case studies are empirical investigations that examine contemporary phenomena in real-life contexts (Yin, 1981a, 2009).

This research provides an overview and explanation of the conditions or symptoms encountered. According to Sugiyono (2020:9), qualitative research methods are used to examine the condition of natural objects, with the researcher as the main instrument. Data collection was carried out to ensure the credibility of the data through source triangulation.

Data analysis uses thematic. Data collection techniques use interviews, observation and documents. The number of subjects was 3 people with the characteristics of 1 parent who had a completely blind child, 1 blind child and 1 National Level Blind SLB teacher. Data will be collected through interviews, observations and documents. Interviews are used to gain in-depth understanding from the participant's perspective. This qualitative approach is used to collect relevant data, observations are carried out to understand the behavior and experiences of subjects directly and documents for documentation

Procedure

In this qualitative research, ethical approval was obtained from Paramadina University before collecting data, and a research permit was given by Paramadina University and then handed over to the school. After that, informed consent was obtained from the school and parents who were willing to participate voluntarily in this research.

Data analysis

This research uses a qualitative research method with a case study approach which aims to explore more deeply the resilience factors of parents who have totally blind children.

Data collection techniques include interviews, observations and documents. Researchers took subjects from one of the National Special Schools for the Blind. The number of subjects in this study was 3 people, namely 1 mother with a completely blind child, 1 blind child, and 1 teacher at a National Level SLB for the Blind.

Data collection was carried out from May to June 2024. The data collection technique was carried out through one-on-one interviews, namely direct face-to-face interviews with the subjects for 40 to 60 minutes. In the data analysis step, the results of the interviews were transcribed verbatim and analyzed using the content analysis method which consists of five stages according to Yin (2011): compilation, compilation, rearrangement, interpretation of reformulation, and drawing conclusions.

Table 1. General Description of Research Subjects

	Subject 1	Subject 2	Subject 3
Name	SA	SN	AG
Age	58 Years	15 Years	50 Years
Status	Mother Who Has a Totally Blind Child	Totally Blind Children	National Level Special School Teacher for the Blind

Result and Discussion

This study aims to describe the resilience of parents who have totally blind children at the National School for the Blind and to identify the factors that influence their resilience. The subjects in this study consisted of 3 people: a mother who has a totally blind child, the blind child, and a teacher from the National Level SLB for the Blind. The research was conducted at the school for two different durations during two meetings.

Based on the results of interviews, observations and documents obtained, the subject described the significance of the three aspects of resilience.

General Description

SA is a parent who has a completely blind child named SN. SN was diagnosed as blind since he was 2 years old. SN experienced convulsions for a long time so he was rushed to the hospital, after which SN was in critical condition for 7 days without being conscious in the ICU. After realizing that SN was critical, he suddenly asked his mother, "Where are my eyes?" After hearing that, Mrs. SA was very shocked, the doctor said that SN's eyes could not see due to permanent nerve damage in her eyes so she was diagnosed as totally blind. SA's mother felt very sad when she saw that her son could no longer see, making SA's mother feel her ups and downs in caring for her child. She also has to care for her children as a single parent, as well as pay for her children's needs. The things he did himself made him feel difficult, one of which was finding a special school for the blind for his child.

1. Social Support Factor (I Have)

In the "I Have" factor, one of the components that forms resilience is social support that comes from outside the individual. This includes having people you can trust and having role models as inspiration in achieving your hopes and goals in life.

In interviews conducted with subjects, it was found that social support factors (I have) include:

a. Family and friend's support

"My family has definitely been very supportive of me, giving me strength by giving advice, I also think that I can get through all of this, even though at first it wasn't easy, but over time I became more willing to accept all of this, where my friends or mothers at school and at home saying "Mamah SN is really strong, I don't think I could be if I were Mamah SN as strong and strong as that" was one of the words that made me even more enthusiastic about getting through all of this. I felt like oh yes yes I am strong up to this point, and there are still bitches that I need to raise and give special attention to." (SA, interview 2, 03 June 2024. 9)

"Since I separated from my husband, I took care of SN with my second child named UL, because at that time UL was not married so I helped take care of SN, after UL married I was also supported by UL, starting from SN's pocket money and daily meals. , I also sometimes entrust SN to my sister, my friend, if I have a need or go away for a while, my friend, SN, is a very patient and painstaking person. SN is also very close to him and talks more with his friends." (SA, interview 1, 08 May 2024. 18)

"I am very close to my older brother, because I always ask UL for anything, such as school needs and my pocket money. because since I moved to this school, my mother no longer sells, so I am supported by my sister. But when my sister got married and separated from home, usually I was with my sister, if my mother needed something outside or visited UL in Bandung. (SN, interview 1, 03 June 2024, 18)

The subject felt the support of family and friends as a source of enthusiasm in caring for SN. Apart from that, family support helps him pay for SN's school fees, helps with daily needs so that SA's mother can focus on caring for SN and also helps look after SN when SA's mother is not at home.

b. Support from parents of fellow blind people

"Usually, I often share with parents at school about the development of SN, or their children too. I also like to ask about education and activities that can be developed later for SN. Sometimes what makes me strong and enthusiastic are the mothers at this school, because some of their children's conditions are much worse than mine, it touches my heart. They are very enthusiastic to get to this point, there are many things that make me more sincere in going through all this." (SA, Interview 1, 08 May 2024, 5)

The support of parents who also have blind children helps them become a motivational inspiration in caring for blind children, become a source of information for educating blind children, and share experiences in caring for blind children.

c. School Support

"This SLB school likes to hold motivational seminars for parents who have children who have the same condition as SN so that we can share or be given good guidance on how to and what questions to ask. I think this seminar is very important to increase knowledge of how we as parents should remain enthusiastic in helping our children in academic areas as well as their interests and talents. (SA, Interview 2, 03 June 2024, 31).

"The school also really supports SN apart from academics, such as involving SN in competitions and helping to increase his interest and talent. It is very clear that SN really likes playing chess, so the school helps develop his talent by having SN take chess training. Yes, initially we also looked for a place for coaching because the school Also collaborating with the sports department so we have a link. gave competition information to SN, thank God it wasn't in vain that I always won and got a bronze medal. (AG, interview 1, 03 June 2024, 7)

"The school helped develop my talents by providing information on chess training. So, it made me even more enthusiastic to continue learning chess to become an athlete, thank God at that time I won 3 bronze medals. (SN, Interview 1, 03 June 2024, 132)

"Because I don't really know braille, SN is fully supported by the school and taught by the class teacher. "Thank God, SN's teacher said he was very dexterous so it didn't take much time for SN to learn braille, it seems like in just 1 month SN was already fluent in using the braille method." (SA, Interview 2, 03 June 2024, 124)

The school is very helpful in providing support for Mrs. SA to become resilient by teaching braille, as well as developing interests and talents in SN.

d. Expert support

"However, one of the doctors told me that currently my focus should not only be on SN's eyes but also focus on his IQ, which also plays a very important role in SN's future growth and development." (SA, interview 1, 08 May 2024, 7)

Expert support provides advice and encouragement so that Mrs. SA does not focus only on weaknesses but also looks for SN's strengths.

2. Personal Strength Factor (I Am)

The strength of "I Am" is built from feelings of attitude and belief, being able to rise from adversity. Independent and also responsible for what is done.

When conducting interviews with subjects, it was found that the self-strength factor (I am) consisted of:

a. Try to keep getting up in stressful situations

"When SN was diagnosed as totally blind, it was not an easy thing for me, I was really sad, I didn't want to eat until I was thin, because my only thought was SN. Here and there I looked for treatment from an eye doctor and alternatives to heal his eyes, but the doctor said it was difficult because SN's eye nerves were permanently damaged, plus SN also suffers from epilepsy to this day where SN likes to have seizures. However, one of the doctors told me that currently my focus

should not only be on his eyes but also on his IQ, which also plays a very important role in SN's future growth and development. From there I started to learn to be sincere that there are still many things I have to think about in the future. I feel that my role is very important for my children, I also do not differentiate between the conditions of my children seeing that SN has shortcomings such as not being able to see which requires me to play a bigger role as SN's parent, fulfilling his needs for love, and a good environment. SN will face it later. So when SN was diagnosed, my role as a mother was very, very important until SN grew up. I always tell stories to my children and my older sister, because their input makes me stronger and more enthusiastic even though the process is not easy" (SA, Interview 1, 08 May 2024, 1)

"I'm starting to recover and have started to accept that SN's eyes can no longer see, but I'm back down again. When SN was 5 years old I separated from SN's father, SN's father remarried which made me have a big fight with him, there I was down again and I also became annoyed when I saw SN because I remembered his father. SN became quiet and rarely interacted, I was stressed and depressed because I thought being a single parent wasn't easy, starting from paying for my children and taking care of SN. I also often entrust SN to his child, but over time I think that SN doesn't know anything if I continue to feel annoyed when I see him, and I feel sorry for him, no matter what, he's my child, and SN has gone through a lot of processes like he was in a coma for 7 when he was still small and also has a congenital disease to this day, namely Epilepsy, where up to now SN still likes to have seizures, but in the past 1 year he no longer has seizures. But he is still outpatient as if he were still taking medication regularly. I also think that I should be able to focus more on taking care of SN after separating because there is no longer anyone who hurts my feelings and heart. I also tell more stories with myself, as well as with my children, so that I am much more relieved of the disappointment or feelings of stress that I face. (SA, Interview 2, 03 June 2024, 43)

"I was also very happy to see SN's chess competition win and to this day I never give up to always make SN develop in his talent interests." (SA, Interview 1, 08 May 2024, 23)

When she is in a stressful situation, Ms. SA never gives up, she always gets up and thinks positively, even though the process she is going through is not easy. Apart from that, he also likes to tell stories to his children and his older brother, making him sometimes more enthusiastic and stronger to face these situations and be able to get through conditions that he feels are making him depressed.

b. Have self-confidence

"When I wasn't separated from my husband, I was also selling and earning my own money, so when my husband remarried, I was used to it and I was sure I could get through all this. When SN was diagnosed until now, I was still strong and enthusiastic, but I just gave up. (SA, Interview 2, 03 June 2024, 70)

"I am also very confident that I will be able to raise SN even though being a single parent is not an obstacle for me to give up, seeing SN's condition, who is always enthusiastic, makes me convinced that I must remain enthusiastic in living my life. I believe that Allah will always help me." (SA, Interview 2, 03 June 2024, 17)

SA's mother always feels confident in herself and is able to prove it by looking at what she has done for SN to date.

c. Have independence and responsibility to solve problems

"Since I separated, I have been making money by selling in the school canteen near my house and also between school SNs." (SA, Interview 2, 03 June 2024, 76)

"Even though I am a single parent, I am still enthusiastic about being by SN's side to see SN's growth and development, that doesn't make me give up even if I do something myself, such as taking SN to school, SN's chess training and taking SN to the hospital to check on SN's disease conditions such as epilepsy" (SA, Interview 2, May 8, 2024, 81)

"Mommy is very responsible, good, seeing mommy alone without her father, it feels like mommy is a very independent person. Until now, he has always been enthusiastic and never given up on taking care of me." (SN, Interview 2, 03 June 2024, 5)

Even though being a single parent is not an obstacle for Mrs. SA, she is able to do things herself, one of which is earning money, and being able to solve problems and getting through them.

d. Being able to measure your own emotions to be able to rise again

"When I felt like giving up and was upset about my situation, I tried to tell my children or older siblings and they gave me input which I thought was true too. Yes, I have been given strength so far, which means I am already very great. Or don't I usually listen to SN playing the keyboard and make me laugh, or do I sometimes sing at home? Or sometimes I take them to Bandung with my second child." (SA, Interview 2, 03 June 2024, 28)

"When mom is angry or not happy, usually she likes to just keep quiet, she likes doing karaoke at home, if she looks bored then she's happy again. don't let it drag on. (SN, Interview 2, June 03, 2024, 8)

The subject was able to measure his emotions when facing a situation that made him give up, by telling stories to his brother and children to make him feel calmer, besides that, listening to Sigit playing the keyboard at home made him more enthusiastic and laughed.

e. Able to focus on solutions in stressful situations

"I also think that I should be able to focus more on taking care of SN after separating because there is no one else who hurts my feelings and heart. I also talk more with my sister and my children so that I am much more relieved of the disappointment or stress I face." (SA, Interview 1, 08 May 2024, 74)

When conditions are stressful, SA's mother is able to focus on stressful situations. Positive thinking can make her focus again on situations that she feels are more important, for example focusing more on caring for SN.

3. Social Ability Factor (I Can)

The social ability factor is built by solving problems and being able to interact with other people.

Regarding the social ability factor (I can), when interviewing the subject, these factors include:

a. Able to look for alternative solutions

"Here and there I looked for treatment from an eye doctor and alternatives to heal SN's eyes, but the doctor said it was difficult because SN's eye nerves were

permanently damaged, plus SN also suffers from epilepsy to this day and still has seizures (SA, Interview 1, May 8, 2024, 3)

AM subjects have the ability to look for alternative solutions such as looking for an expert doctor for SN.

b. Establish good communication

"I always ask the teacher about SN's progress, starting from academic and non-academic, so that I know what is lacking in learning and what talents and interests need to be developed." (SA, Interview 2, 03 June 2024, 109)

"There I was confused about where the SLB for the blind was so I asked my second child UL to help me find an SLB school on Google and social media. Then we met at this SLB for the blind, yes, even though the journey takes 2 hours, it doesn't matter, the important thing is that SN is willing and enthusiastic about going to school again" (SA, Interview 2, 03 June 2024, 132),

"I always share with mothers at school or with my child UL, because I just want to know, sometimes what needs to be evaluated, whether my methods are sufficient to accompany SN's growth and development, or if there is input from the people closest to me. (SA, Interview 2, 03 June 2024, 5)

"SN's mother very often asks about SN's progress in class, such as his learning, as well as existing training such as chess training. (AG, Interview 1, 03 June 2024, 1)

The communication built by Mrs. SA looks very good, starting with teachers, children and parents at the school, in order to get information on SN's development as well as regarding education and other information.

According to Grotberg (2000), resilience is a person's ability to assess, overcome and improve themselves or change themselves from adversity or adversity in life. Everyone experiences difficulties or problems, and no one lives in this world without facing challenges or difficulties. In overcoming unpleasant conditions and developing resilience, it is very important to empower these three factors within the individual. The "I Have" factor includes relationships that are based on complete trust and a drive for independence. The "I Am" factor includes feelings of being loved and liked by many people, a sense of pride in oneself, and the ability to love, empathize and care for others. The "I Can" factor includes the ability to communicate, solve problems, and establish trusting relationships. These three factors influence the length of a person's resilience process, because if only one factor is met, a person cannot be said to be resilient without having these three factors.

Apart from that, in the resilience process there are two very important things: first, life difficulties which can cause dysfunction but can also produce achievements for the individual who experiences them; second, reactions to life difficulties that are initially dysfunctional but can improve over time due to the individual's adjustment to the problem. In other words, resilience is an adaptation process that begins with stress and leads to personal change towards better conditions (Grotberg, 2000). This can be seen from the respondents, namely mothers who have completely blind children, where they have all three resilience factors and are able to bounce back from the adversity they experience.

Judging from the social support factor (I Have), Mrs. SA has support from family members, namely her children and older siblings, support from fellow parents with blind children and school support.

In the self-strength factor (I Am), Mrs. SA has the ability to continue to rise in stressful situations. She is able to convince herself that she is a strong person in facing these situations. He also has independence and responsibility to solve the problems he faces. Even though she is a single parent, she is able to earn her own money, as well as care for and raise her child. Apart from that, Mrs. SA has people who love and care about her, both family members and people in her social environment.

Regarding the social ability factor (I can) possessed by individuals, Mrs. SA succeeded in developing resilience in this factor, namely being able to look for alternatives and doctors and having good relationships and communication with the social environment.

Conclusion

In this study, the researcher concluded that the respondents were classified as resilient individuals where the most indicators of resilience were in the I am aspect. Apart from that, what helped the subject to have resilience was social support consisting of support from family and friends, which was felt by the subject as a source of enthusiasm in caring for SN. Apart from the resilience possessed by the subject, it is strengthened by the social abilities possessed by the subject in the form of being able to find alternative solutions such as doctors and having good communication relationships with the social environment. So, you can get information about SN education and development.

This review shows that although the three main factors have been identified, other dimensions still support this study. This research focuses on the dimensions of Grotberg's resilience theory because it is considered more relevant than other theories. Researchers chose Grotberg's resilience theory because the resilience factors in it are interrelated with the context studied.

Suggestions for further researchers are: 1) Exploring every form of resilience given by parents to totally blind children; 2) Increasing the number of samples so that the data obtained is more numerous and diverse, with more samples will help produce more generalizable findings. In addition, make comparisons with other parents who have totally blind children to understand whether there are significant differences in these resilience factors; 3) Conduct case studies with several parents to get a more detailed picture of the dynamics of resilience in individual contexts; and 4) Providing special interventions or support to increase parental resilience such as coping skills training, counseling services and others.

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