

The Experience of Mothers Caring for Children with Disabilities at the *Persatuan Rakyat Indonesia* Special School in Pekalongan, Central Java: A Phenomenological Study

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ABSTRACT

Background: Disabilities are often called physical, mental and sensory disabilities or disorders that limit a person's ability to carry out daily activities. Parenting a child with a disability is not easy because the child cannot perform any activities independently and the child's behavior is not controlled. This results in a negative impact on the mother psychologically, physically and can disrupt family dynamics such as domestic violence and quarrels. This study aimed to explore the experiences of mothers caring for children with disabilities.

Subjects and Method: This was a qualitative study with a phenomenological approach, conducted at the *Persatuan Rakyat Indonesia* Special School (SLB) in Pekalongan, Central Java. The study subjects were selected purposively as many as four participants, namely housewives without caregivers who have children with physical disabilities, deaf-speech, and mentally retarded children. Data were collected using in-depth interview technique. The tools used in this research are camera, recording device and interview guide. Data analysis using Colaizz's method.

Results: This qualitative research resulted in seventeen themes that show the experience of mothers in caring for children with disabilities, namely destiny, mother's burden, mother's initial psychological response, emotional changes, behavioral changes, limited funds, obstacles in daily life, social stigma, financial support, social support, assistance efforts. health workers, efforts to seek other assistance, the attitude of the mother when the child conveys a choice, the attitude of the mother when the child acts inappropriately, the expectations and limitations of special health services for disability, the wisdom of spiritual improvement and bathing.

Conclusion: Mother's experience in caring for children with disabilities found unstable emotional changes, excessive worry and excessive attention. Support is very influential for mothers in the form of information support, extended family support, nuclear family and the surrounding community. During caring for children with disabilities, mothers gain wisdom, namely increasing patience and gratitude.

Keywords: Children with disabilities, experience of caring, phenomenology study.

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BACKGROUND

Disabilities are often called physical, mental and sensory disabilities or disorders that limit a person's ability to carry out daily activities

(Tigere et al., 2018). Disability is a global public health problem. The World Health Organization (2020) states that more than 1 billion people live with some form of dis-

ability. Central Java has a fairly high number of persons with disabilities in urban areas at 0.99% and rural areas at 0.97% (Ministry of Women's Empowerment and Child Protection, 2020). Data from the Central Java Social Service (2020) shows that the number of people with disabilities based on their disabilities is quite high, including 61,277 people with physical disabilities, 27,366 blind people, 26,177 hearing impaired people, 12,514 speech impaired people, 10,094 hearing and speech impaired people, 4,044 blind and physically disabled people. soul.

Raising children with disabilities is not easy. Alsharaydeh et al (2019), stated that the challenges for parents and families include how to care for them, financial barriers, language, service utilization, discrimination, stigma or negative views of society. Caring for children with disabilities requires a high level of parenting responsibility, especially by mothers. This responsibility creates psychological pressure that causes mothers to experience stress (Sato et al., 2015). The research study by Farajzadeh et al (2021) stated that about half (45%) of mothers as caregivers reported symptoms of anxiety and 40% of mothers experienced symptoms of depression.

Data from the US Children's Bureau (2018) as many as 678,000 children experience violence and neglect due to high financial pressure and difficulties for mothers in caring for children with disabilities (Legano et al., 2021). This requires support, especially family. The provision of social support from family or parents in the form of material or psychological support has a positive relationship to the quality of life and achievement of children's academic skills (Sultan et al., 2018).

Pekalongan City is one of the cities on the north coast of Central Java Province with a fairly high number of persons with disabilities, consisting of the physically disabled (186 people), the blind (107 people), double blind (473 people), the deaf-speech (91 people).

people), mentally retarded (88 people) and physically disabled (384 people) (BPS Kota Pekalongan, 2021). The high number of people with disabilities in Pekalongan City is the background for the establishment of the Special School for the Indonesian People's Association (SLB-PRI). Data obtained from an initial study at the PRI SLB, Pekalongan City, there are three types of persons with disabilities consisting of hearing and speech impairments (hearing and speech impairments), mental retardation (intellectual barriers), and physically handicapped (physical disabilities) with a total of 24 classes. , each class contains a maximum of 6-7 students with the highest proportion of primary school education levels.

This study aimed to explore the experiences of mothers caring for children with disabilities

SUBJECTS AND METHOD

1. Study Design

This was a qualitative study with a phenomenological approach that emphasizes the depth of information on the experience of mothers in caring for children with disabilities so that it reaches the level of meaning.

2. Sampling

Determination of the sample in this study was carried out using purposive sampling as many as four participants with inclusion criteria including housewives without a caregiver, willing to become participants by signing informed consent, able to communicate well, healthy condition and not experiencing mental disorders and dementia. While the exclusion criteria in this study included mothers experiencing mental disorders and dementia, mothers working with the help of caregivers, mothers experiencing severe mental disorders and mothers experiencing speech or speech impairments.

3. Study Instrument

The data collection study instrument was carried out in depth by the researcher himself

with participants for 30-60 minutes for 3 meetings until data saturation was reached. The tools used in data collection were in-depth interview guides, cameras, recording devices and writing instruments.

4. Data Analysis

The data that has been obtained will be analyzed using the Colaizzi method, starting from understanding the meaning of the transcript, grouping it into themes to making clear and concise descriptions of phenomena regarding the experience of mothers caring for children with disabilities.

RESULTS

1. Characteristics of Participants

The participants in this study consisted of 4 housewives who have school-age children with disabilities who are deaf-speech, physically disabled (cerebral palsy), mentally retarded (down syndrome and microcephaly). The age range of participants is 44 years-57 years. The lowest participant's educational background is Elementary School (SD) and the highest is Bachelor (SI). The number of participants' children is at least 4 and at most 6. Most of the participants live at home with their husbands and children. Two participants have husband's livelihood as entrepreneurs, one participant is a laborer and one participant is a retired State-Owned Enterprise (BUMN) with income ranging from Rp 1,000,000 to >Rp5,000,000. Frequency of seeking treatment at health service facilities is at least 1 time and at most not infinite for 6 years.

2. Characteristics of Children

Child participants in this study had an age range of 13 years-20 years with the most gender being female and one male. Participants' children were born as children number 2-6. The age at which a disability was detected varied from birth to 2 years of age. All children have problems in cognitive, motoric, hearing and speech functions. Meeting the needs of all participating children is not yet independent.

Some children have good adaptation to their environment and two other children have difficulty in socializing. The causes of children experiencing disabilities in this study varied from fever accompanied by seizures, hypertension and weak contractions, premature rupture of membranes during pregnancy and genetic disorders from birth.

3. Thematic Analysis

The themes identified from the results of in-depth interviews with 4 participants using the Colaizzi analysis method, found 17 themes that describe the experiences of mothers in caring for children with disabilities, namely:

a. Theme 1: Fate

The theme of destiny is divided into sub-themes, surrender to God and sincerely accept reality.

Sub-theme surrender:

"At first I was sad, why was I given a child like this, but after I studied religion, I had to accept whatever God gave me" (P2), "yes... how can I do that, if I was told to choose, I don't want to, but I have to how else, I have to accept" (P3).

Sub-theme sincere:

"How is it... it is the responsibility of the parents (how is it... it is the responsibility of the parents" (P1), "At first it was a shock, it took a few days to finally be willing to accept it" (P4).

b. Theme 2: Family Burden

The family burden theme is divided into sub-themes of physical burden, financial burden and social burden.

Physical load sub-themes:

"yes, I'm tired and tired, how else is it like it's innate" (P1), "I feel angry, tired of taking care of him since he was little until now he's not independent" (P2), "There is, I'm not young anymore, I'm more tired" (P3).

Sub tema financial burden:

"Yes, there is, because you have to be extra if the child is generally big and just

let it go, until now he has to be really taken care of" (P4),

"Yes, it's burdensome. He eats a lot, it's 20,000 a day, we pay expensive school fees, still 2,900,000 in arrears (yes it's a burden, "He asks for a lot of snacks a day 20,000. We pay for expensive school, you still owe 2,900,000" (P1), "yes ... definitely because it costs more for therapies and school fees in special schools are more expensive, not to mention "the child's request if he is not given there will be a tantrum" (P3).

Social burden sub-themes:

"There is, when people play, they say they are afraid when they see my child, if they don't want to play, if my child comes, they will go and sometimes they will be bullied" (P3).

c. Theme 3: Mother's psychological response.

The mother's psychological response is divided into sub themes of shock and anxiety.

Shock sub-theme:

"Flighty. It was a shock, there were no descendants of the deaf, mute, no one like that. It can't be helped, I can only surrender (yes, it's not clear what it feels like to be surprised, there are no descendants, can't hear, can't talk, no siblings like that)" (P1), "At first I was wondering why... I was also surprised what I had something wrong with God, I don't know what" (P2), "I was in shock at that time, I cried, I felt like I did something wrong with God, how come God was given a trial like this" (P4).

Anxiety sub-themes:

"Initially I thought it would be normal with therapy, now it's going slowly, I'm worried what will happen next"

d. Theme 4: Emotional changes

This theme comes from the sub-themes of unstable emotions and excessive worry.

Unstable emotion sub-themes:

"sometimes there's emotion when my child is fussy and doesn't want to be obeyed, if he wants to eat something delicious, he likes it" (P1), "the name is human emotion. I am sure of my child because sometimes I want to pee before I get to the bathroom, and it comes out because I'm slow to take off my pants. My emotions are still unstable" (P2), "Sometimes I'm upset after that I regret it. It is because when my child gets angry on the street, he throws my hood off, my face clawed until it bleeds outside like that" (P3), "sometimes emotions arise when my child difficult to handle, doesn't want to be asked to go, it's hard to go to a doctor to ask for forgiveness, sometimes he pees in his pants" (P4).

Sub-theme of excessive worry:

"worried that if there is no soul mate, I want to be independent and earn my own money" (P1), "I was worried if I wasn't there then what would you do... (P2), "I'm afraid that if I die first, if it's not with my parents, it will still be different, what will happen tomorrow because I can't be independent yet" (P4).

e. Theme 5: Behavior change

Changes that occur in the mother:

"I really pay attention when I ask for anything, until I borrow money" (P1), "Of course I have to pay attention to my child, sometimes the older brother is jealous if the younger brother asks for it immediately" (P3), "attention must be paid. more than others, because he is like a child all the time" (P4).

f. Theme 6: Cost limitations.

This theme comes from the sub-themes of treatment costs (therapy) and education costs.

Sub-theme of maintenance costs:

"The cost is certain...because the expenses for him are more than the other siblings, especially for unassisted therapy" (P3).

Sub-themes of special education costs:

“terutama biaya pendidikan teng SLB tiap tahun mundak, wis nunggak SPP karo kepinginane anake katah (especially the cost of education in special schools increases every year, the tuition fees are in arrears and there are many children's desires)” (P1).

g. Theme 7: Obstacles in everyday life

This theme comes from the sub-themes of barriers to independence and behavior.

Sub-theme of independence:

"It's troublesome when I have to pick up my children because I also take care of my grandchildren and because my child's right hand is weak so I still help him in his daily life, especially going to the bathroom" (P2), "it's difficult to be independent, when he's sick it's difficult to go to a health worker to check his teeth, It's hard to be asked to go out, if I take a shower it's not clean so I keep re-showering and when I go to school I have to be accompanied" (P4).

Behavioral barriers sub-themes:

“Yeah... sometimes when he asks for something, when he doesn't understand his account, he gets angry when things are thrown, he likes to scream” (P3).

h. Theme 8: Social stigma

The theme of social stigma comes from the sub-theme of a negative assessment of mothers with children with disabilities.

"Once a neighbor who won't sing says why a dumb boy wants to go to public school (once a neighbor said why a mute child wants to be sent to school in public)" (P1), "there might be a problem, you don't know how it looks on the outside like how I don't You know, sometimes I feel sorry for my children when they want to play, other children are even scared and cheated" (P3), "Never dare to speak in front of me, maybe behind my back, have someone said this is my fault" (P4).

i. Theme 9: Financial support

Financial support expressed by participants:

“their sister and brother gave me money to buy some snacks or food) (P1), "Usually from the in-law and sibling who help if we don't have money" (P2).

j. Theme 10: Social support

This theme is divided into sub-themes of emotional support, informational, extended family, nuclear family and community.

Emotional support sub-themes:

“People told me to be patient” (P3), “pada bilange wes ndakpapa sing sabar yowes kui rezekimu (they say it's okay, be patient, that's your sustenance" (P4).

Informational support sub theme:

“In terms of information, we usually get it from friends who have children with disabilities, we share information with each other” (P3), “we also get a lot of information from people. A friend who provides information about therapy for my child so that he can be normal” (P4), “if it is information, I usually ask the therapy doctor directly, it is best to consult with him” (P2).

Big family support sub theme:

"All is well with my son. They're even nice. My grandmother likes to bribe and ask to leave” (P4), “yes...everyone supports me. Brothers and sisters already know from my side or my husband. If my child is sick, it will be delivered immediately” (P2)

Sub-theme of main family support:

“my family and I are looking for some information. Usually it is the children who provide therapy information (P1), "if it's finances, we just try to do it from the family" (P3).

Community support sub-theme:

“They are supportive. Everyone is like a brother and already understands my child's condition. Sometimes when they come here, my child is encouraged” (P2).

k. Theme 11: Efforts to help health workers expressed by participants

From a medical point of view, I have been in therapy for 6 years” (P2), “when I was little, I often went to the doctor for regular check-ups” (P1), “I went to Semarang to Dr. Anak for a test down syndrome” (P4).

l. Theme 12: Attempts to find other help.

The themes are divided into sub-themes of spiritual assistance, alternative medicine and special education.

Spiritual help sub-theme:

“From a religious perspective, every night I pray at tahajjud and in front of the Kaaba directly” (P2).

Alternative medicine sub-themes:

“I have taken it everywhere including alternative medicine because going to the doctor is also expensive” (P1), “I once took it for a massage” (P3), “I want my child to be normal. I did everything using herbal medicine, someone told me to drink with water and prayed for it” (P4).

Sub-theme of special education (SLB):

“Most..now focus on education at the current special school” (P3).

m. Theme 13: Mother's attitude when child conveys choice

This theme is divided into sub-themes of mothers with permissive and authoritative parenting.

Permissive type sub theme:

“approved immediately, if you ask for anything, let's go, if you don't obey, you'll get angry” (P1), “I still obey the child, he will definitely ask for it, more often than not I obey no matter what” (P3), “Usually if he wants toys, I follow. If I give a choice, I believe in my child” (P4).

Authoritative or democratic type sub-themes:

“Yes...it depends, if the choice doesn't make sense, I won't follow it. Sometimes I invite you to discuss, I never indulge” (P2).

n. Theme 14: Mother's attitude when her child acts inappropriately.

This theme is divided into sub-themes of not being punished (permissive) and giving of punishment (authoritative).

Sub-themes are not penalized (permissive):

“Yeah..I'll just let it go” (P1), “if he's angry, I'll just calm him down. I hug him, I never punish him” (P3), “it depends on my emotions, but never punish him” (P4).

The sub-themes of punishment (authoritative type) were expressed by participants:

“I sometimes have angry reflexes, the name is human. Usually I hide his cell-phone for a few days if he doesn't want to study” (P2).

1) Theme 15: Expectations and limitations of disability-specific health services

“So far there is nothing specifically for children with disabilities, only for regular check-ups...I wish there was a special service for children with disabilities, such as special health workers who both understand sign language and have direct check-ups come to the house” (P1), “there has never been information or health education up to disability or the correct and appropriate way of parenting” (P2), “So far there have been no special services for people with disabilities like my child, I wish there were special services and more attention” (P3).

Participants also stated that they had not received maximum supporting facilities:

“So far, it's been good, unfortunately my children only lack the facilities and for therapy it's not optimal, so I have to go out of town, I hope that the facilities will be more equipped and improved and for staff who specifically handle children with disabilities such as Down syndrome” (P4).

2) Theme 16: The wisdom of spiritual uplift

This theme is divided into sub-themes of increasing gratitude and patience in caring for children with disabilities.

Sub-theme of increasing gratitude:

"I'm grateful" (P3).

Patience sub theme:

"(be more patient, how else are you given sustenance from God)" (P1), "The lesson is, I can be more patient and more sincere, maybe that's the wisdom from God that I live" (P2), "yes... I train my patience more, if people are free to go and go, if I don't" (P4).

3) Theme 17: Independence.

"I want my son to be independent, to be able to work generally with his friends" (P1)

"Yes.. my prayer is that one day there will be a miracle that my child will be given the strength to be independent, so that the efforts so far have yielded results" (P2), "I just want to be independent. I don't want anything else." (P3), "I hope, I want it to be normal, if I can't be independent, I can take care of myself, I can take care of myself" (P4).

DISCUSSION

Theme 1: Destiny

Mothers who have children with disabilities have the perception that children are a gift from God that must be accepted as they are. This is in accordance with the research of Desriyani et al (2019) which states that the process of accepting children with disabilities in the family requires a process that starts from the rejection process to the awareness stage to accept what is because of the deposit given.

Theme 2: Mother's burden

A mother caring for a child with a disability is physically, financially or socially burdened. This is in line with Caicedo's research (2014) which states that parents experience a physical fatigue burden when they have to take care of children with special needs. Meanwhile, mentally unstable emotions, frustration, anxiety

about the future of children and feel helpless.

Theme 3: Mother's initial psychological response

The mother's initial response when she found out her child had a disability was shock and anxiety. This is supported by research by Naufal et al (2020) which states that the first reaction when they find out their child has a disability is shock, surprise, rejection, fear and even anger with the reality that happened.

Theme 4: Emotional changes

Mothers who have children with disabilities tend to have unstable emotions. This is in line with research which states the negative impact that children with disabilities have on their families, especially in terms of stress experienced by mothers and poorer emotional health when their children have problems (Samadi et al., 2014).

Theme 5: Behavior change

Mothers with children with disabilities tend to give more attention and protection to their children. This is contrary to Dewi's research (2017), that overprotective attitudes have an impact on children's creativity, dependence and independence in the child.

Theme 6: Cost limitations

Mothers who have children with disabilities experience limited costs of treatment (therapy) and education, especially if their husbands have irregular incomes. This is supported by research by Asa et al (2021) that the cause of financial constraints in families is due to lack of permanent work and increased health care costs.

Theme 7: Obstacles in everyday life

Children with disabilities who are unable to be independent have an impact on negative pressures on mothers and cause parenting stress (Rusmariana et al., 2021). Meanwhile, in terms of behavior, Muller et al. (2020) reported that children with disabilities tend to behave in problems such as arguing,

tantrums, inattention, stereotypes, and aggression.

Theme 8: Social Stigma

Social stigma or negative judgment by the community is an inhibiting factor in caring for children with disabilities. This is in line with the research of Asa et al (2020) which states that mothers experience significant psychosocial challenges including feelings of frustration, sadness, anger, worry, inferiority due to discriminatory behavior.

Theme 9: Financial support

Financial support to the family affects the process of nurturing and caring for children, especially to reduce stressor levels for mothers. One of the causes of the need for financial support is due to uncertain income.

Theme 10: Social support

Social support by most mothers is in the form of emotional, informational, extended family, nuclear family and community support. This is in line with the research of Alsharaydeh et al (2019) which states that social support groups are not only provided with information but also with encouragement, support, optimism and hope.

Theme 11: Efforts to help health workers

The role of health workers in the welfare of children with disabilities is very important, one of which is pediatricians as a key element for monitoring children's physical, psychological, and emotional health (Eickmann et al., 2016). This is contrary to the reality on the ground that so far health workers have never provided information related to disability or how to take care for them.

Theme 12: Attempts to find other help

Mother's efforts in caring for children with disabilities include spiritual efforts, alternative medicine and special education (SLB). Alsharaydeh et al (2019) also explain the same meaning that religion and spirituality are strong coping mechanisms or sources of comfort, peace, and hope.

Theme 13: Mother's attitude when children make choices

Most mothers apply permissive parenting, where participants do not forbid whatever their children want. However, this parenting pattern causes children to always demand others to follow them, do not learn to respect others and find it difficult to socialize (Park et al., 2012).

Theme 14: Mother's attitude when children act inappropriately

Most of the participants stated that they did not give any punishment when the child made a mistake, including when the child had a tantrum. This parenting is included in the permissive type where according to Fuentes et al (2014), excessive permissive parenting will make it difficult for children to develop themselves, respect rules and can cause problems.

Theme 15: Expectations and limitations of health services

Health facilities and services that support children with disabilities are very important to ensure that people with disabilities receive appropriate services in order to achieve optimal health status (Syukria et al., 2016). This is contrary to the conditions on the ground that mothers with children with disabilities experience limitations in terms of facilities and special health workers with disabilities.

Theme 16: The wisdom of spiritual uplift

Most of the mothers stated that there was an increase in patience because the condition of the child who was not fully independent and an increase in gratitude had been given to the child with limitations. This is in line with the results of research by Beighton et al. (2017) who reported that their children had brought positive changes and lessons for the family, such as increasing faith or spirituality.

Theme 17: Independence

Mothers with children with disabilities are afraid that one day they will die first. This is because the main caregivers are the mothers

and children of the participants who have not been able to be independent. This study is in line with Sim et al (2021) who stated that they were worried about their children's abilities and hoped that their children would be independent in the future.

AUTHOR CONTRIBUTION

Amanda Via Maulida is the lead researcher who selects the topic, searches and collects research data. Bhisma Murti and Rita Benya Adriani analyzed data and reviewed research documents.

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CONFLICT OF INTEREST

There is no conflict of interest in this study.

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