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POSITIVE ASPECTS IN PARENTS WITH NEURODEVELOPMENTAL DISORDER CHILDREN: A PHENOMENOLOGICAL QUALITATIVE STUDY

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Abstract. Neurodevelopmental Disorder (NDD) is a neurodevelopmental disorder related to the functioning of the nervous system and brain. Parents of children with NDD experience increased stress in managing various daily chores and activities such as feeding, autonomy, leisure, and schooling of the child. However, some parents cope very well and derive great benefits from their parenting role. Several studies have found a variety of benefits for parents while caring for their children. Caregivers who reported positive aspects had better health, fewer depressive symptoms, higher parenting competence and greater family adjustment. This study is a qualitative study with a phenomenological approach that aims to find out the positive aspects that parents feel while caring for children with a diagnosis of neurodevelopmental disorder. Parents with children diagnosed with NDD (N=3) underwent a semi-structured interview process after agreeing to informed consent. The results of the study showed that the positive aspects experienced by parents during parenting were feeling the child as a source of happiness, receiving support from the community, and increased spirituality.

Keywords: lead time manufacture; lean manufacturing; value stream mapping; process activity mapping

I. INTRODUCTION

Neurodevelopmental Disorder (*NDD*) is a neurodevelopmental disorder associated with the functioning of the nervous system and brain. Examples of *NDD* in children include *attention-deficit/hyperactivity disorder* (*ADHD*), autism, learning disabilities, intellectual disability (mental retardation), behavioral disorders, *cerebral palsy*, and visual and hearing impairments.**[1]**. Raising a child with *NDD* puts more stress on parenting than other children. In fact, parents of children with *NDD have* shown high levels of parenting stress across multiple studies **[2][3]**. Parenting a child with a diagnosis of *NDD* brings challenges for parents. A child with *NDD* may require more care and attention from parents/caregivers until the child becomes independent. Caring for a child with *NDD* can interfere with parents' interpersonal relationships, social activities, productivity, and their health-related quality of life. **[4]**.

Various studies have focused on the level of parental stress in parenting a child with *NDD***[4][3][5]** The state of parental stress is determined by a variety of factors, particularly the intrinsic characteristics of the child and parent and the interplay of environmental factors. Furthermore, parents of *NDD* children experience increased stress in managing various daily chores and activities such as eating, autonomy, leisure, and the child's schooling. **[3]** Parents are required to cope with stress by using adequate resources and providing high-quality care at the same time. **[6]**.

Despite the stresses experienced, some parents cope very well and derive great benefits from their parenting role. Slattery found a range of benefits for parents while caring for their children, including cognitive (perceived personal growth), social (better relationships) and spiritual dimensions (increased sense of purpose).**[7]** Positive aspects have been investigated in various groups of caregivers, for example in those caring for people with cancer, stroke, alzheimer's disease, dementia, and developmental disorders. Positive aspects are situations where the person perceives caregiving as enhancing or enriching the meaning of their life. Caregivers who reported positive aspects had better health, fewer depressive symptoms, higher caregiving competence and greater family adjustment. Parents of children with intellectual disabilities may experience positive aspects differently to other groups of caregivers as they provide lifelong support for their child.**[8]**. Positive aspects in caregivers of children with a diagnosis of *NDD* can provide motivation for parents with NDD children in caring for their children. However, research on the positive aspects of caring for children with NDD is still very rare. This study aims to provide descriptive information about the positive aspects perceived by parents with NDD children.

II. RESEARCH METHODS

The type of research used in this study is qualitative research with a phenomenological approach. The phenomenological approach is an approach to describing a common meaning for several individuals of certain concepts or phenomena. **[9]**. The research subjects were selected using purposive sampling technique where a diagnosis from the relevant specialist was needed to determine the child's condition. The desired subject characteristics are: 1) a parent with a child diagnosed with neurodevelopmental disorder, 2) physically and psychologically healthy, 3) living with the child, 4) directly involved in parenting, and 5) willing to be a research subject. Data collection in this study used a semi-structured interview method that was recorded with the consent of the participants. The main questions asked refer to several items from the parental aspects of the Parenting Stress in Parents with Autism Spectrum Disorder Children in Indonesia measurement tool. **[10]** including how they feel during caregiving, what they do when they face difficulties in caregiving, and what makes them feel able to face challenges in caregiving. Follow-up questions were developed based on each participant's answers. Participants gave informed consent before the interview began.

Participants. The participants consisted of three, two of them were a married couple. The first participant was a father with the initials DP who has a 10-year-old child with a diagnosis of autism spectrum disorder. He is a private employee. The second (L) and third (A) participants are a married couple who have a 16-year-old child with a diagnosis of cerebral palsy. L is a mother who has a busy entrepreneurship at home, while A is a private employee. The three participants were interviewed separately.

III. RESULTS AND DISCUSSION

Response after diagnosis

All three research participants admitted that they were in *shock* and could not accept the diagnosis given to their child by health professionals. All three were shocked even though they had realized early on that there was something different about their child's development.

This is a new experience, we (my wife and I) were quite shocked when we first found out about my child'sthat my child had special needs. (Participant DP)

After being diagnosed by the doctor, I couldn't accept it, until 3 am I didn't want to go home after returning from the doctor. But as time went by, because my husband and I were complementary and became a team work . . . (Participant L)

. . I was told that my child wouldn't be able to walk, wouldn't be able to sit, wouldn't be able to talk. I was in shock, for a few months, until two-three months I didn't accept why from a hot illness, how come it could be like this. But after that I started to accept . . . (Participant A)

In line with previous research conducted by Boshoff regarding the parenting experiences of parents with children with *autism spectrum disorder*, parents experience rejection, confusion, and feeling emotionally overwhelmed. According to Luong in Boshoff, parents who receive a diagnosis of a disorder in their child may experience two phases. First, parents report denial and passive *coping* where parents become aware of their concerns but do not acknowledge the problem and do not take action due to lack of knowledge. In the second phase, parents become increasingly anxious about the problem and have a sense of urgency to get answers. It is described that parents take various steps to cope with their feelings of fear and helplessness.**[11]**

As can be seen in participants L and A who stated that they experienced a period of rejection until they finally accepted and decided to find various solutions for their children. The process of seeking and receiving a diagnosis elicits a range of emotions that can affect parents' well-being, including guilt before diagnosis and grief afterwards. Parents have clear emotional, informational and relational needs as they go through the process of understanding their child's range of conditions. A good relationship with professionals is needed at this time for parents to manage expectations after diagnosis, information about services for their child, and to manage their own difficulties.**[12]**

Positive Aspects

The positive aspects described across the studies were diverse and most of the themes identified related to intrapersonal factors stemming from the parents' orientation. These included personal growth/strength, personal development, having a changed outlook on life, having broader relationships with others, their child being a source of happiness and fulfillment, having increased spirituality/religion and the nature of the parenting role.**[8]** In all three participants, there were positive aspects such as children being a source of happiness, having support from the community, and increased spirituality.

Children as a source of happiness.

Participants DP, L and A seemed to agree that despite the difficulties they faced while parenting their children, they could still feel happy when their children were happy. All three of them made various sacrifices in various aspects. Participants admitted that money was not a problem to accommodate their children's needs. DP and L are also willing to leave their jobs to be closer to their children.

I had to resign to be closer to my son, who used to work outside the city. We are committed, we have to take care of him. One of them is by giving him what he wants as much as we can. Giving whatever it is as long as he is happy. (Participant DP)

. . . I always ask E if she's happy. The important thing is that she's happy. (Participant L)

Here and there, the important thing is that she's happy. I'm still trying, but the (most) important thing is that she's happy. . . (Participant A)

Interestingly, the child diagnosed with *NDD* in all three participants is their only child with their current partner. They admitted that this is what keeps them enthusiastic about caring for God's entrustment to them. One of the participants said that the child had been awaited for a long time and he and his partner were committed to continuing to look after their only child.

Hi, this is our only child. When we planned to have this H, it was a long journey until my wife finally got pregnant at the age of 36. . . We are committed, we have to keep it. (Participant DP)

What makes me always excited about my child, first of all, my child is only one, my only child, from there whatever *happens I devote everything to him. Really anything for him*. (Participant A)

The presence of a child with intellectual disability brings its own pressures to every family, such as greater financial burden, frequent disruption of family routines and leisure time, and communication difficulties with health care providers. Parents have to make changes in lifestyle, restrictions on social life, and they have less time for themselves.**[13]**. As felt by participant DP who had to leave her job to spend more time with her child. However, various studies report that parents with intellectually disabled children feel that their children are a source of happiness. This is because they feel that they gain a new perspective on life and appreciate an unexpected achievement made by their child. **[8]**

Gain support from the community

The support and information from the community was recognized as helping the three participants to help them through this difficult time. Two of the participants admitted to traveling out of town to find a community of parents with children who have similar conditions.

I also often go to communities, as far as Bandung. Observing other children and parents. (Participant L)

Parents go through difficult conditions and obstacles in the parenting process in various ways. For example, emotional, physical, and financial burdens, as well as reduced leisure time and even leaving work because of having to care for children all day. **[14]**. Parents claimed that the burden of caregiving can be moderated through both formal and informal social support. According to Masack and Samuel, giving credence to informal social support has benefits for families and parents of individuals with special needs, including reduced stress levels and greater well-being for parents.**[15]**

Increased spirituality

Parents in this study reported that they remember that children are entrusted to them by the Creator and that this makes them feel able to face challenges during the parenting process.

We think this is the only thing we expected when we got married, the Creator entrusted to us. (Participant DP)

Religion and spirituality play an important role in the meaning-making process as they are core aspects of meaning globally. Faith, religious beliefs or spirituality have all been identified as *coping* mechanisms related to psychological adjustment to stress.**[8]**. In line with research that **[16]** on mothers of children with *autism spectrum disorder*, spirituality was found to be a significant predictor of positive experiences and thoughts during caregiving. Spirituality can increase the ability to feel positive contributions through a focus on finding meaning in life.**[16]**

IV. CONCLUSION

Parenting a child with a diagnosis of neurodevelopmental disorder presents its own challenges for parents. The dependence of the child in doing all activities makes it difficult for parents to do other activities, causing stress. However, in addition to all the negative aspects that parents feel, positive aspects are also felt. The positive aspects found in the parents involved in this study included feeling their children as a source of happiness, receiving support from the community, and increased spirituality. These positive aspects are known to enable them to cope with difficult and stressful situations during the parenting process.

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