

A Mother's Journey: Finding Meaning While Raising a Child with Cerebral Palsy

Anisa Nurul Imaniana^{1*}, Gamal Maulana²

Faculty of Psychology, Master of Professional Psychology, Persada Indonesia University YAI

E-mail: anisaimaniana@outlook.com^{1*}, gamalmaulana@outlook.com²

Abstract

This study originates from the researcher's interest in a mother who has a child with cerebral palsy but is able to find meaning in life despite the challenges she faces. Being a mother to a child with developmental disabilities is not easy, yet the subject of this study strives to find meaning in every difficult experience. The purpose of this study is to understand how the subject, as a parent of a child with cerebral palsy, discovers meaning in life. Life's meaning encompasses what is considered important and valuable, providing special significance to an individual's life. This meaning can be found in both positive and negative circumstances, in happiness and suffering. The process involves realizing opportunities within certain situations and understanding what can be done. This qualitative study employs a descriptive case study design, with data collected through interviews and observations of a single subject. Data validity is ensured by also interviewing a significant other. The analysis reveals that the subject's meaning in life is reflected in her life goals, such as improving her living conditions, owning a house, and hoping her child becomes independent.

Keywords meaning of life, cerebral palsy, mother, life meaning stages

INTRODUCTION

Having children is every parent's dream, of course children are the most beautiful gift that God has given to his servants. Every parent has the hope of having a child who is born physically and mentally perfect, but what happens if the child is born different from normal children in general who can carry out developmental tasks appropriate to their age.

Talking about child development, according to Santrock (2010), a child's development period is generally described in certain periods, with estimated age ranges for each period, namely prenatal period, infancy, early childhood, middle and late childhood and adolescence.

The prenatal period is the time from fertilization to birth, approximately nine months infancy is a period of development that continues from birth until around 18 to 24 months of age. Many new psychological activities begin, from the ability to speak, organize the senses and physical actions, think with symbols, and imitate and learn from other people.

Early childhood is the development that occurs from the end of infancy to around five or six years. During this time, children will learn to be independent and care for themselves. They develop school readiness skills (following commands, recognizing letters) and they spend hours playing with peers.

Middle and late childhood is a developmental period starting from the ages of 6 to 11 years, sometimes this period is referred to as the elementary school years. Children master the basic skills of reading, arithmetic, and they are formally exposed to the world of children, and self-control increases.



Adolescence is a period of transition in development from childhood to early adulthood, entering this period around the age of 10 to 12 years, starting with physical changes and the search for identity and freedom.

From what Santrock stated, it can be concluded that if a child cannot carry out activities appropriate to his age, it can be predicted that he will have problems, namely problems with emotional, mental or physical development. Congenital or hereditary factors are the biggest factors that cause various disorders or diseases in children who are usually called children with special needs.

In general, caring for children who have special needs is not easy, there are many obstacles and difficulties that can be experienced both physically and mentally. Having a child who has a serious illness usually has a stressful impact on the family. Mc Cubbin, Patterson and Wilson (1983) in Friedmann (2003) have studied or accumulated family stressors called the Family Inventory of Live Events and Change (FILE), the results obtained from this test indicate that family members who have physical disabilities / illnesses chronicle ranks fifth as a source of stressor in the seven life events that cause the most stress.

A mother is a person who has a special closeness to her child, because she is the one who cares for and takes care of the child, therefore the heaviest stressor in caring for children lies with the mother. A mother who has a child with special needs has psychological and sociological burdens that must be borne, such as whether the community around her is willing to accept her situation of having a disabled child or not.

One phenomenon that is interesting for researchers is the case experienced by Mrs. E. She is a mother of a child with Cerebral Palsy. Her child was diagnosed at the age of 7 months, when she found out that her child was experiencing this, it was not an easy thing to accept, especially since the cost of medical treatment for her child's therapy was not cheap. Mother E ran out of finances to take care of the treatment and therapy that her child had to undergo. Until finally he sold his house. At a time like that, her husband died and this added to the burden on her.

To be able to accept the situation he was experiencing and be able to learn lessons was not an easy thing, he felt stressed and blamed the fate given by God. However, E's mother said she was slowly learning the lessons and trying to live it well after seeing her son's condition again.

According to Mrs. E, what kept her going was her own child. If she hadn't seen her child, perhaps she wouldn't have had the strength to face all of this. Even though it looks difficult, he hopes that one day his child will be able to carry out independent activities.

According to what Frankl said, the meaning of life can be found in every situation, pleasant or unpleasant, happy and suffering (in Bastaman, 2007).

LITERATURE REVIEW

Understanding the Meaning of Life

According to Frankl (2004), the meaning of life is the things that a person considers important. It feels valuable and provides special value to someone. So, it is worthy of being a goal in life (the purpose in life). And the meaning of life turns out to be in life itself and

can be found in pleasant and unpleasant circumstances, states of happiness and suffering (Bastaman, 2007).

Craumbaugh and Maholick (in Koeswara 1992) define the meaning of life as an individual's ability to determine an integrated pattern of goals and values in life. Or in other words, the meaningfulness of life is related to the individual's ability to adapt efficiently to various problems in his life.

Characteristics of the Meaning of Life

According to Frank (in Bastaman 2007), the meaning of life has several characteristics, namely:

- 1) It is personal, temporary and unique, meaning what is considered important can change from time to time. and when it means something to someone, it doesn't mean anything to someone else
- 2) Concrete and specific, namely the meaning of life can truly be found in real experiences with abstract and philosophical things, idealistic or amazing works of art and academic achievements. Considering this uniqueness and specificity, the meaning of life cannot be given by anyone but must be sought, explored and discovered by oneself
- 3) Providing guidance and direction to our activities so that the meaning of life seems to challenge us to be found and the purpose of life determined.

Sources of Meaning in Life

- 1) Creative values, work and create and carry out tasks with full involvement and responsibility for work. Actually, work is only a means that can provide opportunities to find and develop the meaning of life. The meaning of life does not lie in work but in attitudes and ways of working that reflect personal involvement in one's work.
- 2) Experimental values (appreciative values), believing and appreciating truth, virtue, justice, faith and values that are considered valuable. In this case, love is a very important value in developing a meaningful life.
- 3) Attitudinal values (attitude values). That is, accepting with full fortitude and courage all forms of suffering that cannot be avoided after all the efforts and efforts have been made.

The Process of Discovering the Meaning of Life

According to Bastaman (1996), the process of finding the meaning of life is categorized into 5 things, namely:

- a. Stage of suffering
- b. Self-acceptance stage
- c. Stage of finding the meaning of life
- d. Meaning realization stage
- e. Meaningful life stage



Logotherapy

The concept of the meaning of life put forward by Frankl is outlined in a school called logotherapy. According to the root of the name "logos" which means "meaning" and "spiritually". Logotherapy is a school of psychology that recognizes the existence of a spiritual dimension in addition to the physical, psychological and socio-cultural environmental dimensions and assumes that the desire to live a meaningful life is the main human desire.

According to Bastaman (2007), Logoterapu has principles and teachings, namely:

- a. Freedom to will
- b. The desire for meaning
- c. Live messages

Understanding Cerebral Palsy

Cerebral palsy is a term used for a group of characteristics due to motor disabilities resulting from progressive brain damage early in life (Levitt, 2004).

According to Soeharso (Abdul Salim, 2007), cerebral palsy comes from the words Cerebrum which means brain and palsy which means stiffness.

According to Kuban (1994), cerebral palsy is more accurately described as a complex symptom rather than a specific disease.

The classification of cerebral palsy according to Swaiman 1998 in Rosenbaum 2003 includes:

1) Level 1 (mild)

Children can walk without restrictions/assistive devices. Does not require parental supervision, gait is quite stable, can go to normal school, daily life activities can be carried out 100%

2) Level 2 (medium)

Children walk with or without assistive devices, the equipment for ambulances is a tripod brace or crutches. The feet/legs can still function as a controller of body weight

3) Level 3 (severe)

Able to eat and drink independently, able to sit, crawl or slide, able to socialize with friends, daily life activities require assistance, but still able to go to school. The appropriate ambulation tool is a wheelchair

4) Level 4 (very heavy)

There is no ability to move arms and legs, vital life needs (eating and drinking) depend on other people.

METHOD

The method used in this research is a qualitative approach. This approach is carried out to develop understanding in interpreting what is behind events, the background of human thinking involved in them and how humans attach meaning to the events that occur (Sarantakos in Poerwandi 1998).

The variable in this research is the meaningfulness of life. The operational definition in this research is a description of the meaningfulness of life of a mother who has a child with Cerebral Palsy based on the process put forward by Frankl, namely: The stage of suffering, the stage of self-acceptance, the stage of finding the meaning of life, the stage of realizing meaning and the stage of meaningful life.

The subject in this study was a 37 year old mother who had an 8 year old child with cerebral palsy who was the sole parent of the child. Data collection techniques in this case are through interviews and observation.

RESULTS AND DISCUSSION

Based on the results of interviews and observations made with Mrs. E, it can be said that Mrs. E gained a better picture of the meaning of life through her life goals, including firstly, Mrs. E considered that what she experienced was a gift from God so she should still be grateful. Second, he tries to educate his children well and independently, he also wants F to recover. E's three mothers want to have a better life, one of which is by owning a private house. Mrs. E has the meaning of life through five processes, namely the suffering stage, the self-acceptance stage, the discovery of the meaning of life stage, the meaning realization stage and the meaningful life stage.

The Process of Discovering the Meaning of Life

Aspects	Subject	Significant Other
Stage of suffering	<ol style="list-style-type: none"> 1) Stress as a second wife 2) Often cries 3) Shock 4) Blame the situation 5) Feeling unfair 	<ol style="list-style-type: none"> 1) Shock 2) Down 3) Unable to accept the situation
Self-acceptance stage	<ol style="list-style-type: none"> 1) Through reflection, compare the condition of your child with other people 2) Often attends recitations and shares with other friends 	<ol style="list-style-type: none"> 1) Comparing one place with another 2) Attend lectures
Stage of finding the meaning of life	<ol style="list-style-type: none"> 1) The incident that happened to her child provided a lot of wisdom for E's mother 2) His main hope is his children 	<ol style="list-style-type: none"> 1) Provides a lot of wisdom for Mrs. E
Meaning realization stage	<ol style="list-style-type: none"> 1) Have hopes of owning a house 2) I want my child to recover 	<ol style="list-style-type: none"> 1) Have hope that their child can grow normally 2) Strive through work



Aspects	Subject	Significant Other
Meaningful life stage	1) Feeling that life is more meaningful 2) It's all calmer 3) Keep working to achieve your goals	1) Now live life more positively 2) You can't feel satisfied yet and still try to do what you have

CONCLUSION

This research found that mother E, who has a child with cerebral palsy, was able to achieve meaningfulness in life through the five stages described by Frankl, namely the stage of suffering, self-acceptance, discovery of the meaning of life, realization of meaning, and meaningful life. Mrs. E managed to find the meaning of her life by being grateful for the circumstances she experienced, educating her child in the hope that her child could be independent, and aspiring to have a better life. These findings emphasize the importance of acceptance and self-development in facing life's challenges, especially for parents of children with special needs.

This research also provides suggestions so that parents who have children with special needs, such as cerebral palsy, can learn from Mother E's experience, and further researchers are advised to explore other factors that might influence the meaning of life, such as spiritual well-being or self-esteem.

REFERENCES

- Abdul Salim Ch. (2009). *Pediatri Sosial dalam Pendidikan Luar Biasa*. Jakarta: Direktorat P2TK dan KPT, Dikti, Depdiknas.
- Abdul Salim & Munawir Yusuf. (2009). *Pendidikan Anak Berkebutuhan Khusus Secara Inklusif*. Surakarta: FKIP Universitas Sebelas Maret.
- Anggraini, R.R. (2013). Persepsi Terhadap Anak Berkebutuhan Khusus. *Jurnal Ilmiah Pendidikan Khusus*, 1, 258-264.
- Bastaman, H.D. (2007). *Logoterapi: Psikologi untuk Menemukan Makna Hidup dan Meraih Hidup Bermakna*. Jakarta: P.T. Raja Grafindo Persada.
- Budiman, Arif. (1973). Chairil Anwar: Sebuah Pertemuan. Jakarta: P.T. Dunia Pustaka Jaya.
- Frankl, V.E. (1959). *Man's Search for Meaning: An Introduction to Logotherapy*. New York: Pocket Books.
- Frankl, V.E. (1984). *Man's Search for Meaning: An Introduction to Logotherapy*. New York: A Touchstone Book, Simon & Schuster.
- Friedmann, M.L. (2003). *Family Nursing: Research, Theory, & Practice*. 5th Edition. New Jersey: Pearson Education, Inc.
- Irwanto, Kasim, & Rahmi. (2010). *Analisis Situasi Penyandang Disabilitas di Indonesia*. Jakarta: Pusat Kajian Disabilitas, Fakultas Ilmu Sosial & Politik, Universitas Indonesia.
- Koeswara, E. (1992). *Logoterapi: Psikoterapi Victor Frankl*. Jakarta: Kanisius.

- Levitt, S. (2004). *Treatment of Cerebral Palsy and Motor Delay*. 4th Edition. Massachusetts: Blackwell Publishing.
- Mangunsong, F. (2011). *Psikologi dan Pendidikan Anak Berkebutuhan Khusus Jilid I*. Jakarta: Lembaga Pengembangan Sarana Pengukuran dan Pendidikan Psikologi (LPSP3), Universitas Indonesia.
- Papalia, D.E., Olds, S.W., & Feldman, R.D. (2009). *Human Development: Perkembangan Manusia*. Jakarta: Salemba Humanika.
- Rosenbaum, P. (2003). *Cerebral Palsy: A Guide for Care*. Baltimore: Brookes Publishing.
- Santrock, J.W. (1998). *Perkembangan Masa Hidup: Life-Span Development*. Jakarta: Erlangga.
- Santrock, J.W. (2001). *Life-Span Development: Perkembangan Masa Hidup (Edisi Kelima, Jilid II)*. Jakarta: Erlangga.
- Sugiyono. (2007). *Metode Penelitian: Pendekatan Kuantitatif, Kualitatif, dan R&D*. Bandung: Alfabeta.

