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**Health Communication Study: Self-Meaning of the Oligodactyly Suffering in The Village of Ulutaue, South Sulawesi, Indonesia**  
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# Health Communication Study: Self-Meaning of the Oligodactyly Suffering in The Village of Ulutaue, South Sulawesi, Indonesia

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## Abstract

A health communication of oligodactyly sufferers aims at exploring the meanings associated with deformities of physical organs in fingers and/or toes from birth. This study discusses how fifteen people suffering from oligodactyly in The Village of *Ulutaue*, South Sulawesi, Indonesia, construct themselves having physical abnormalities and physical organs which are different from those of other people through communicating with the surrounding environment. This research uses subjective interpretive method with health communication approach. The results of this study explain that the people with oligodactyly are as the subjects and are considered to have self-meaning, the meaning of the physical abnormalities with the positive and negative self, the physical organ limitations with the self-meaning of causing shame, pity, the willingness of hard work, patience and encouragement. The physical organ abnormalities provide a "scary, goose-bumpy, pity, and disgusting" image for the people who see them. To feel as "like anything" becomes the basis for the appearance of subjective meanings of every action in constructing oneself.

**Keywords** Oligodactyly suffering . Self-meaning . Physical abnormalities . Physical organ forms

## Introduction

The phenomenon of a social reality experienced by people with disabilities shows that there are no private companies that accept employees. Not to mention the existence of the political rights of people with disabilities that have not been maximally protected and tend to be ignored. Other people with disabilities often accept stigma as a discriminatory act and others consider them to be a second class population community in gaining access and participating in development. People with disabilities are considered abnormal, where other people do not feel good or are unable to interact with them. The surrounding environment has given a stigma to people with disabilities, that they are seen as incapable of everything. This stigma is a social construction, related to the social role and social conditions of people who see people with physical disabilities as a social community to.

Over the years, oligodactyly suffering have been lacking social support from health, social, religious, maritime and fisheries, industry, and trade officials, and local government officials. The lack of social support for oligodactyly suffering can be in the form of the realization of aid that was promised never to be realized as well as medical examinations related to physical abnormalities. This does not mean that due to the closed communication between individuals with oligodactylis, they carry out life activities like humans without physical disabilities, but oligodactyly suffering seem to be isolated from the patterns of livelihoods of the rural poor.

The cause of physical abnormalities from birth in oligodactyly suffering is still a difference of opinion between health workers in Bone District with the oligodactyly suffering themselves. According to health workers, the cause of physical abnormalities is genetic (genetic). People with oligodactyly suffering assume that what the health worker communicates is not based on the results of medical tests and or health research. The uncertainty of this information will become a debate among many people and become confusing information for oligodactyly suffering.

The concept of health can be understood in varying ways of across cultures, different perspectives on illness and disease and its causes. Different perspectives create the different understanding of health and illness related to culture, religion, race, values, beliefs, and socio-economic circumstances. The diversity of health perspectives, illnesses, and diseases in health models include biomedical, personalistic, and naturalistic. The biomedical paradigm, including the oligodactyly sufferers, is not just a phenomenon of physical abnormalities and physical

organ deformities only, but it must be through biopsychosocial approaches in the transactional communication model of the oligodactyly sufferers.

Oligodactyly suffering who lived in the village of Ulutau during this study, his village was associated with the village inhabited by people of "*Lobster-Claw Syndrome*," although many normal people lived around the neighborhood of the village. The Ulutau village was constructed by the media as "the village of crab human," causing a resistance from some communities in the village, including from the oligodactyly sufferers. Some of them realized that the television media constructed the village solely due to profit-oriented aspect regardless of the physical, psychological, and economic conditions of the oligodactyly sufferers.

Axiologically the oligodactyly suffering has a novelty value in terms of the meaning of physical limitations, and can provide knowledge to interpret him, so that the crisis of public awareness, especially normal people, of the importance of understanding the sociological awareness competence of oligodactyly suffering persons who are no different and or exceed the competence of normal people. It is not easy for people outside of disability to respect and respect the feelings of oligodactyly suffering. This is caused by the treatment of discomfort acceptance that is different from normal people accompanied by the provision of nicknames, stigma, and discrimination against the oligodactyly suffering. Another factor is the limitation of normal people to understand and know about what and how people with oligodactyly suffering who are not contagious and disgusting, but who have physical disabilities.



Figure 1. The Oligodactyly Sufferers in the Village of Ulutau, South Sulawesi, Indonesia

Oligodactyly suffering has experienced difficult circumstances in their life. As they face a complex inner struggle in dealing with different physical conditions and being perceived as less able than the "normal" person. It is a difficult problem to be understood by people who have no defect in their physical and mental health. Abnormalities of physical organs are experienced as a symbol of "personal identity" of the oligodactyly sufferers which has been given by normal people in daily life and mock them with their condition, such as "stalked finger, crab claw man, and or crab family" which is pervasive, a traumatizing stigma which can harm the people with oligodactyly. By considering of the oligodactyly sufferers as subjects rather than as objects with the health communication approaches through transactional communication, such as their psychological, beliefs, behavior, social norms, traditions, and their lifestyles.

### Conceptual Scope, Theoretical, and Methodological Considerations

Research studies are focused on previous research that is intended to strengthen this research so that the substance aspects of previous research that have not been studied can be done in future research. Previous research also shows the originality of research on the self-meaning of the oligodactyly sufferers.

#### Conceptual Scope

There has been a lot of research on healthcare based on the social construction theory (often associated with phenomenological theory and the symbolic interactionist theory). This overwhelming research includes the following works: Davis (1972), Musgrove (1977, Chapters 5 & 6), Vittoria (1999), Nguyen (2006), Kovarsky et al. (2007), Hinojosa et al. (2008), and Binder et al. (2012). In Indonesia research into health communication based on the social construction theory includes the following: Teja (2006) who investigated patients' social construction of leprosy at the Sinatala Hospital in Tangerang; Kadri (2007) who investigated the social construction of blindness in the Wyata Guna Residence in Bandung; Hadisiwi (2011) who explored the meaning

of Filariasis as constructed by those who suffered from such illness in Bandung Regency; and Hafiar (2012) who explored the phenomenological experiences of disabled athletes in Bandung. Each of these studies is unique as it explores the deep feelings of the subjects which vary from one group of subjects to another. Kadri found, for instance, that the identity transformation of blind people underwent through five stages: internal self-shock, self-isolation, self-openness, self-improvement, and self-subjugation. Hadisiwi found that the sufferers of Filariasis defined themselves in four categories: Those with resignation, those with despair, those who never surrender, and those who feel as if they have no illness. People suffering from Filariasis interpreted their ailments as selfhumiliating and to be pitied, but in some cases as a driving spirit. Meanwhile, Hafiar discovered that the excelled disabled athletes had special identities which distinguished them from other disabled people; they gained more respect and were regarded as people with a better quality of life who could be taken as significant role models.

The subjects of this study were oligodactyly sufferers in Ulutaue village, Indonesia. The focus of this research is the self-understanding of oligodactylis with different research approaches and methods that can provide an overview of the limitations of the fingers and toes from birth in contrast to normal people in the surrounding environment so that a variety of themes can be studied judging by the results of previous research findings.

### Oligodactyly Suffering

People with disabilities are categorized in the degree of disability in terms of the severity of the disability. However, the degree of disability is considered to be able to hamper daily activities which have led to a separate debate about the conditions of the limitations for persons with disabilities. Disability is not only limited to the absence or dysfunction of one part of the body that can affect physical activity as it should but more broadly the limits of disability are developed into malfunction caused by certain diseases and or physical disorders. However, not all parties are willing to be categorized as people with disabilities, because they are reluctant to be disabled by the majority of the community as deviants.

Based on Government Regulation No. 36 of 1980 concerning the social welfare efforts of people with disabilities states that disabled people are individuals according to medical science declared to have a physical or mental disorder which is an obstacle or obstacle for him to carry out activities properly, consisting of bodily disabilities, blind disabilities, mental disabilities, deaf speech, and disabilities used by chronic disease. This category of persons with disabilities was perfected by the issuance of Law No. 4 of 1997 concerning persons with disabilities, including those with physical disabilities, mental disabilities, persons with physical and mental disabilities, and including oligodactyly persons who were termed "hypodactyly."

People with oligodactyly are termed "hypodactyly," which are fingers and toes less than normal (Hartanto in Sulaeman, 2018: 662). Persons with oligodactyly with limited physical abnormalities and physical organ shapes on the fingers and toes that are more than normal. According to Turnpenny et al., (1998: 659-662) oligodactyly is a sign or symptom of a syndrome, including Poland syndrome with a type of dysmelia (lack of limbs). Poland syndrome as a physical deformity since birth is characterized by abnormal fingers which are more commonly experienced in men than women, caused by genes. Oligodactyly in medical science is caused by genetic factors.

### Self-Meaning

If we look at the phenomenological theory, at least the meaning is "... is a certain way of directing one's gaze at an item of one's own experience" (Schutz, 1966: 42). The meaning is the result of construction, develops along with the subject's life experience. The meaning of an oligodactyly sufferers will change with the development of the experience they have of the elements that are part of the construction of physical abnormalities and the shape of physical organs.

The meaning of an oligodactyly as "... the heart of perceiving, remembering, judging, feeling, and thinking ... when we reflect upon something and arrive at its essence, we have discovered another major component of meaning" (Moustakas, 1994: 68-70 ). It was also stated that "... without meaning we would not make choices, because the concept of choice would not be available to us" (Lindlof, 1995: 6). The meaning of people with oligodactyly is in the form of their self-assessment and actions with physical disorders and the shape of physical organs is different from others.

Symbolic interaction figures from George Herbert Mead have the concept of "self," as well as Charles H. Cooley defines it as "a process originating from the social interaction of individuals with others" (Mulyana, 2006: 73) and for Mead and Cooley, "self "Arises because of communication. The meaning of self is built by oligodactyly through interaction and communication with the surrounding environment. If you use Cooley's view of self-meaning, it will facilitate understanding of how an oligodactyly determines his or her meaning and then builds meaning about others around him.

Subjective interpretation arises as a result of interactions carried out by oligodactyly sufferers with the surrounding environment. Berger and Lukmann (Poloma, 2007: 299) revealed that society as a subjective reality

implies an objective reality interpreted subjectively by individuals. The subjective interpretation of an oligodactyly about himself will vary depending on the social interaction he does. Remembering interpretation is an active process of thought and creative action in clarifying personal experiences (Littlejohn and Foss, 2009: 58).

Through their interactions with others, individuals think to modify and give meaning or change meaning based on the interpretation of the situation at hand (Ritzer in Mulyana, 2006: 73). Formation of meaning is a production process in which oligodactyly tries to understand something and convey it to others based on experience as part of their daily lives in the social process.

## Theoretical Perspective

Quantitative-statistical research is different from "qualitative" research. To explore individual by using a distinctive construction process, then give the meaning to the oligodactyly sufferers by using an "interpretative" perspective or more specifically, the perspective of social construction and symbolic interaction. To use Berger and Luckmann's perspective (1966), the social construction of reality is a symbolic interplay between an actor's own consciousness and the consciousness of other actors in their shared life. Using the symbolic interactionist theory, individuals' actions are based on their definition of a person, an object or the environment they confront, and they may change their actions based on their interpretation of others' actions (Blumer, 1969).

The assumption of this theory, how people the oligodactyly sufferers explore themselves with the self-meaning of having physical abnormalities and physical organs deformities which are different from other people through communication with other people around their environment in daily life. As Marks et al. (2000:6) point out, "People's accounts of health and illness are interesting and illuminating topics of study in their own right." Oligodactyly may be assumed by medical doctors and nurses solely as a disease, that is, an objective reality (physical or organic symptoms) that can be diagnosed and examined in clinics or laboratories. However, we contend that for the purpose of this research, Oligodactyly should be considered an illness rather than the disease. Kleinman et al. (1978) define a disease as "organic malfunctions and pathological processes whose signs and symptoms typically can be observed and quantitatively assessed," while illness is "the patient's experience of disease or ill health" (cited Scharf and Vanderford, 2003:14).

There has been many research on health based on social construction theory (often associated with phenomenological theory and the symbolic interactionist theory), for instance the research by Davis (1972), Musgrove (1977, Chapter 5 and 6), Vittoria (1999), Nguyen (2006), Kovarsky et.al (2007), Hinojosa et.al (2008), and Binder et.al (2012). In Indonesia research into health communication based on the social construction theory includes the following: Teja (2006) who investigated patients' social construction of leprosy at the Sinatala Hospital in Tangerang; Kadri (2007) who investigated the social construction of blindness in the Wyata Guna Residence in Bandung; Hadisiwi (2011) who explored the meaning of filariasis as constructed by those who suffered from such illness in Bandung Regency; Hafiar (2012) who explored the phenomenological experiences of disabled athletes in Bandung; and Sulaeman (2014) the research on meaning construction and communication behavior with oligodactyly in The Village Ulutau Bone Regency South Sulawesi.

Through the health communication approach, communication as a symbolic act, then the health communication for the oligodactyly sufferers aims to explore the meaning through transactional communication related to physical abnormalities and physical organ deformities since birth. As a comparison, it can be seen from the extended idea of Schutz (1966:42) that "... is a certain way of directing one's gaze at an item of one's own experience." The meaning as the result of a construction, evolving with the subject's life experience. The meaning of physical abnormalities and physical organ deformities will change with the development of the experience of the oligodactyly sufferers related to the elements which become the parts of the meaning construction. The meaning possessed by the oligodactyly sufferers is formed from their own judgment and action by using interpretative perspective. The Individuals as the person with oligodactyly can give a certain meaning about themselves having physical abnormalities and physical organ deformities. The interpretive perspective is considered as more appropriate and holistic to examine the uniqueness of individual experience. In other words, their experiences of having physical abnormalities and physical organ deformities are subjective. This is their understanding, oligodactyly is not a disease, as objectively understood using scientific and/or medical measurements.

Based on an objective interpretive perspective, the oligodactyly sufferers have an experience that is assumed to be a subjective reality. In this context, the illness experience may be connected with one's personal, social and cultural beliefs and values. It is interesting to observe, to understand and describe how the subject, the oligodactyly sufferers construct themselves with the self-meaning when they have physical abnormalities and physical organ deformities with limitations of fingers and/or toes since birth, which are different from those of other people in the surrounding environment.

## Methodological Considerations

The limitations of oligodactyly suffering fingers and toes are the experience of a series of events experienced through various stages using the method of the phenomenology of communication, a study that seeks to reveal reality based on awareness based on experience through communication and interaction with oligodactyly suffering in the surrounding environment. This study refers to the statement "... *phenomenologists explore the structures of consciousness in human experience*" Creswell in Sulaeman (2017) with a qualitative interpretive approach, focusing on observation and natural atmosphere.

It is this awareness and experience of the oligodactyly suffering that shapes the meaning of a social reality that is different from normal people in the surrounding environment. This interpretation is associated with the object of research in persons with oligodactyly, which can be verbal or nonverbal which can be observed in communication and interaction in the surrounding environment. This study uses a qualitative research approach (Sulaeman, 2018) on subjective interpretive perspectives to find and explain the self-meaning of oligodactyly suffering.

The subjects in this study were oligodactyly suffering in Kampung Ulutaue, Bone Regency, South Sulawesi Province. This study involved 15 subjects including 10 men and the rest women. Their ages ranged from 15 to 78 years when the researchers conducted the study. 10 subjects were not married, others were married. Ten subjects had jobs as entrepreneurs, mainly sea scavengers (small shrimp, small oysters, and shellfish), one subject was unemployed. Most subjects have never been to school, they are not able to count, read, and write, and others. One subject is a Bachelor's degree at Hasanuddin University Makassar, and three subjects are studying at SLTP. Its uniqueness is that oligodactyly suffering men and women marry normal people. Most oligodactyly suffering has three fingers and/or toes. The rest have two and or four fingers and toes. Their hands and feet are very different from the fingers and feet of normal people. The selection of research subjects was based on the consideration that they were considered to have important characteristics and knew the information to be examined as illustrated in Table 1.

Table 1. Research Subject Identification

No.	Pseudonym	Age/Year	Gender	Education	Work	Population Status
1.	Ambo Asse	78	Man	Never attended school	Does not work	Married
2.	Kaharuddin	52	Man	Primary school	Fisherman	Married
3.	Gambur	32	Man	Never attended school	Fisherman	Single
4.	Ulhadi	38	Man	Never attended school	Cattle rancher	Single
5.	Cahaya	56	Woman	Never attended school	Sea scavenger	Married
6.	Hafid	23	Man	College	College student	Single
7.	Abditiro	40	Man	Never attended school	Farmer farm worker	Single
8.	Matahari	35	Woman	Never attended school	Sea scavenger	Married
9.	Antokaseng	15	Man	Never attended school	Cattle rancher	Single
10.	Nahriah	32	Woman	Never attended school	Sea scavenger	Married
11.	Renita	40	Woman	Never attended school	Fisherman	Single
12.	Ihwanullah	15	Man	Never attended school	Sea scavenger	Single
13.	Subaco	18	Man	Junior high school	Learn	Single
14.	Rahmat	15	Man	Junior high school	Learn	Single
15.	Nurhalijah	18	Woman	Junior high school	Learn	Single

**Source:** processed from various sources.

Data collection techniques used were in-depth interviews, participant observation, and literature study. In this study, researchers used structured interviews. This is applied because researchers want to explore the experiences, views, and knowledge possessed by the subject without being burdened by his mind. This means that when researchers conduct the interview process, people with oligodactyly suffering will have the flexibility of the structure of words and ideas in answering questions raised by researchers.

The researcher observed participation to reveal the subject's self-meaning when conducting interviews. The researcher not only observes but joins the subject when communicating and interacting with the surrounding environment. When engaging, the researcher communicates humorously by showing sympathy and feeling what he feels. Researchers also enter the world of life about what he experienced intending to see the actions and changes that occur in the subject in a different meaning of his relationship with others. Also, researchers conducted remote observations with the aim that the researcher's whereabouts were unknown. With this, researchers do not interfere with the subject's actions, so they do not feel intimidated. Researchers go directly to the field, acting as observers to create action categories, observe symptoms, and record and record the speech of subjects using media such as notes, cameras, and tape recorders. The aim is to obtain a complete and complete picture of the meaning of the oligodactyly suffering person.

The results of data collection obtained from the field are then analyzed through the flow of qualitative data processing activities carried out simultaneously, namely data reduction, data presentation, drawing conclusions, and verification conducted by the researcher through the interpretation of the data according to the context of the research question and related research objectives. This verification is obtained conclusions to answer the meaning of the person with oligodactyly suffering. Then verified with other data or with the research subjects.

## Physical Abnormalities of the Self-Meaning Oligodactyly Suffering

The reality of the experience of the oligodactyly sufferers with the self-meaning who has a physical deformity "fingers and/ or toes" from birth with self-positivity (accepting, spirit, optimistic, not disabled) and self-negativity (pessimistic, hopeless, socially withdrawn, and lazy).

### Accepting of the Self-Meaning

People with oligodactyly suffering accept themselves of the physical abnormalities they experience. Self-acceptance is the will of Allah, a test or trial that must be received, grateful for the sincerity of the heart, and not compared to the pleasure He has given, *"He wants to be perfect, not only a sharp nose, ... a self like this, a part of life, from Allah, I'm grateful for the longevity"* (Ambo Asse). From this it is understood that physical deformities are experienced, gifts must be accepted as creatures. For them, world life is a "disaster," to be lived even though he is physically different from others.

Self has like this, willingly accept what it is and try to improve themselves as humans are born with imperfections, the spirit to live life and provide help to others according to ability if someone asks for help, such as repairing pond embankments and celebration events (Abditiro).

Oligodactyly suffering gives meaning to themselves with "self-acceptance." The self-meaning of "accepting" is supported by Purwanti's research (2011:300-302), "Filariasis sufferer reconciled themselves by accepting the condition.....affecting their development to be not optimal, their illness conditions make them resigned." The self-acceptance of the Oligodactyly sufferers toward their physical deformity of the fingers and/or toes is the will and the test from Allah the self-acceptance of the Oligodactyly sufferers toward their physical deformity of the fingers and/or toes is the will and the test from Allah SWT which has happened as fate and must be accepted, be grateful to the sincerity of the heart, because it is not comparable with the blessings and enjoyment that God has given.

The acceptance of what they are does not mean that they never feel disappointed to have physical abnormalities. From says that "the love toward ourselves is a prerequisite for being able to love others" (Calhoun and Aocella, 1995: 74), by accepting oneself of having a physical abnormality, one may also accept others a human wants to have a perfect physical and not as an individual having physical abnormalities, but he does not seek treatment, because he feels embarrassed to be humiliated and ridiculed.

### Spirit of the Self-Meaning

The self has a physical disorder with enthusiasm in living life, is part of the life process like other people, does not inhibit communication by fostering good relations in the environment. Live life by doing self-introspection and not being silent, not as a hindrance to life, the spirit of life, helping family activities. People with oligodactyly suffering illustrate, the spirit of life never gives up. Give the spirit of life never give up in trying to do himself and accept his condition as an individual who must live their daily lives. Do not feel weak and assume physical abnormalities experienced are not obstacles in life. Believe, Allah gives trials according to ability.

Prefer to call themselves as physically deficient people. This deficiency does not prevent you from meeting others and striving to live this life as a life process as other people experience it. This lack, always self-introspection, is not silent, must try to live everyday life (Kaharuddin).

The self-meaning of having a physical abnormality comes from, "spirit" as the self-meaning of "live his life" in the process of life like other people, not hampering to communicate by fostering good relations with the environment. This statement is in line with the psychologist (Mulyana, 2010:40), that "Our primary need as human beings, and to become spiritually healthy people, is the need for friendly social relations. It can only be achieved by fostering good relations with others." Living our life with introspection, not doing nothing, not as a barrier to life, the spirit of life, helping family, struggling never giving up, not regretting ourselves in communicating with the surrounding environment.

### Optimistic of the Self-Meaning

Not surprisingly, interpreting physical abnormalities from the standpoint of "optimistic" self in the context of "ideal self" with an understanding as an expectation of the ability of his potential and deficiencies. Not all

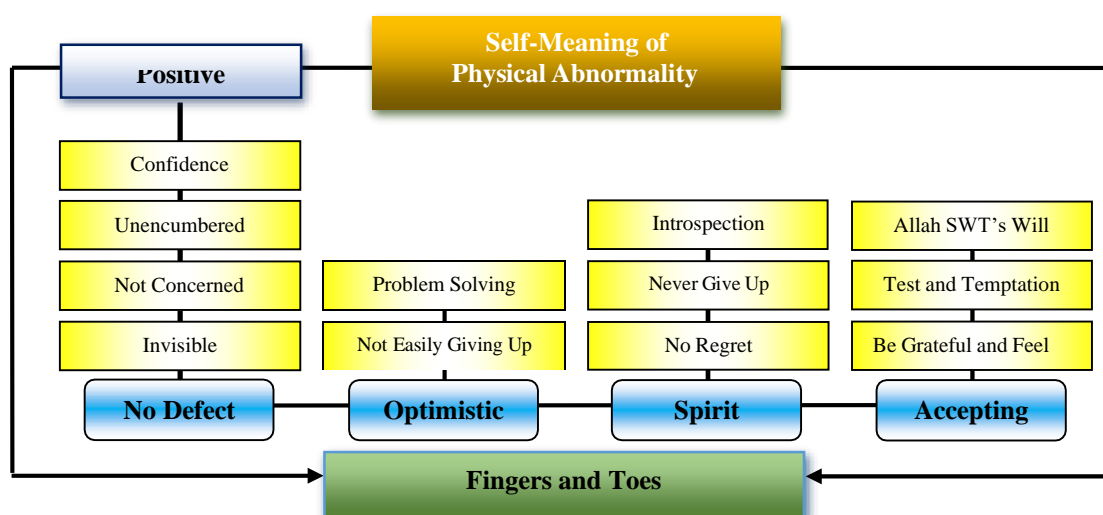
oligodactyly sufferers have an attitude of hope, but other informants still exist and can recognize their potentials and weaknesses. The self has physical abnormalities, found the category of optimistic self-meaning. Having an attitude of hope, staying in existence, and being able to recognize one's potential. Or hope for himself as an individual.

School to be smart. Do not want to be insulted by others, so you have to go to school as long as parents can still pay for it, but I also hope for others, ... can provide school assistance (Rahmat).

It is not surprising of the oligodactyly sufferers define physical abnormalities from an "optimistic" self-perspective in the context of the "ideal-self" with an understanding of having an expectation of the ability of his own potential and shortcoming, as Rogers explains "the individual has the hopefulness for himself. This expectation is self-ideal" (Calhoun and Acocella, 1995:71). The hopefulness of self-ideal of the oligodactyly sufferers as the hope of life in the future as Harre proposes about self-meaning is formed through intermediaries "... ourselves is connected with future circumstances. Intermediaries will be visible when individuals conduct activities. ... the ability of the individual, the possibility of what exists for the future" (Littlejohn and Foss, 2009:124). Having the hopefulness means the ability to recognize their potential in overcoming life's difficulties, not easily giving up, and being confident and not being afraid of their physical abnormalities from birth.

### No defects of the Self-Meaning

The level of desire to eliminate the stigma in the surroundings of an individual who has a physical abnormality, creating "no defects" as the self-meaning of the oligodactyly sufferers, the condition that is understood as "has no physical abnormalities." This meaning is defined as physically they are not different from others, they only assume if their fingers or toes are "Sticking" with other fingers or toes. Socially, the self-meaning of not having any physical abnormality means that they already have self-confidence, feeling himself has the same physical condition as others, unencumbered and thinking of having physical abnormalities.



Picture 1  
Positive Self-Meaning Based on Physical Abnormalities

### Pessimistic of the Self-Meaning

The rejection from the surroundings and the low self-esteem of the oligodactyly sufferers are the determinants of what they are able to do and what they are not able to do (Coleridge 1997: 53). Their self-meaning "pessimistic" often as "incapable" to have the hopefulness in the future, is the inability to generate power to push themselves toward a better future, self-blame, self-rejection by others. Seeing and believing if "they are weak, powerless, unable to do anything, ... and have no will to live" (Sham, 2012: 56). Being pessimistic, unable to interact and communicate well socially and feel as the inferior actor compared to others, eventually, they will feel insecure, afraid, and embarrassed to do social interaction and communication with the surrounding environment.



## Hopeless of the Self-Meaning

Physical disorders are not desirable, let alone have to suffer for a lifetime, until now there has been no solution given medically. Physical disorder that is interpreted as "hopeless" by "having no hope" of his ability to keep the spirit to face a life full of trials, because life is a gift that must remain grateful for, "*this physical deficiency, hurt yourself and make discouraged as a wife with physical like this*" (Matahari).

This physical deficiency hurts oneself and discourages me as a wife with this physique (Matahari).

I was disgusting and always looked down on, including my husband not accepting this situation. This situation makes inferior to meet other people because other people consider themselves higher degrees than themselves experiencing physical deficiency (Nahriah).

Physical abnormalities mean "despair" with "no hope" of his ability to keep the spirit of facing obstacles in life because life is a gift that must be cherished. As Purwanti (2011: 303) stated, "people who have the diseases and desperate for filariasis and has no spirit for life, they have a desire to die rather than to face the burden of the disease." The experience occurred because they have no hope for a happy life in the future and have a desire to commit suicide, be humiliated, felt discouraged, cannot survive in life, boredom, self-pity, heartbreak, less confident, the eyesore and no self-esteem as of the oligodactyly sufferers.

## Socially Withdrawn of the Self-Meaning

As "avoidance" acts of communication with the surrounding environment. Negative thoughts and assume others will insult and ridicule themselves when interacting. When communicating with the environment, tend to shut down, lack of confidence. This condition will have implications for inhibited interactions with others and always think negatively and assume that new people who enter the village will insult and ridicule them if they meet. He assumed, that people who are not known would meet him. They also assume that others will laugh at, ridicule, and insult their physical condition.

Like to be alone and do not want to get together in a crowd, ... if I'm working and people want to meet me (people who are not yet known), ... I'm not dizzy, avoid, sometimes I get angry and drive them away and say You just want to see my physical condition and take photos of myself for sale and even insult myself (Renita).

Now there are many people I don't know in the village, ... because since this village is known to other people, every day I see through the window of the house there are just new people coming to the village. ... Always wanting to meet someone like me ... sometimes I feel myself that that person is laughing at, mocking, and insulting my condition. In fact, I always scold my brother "do not meet new people, and I often expel these people to go from the village (Ulhadi).

If they are communicating with their environment, they tend to disguise themselves as a result of low confidence, as Maltz (1970:55) pointed out "to increase self-confidence, cultivating a positive perspective becomes necessary" it creates an avoidance of self-exposure, such as hiding, anti-social behaviour, apathy, inferiority, fear of their physical abnormalities.

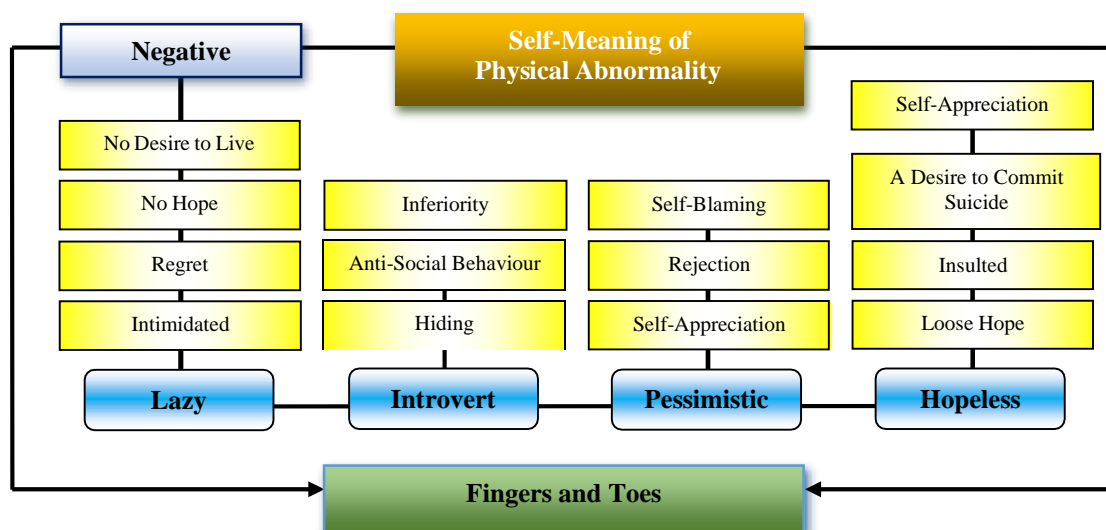
## Lazy of the Self-Meaning

This self-meaning of "lazy" is related to "life uncertainty," in the future. The meaning is in conformity with the statement of Syam (2012: 56-57) "... inappropriate and negative parenting skill, or a less supportive environment, tends to have a negative outlook....." The inability to cope with themselves is influenced by the surroundings such as parenting way which neglect and lack of attention, quick-tempered, and abusive to people with the oligodactyly.

Feeling disappointed and regretting this physical deficiency. ... I was the same age as school, but in reality, I experienced the opposite or was illiterate. Feeling depressed, having no hope for the future, no passion for working..... Every day is spent by being a sea scavenger and working as a fisherman worker. This job I feel bored doing it because it is considered this job can not change my life as a person with physical disabilities (Subaco).

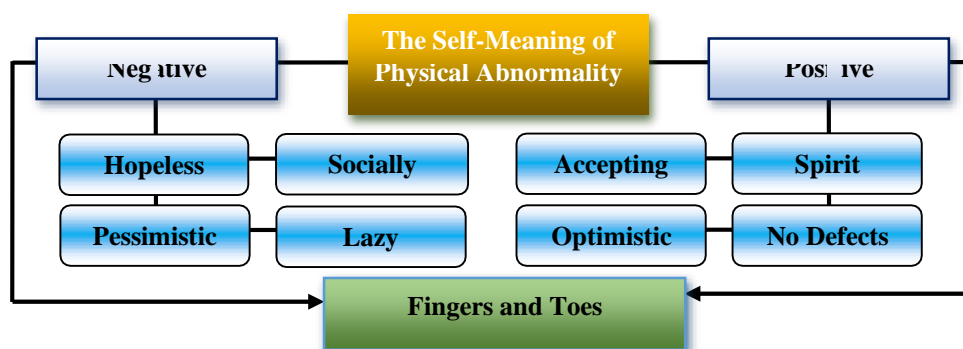
This way of parenting is inappropriate and tend to give negative self-meaning as individual who is "useless and have no hope for the future, such as the story from Alex Phiri (Coleridge, 1997: 40), role models for the

movement of people with disabilities in Zimbabwe and Southern Africa. Since the age of ten years was abandoned by his family in a hospital when he lost both of his legs.



Picture 2  
Negative Self-Meaning Based on Physical Abnormalities

The more experience and knowledge that is assessed from a certain point of view, the deeper meaning of the physical abnormalities can be analyzed; as the Musgrove (1977: 106) on the residents of nursing homes of disabled people at Leonard Cheshire Home. It was stated that "past events which are deeply entrenched in memories influence the meaning of something in the present". "Indeed, the meaning of physical abnormalities will change with the development of the experience of the oligodactyly sufferers related to the elements that are part of the construction of meaning. The meaning of oligodactyly sufferers is as "...the heart of perceiving, remembering, judging, feeling, and thinking ... when we reflect upon something and arrive at its essence, we have found another major component of meaning" (Moustakas, 1994: 68-70). Also mentioned "... without meaning we would not make choices because the concept of choice would be not available to us" (Lindlof, 1995:6). The meaning of oligodactyly sufferers is formed from the judgment and the actions of themselves having physical abnormalities in fingers or toes since birth.



Picture 3  
Self-Meaning Based on Physical Abnormalities

Using Cooley's view of the meaning of physical abnormalities in fingers and or toes, it will facilitate the understanding of how the oligodactyly sufferers define their self-meaning and then build the meaning of others around them. Through the communication with the surrounding environment, individuals think to modify and give meaning or change meaning based on the interpretation of the situation encountered (Ritzer in Mulyana, 2006). The formation of the meaning of physical abnormalities is a production process in which the oligodactyly sufferers seek to understand something and to communicate it to others based on the experience as part of their daily life in the social process.

## The Self-Meaning of the Physical Organ Forms Oligodactyly Suffering

The form of physical organs of the oligodactyly sufferers is characterized by the imperfection of three fingers and three toes; four normal fingers and four normal toes; four left fingers and four left toes, normal right fingers and toes; four right fingers, three toes and normal left fingers; four right fingers, normal left fingers and normal left toes; and three fingers and two toes. This form of the physical organ is owned from birth and see themselves as the different person to other disabled people in general, so it creates a self-meaning that causes them to feel shame, pity, the willingness of hard work, patience, and feeling encouraged.

### Feel Ashamed of the Self-Meaning

The physical organ form is meant to cause "feeling ashamed" with "discomfort" to live their life, always using "*sandal terompa* (pumped sandals)" to cover her toes.

The husband left his family, left without a reason, ... left by the husband since the second child was born, my burden as a heavy wife, ... left the husband and child also experience conditions like fingers and feet like this (Cahaya).

The feeling ashamed affects their behavior when they are away from home or when the walk on the street, they will walk quickly and ignore other people in their surrounding environment as the statement said "...hiding themselves from the views of others" (West and Turner, 2007: 103) see themselves through the ability of taking a role, such as wearing "*pumped sandals*" to cover the toes which are different from the other people's toes, indicating id their self-appearance that refers to Cooley, the concept of "*the looking-glass self*" that is "the ability to see themselves through the reflection of the view of other people" (Mulyana, 2006:74). Oligodactyly sufferers have the ability to reflect the judgment of others, such as the fearsome and frightening toes that eventually are covered by "*pumped sandals*."

### Worthy to be Pitied of the Self-Meaning

The self-meaning of "worthy to be pitied" is expressed in the form of physical organs as "concern" of having the imperfect fingers and/or toes compared to others.

Feeling poor life, ... working odd jobs, not eating in a day, ... tortured it feels like this life, ... want to work moreover, ... work to be a fisherman worker, ... the owner of the chart does not want to include, ... I am considered different from them, ... later fish will not be bought by people, because those who catch people like me are considered disgusting (Ulhadi).

They accept the stigma of family and community treatment for themselves. This treatment is similar to Goffman (1973: 11) expressed "stigma is often occurred on skin and physically defect," the acceptance of stigma as a denial and negation for themselves lead to the discrimination of generation and workplace which needs more attention, in line with the statement "... some institutional discriminations in the social system performed unfair treatment of certain groups of people, for instance, the existence of certain jobs which are difficult to get into it" (Eitzen 1986: 173). Discrimination is accepted and creates social anxiety and communication barriers, such as socially withdrawn, feeling depressed, introvert, and negative attitudes toward others.

### Willingness to Work Hard of the Self-Meaning

For of the oligodactyly sufferers, the deformity of physical organs is interpreted as "willingness to work hard" in facing the "life" by showing the integrity of the life spirit to support their family members, so that their child will have a better future "... deformity will make them stronger and/or harder worker ... having self-motivated and always trying to be stronger" (Gilson, 2012).

Work, ... not discouraged, don't give up sir, ... but why do you live like this, ... get enough money just to eat just every day, ... life can't change, life like this is tiring and disappointing with a limited physical condition, because I could not support myself and family members better (Kaharuddin).

This spirit of life reflects optimism, confidence and always be positive toward everything (Syam, 2012: 56). Having a passion for life does not give up with the ability to respect themselves, as a compulsory to fulfill the

basic needs of the family with the spirit of working merely for buying foods, cigarettes and not enough to afford children's education.

### Patience of the Self-Meaning

The oligodactyly accepts his situation with the meaning of "patience" with the act of "surrender" to Allah. Accepting the life and hope in his life will change someday if Allah wants a change of his life. The physical form of the organ is not their will, everything has become the destiny of Allah, although acceptance of stigma as the negative nickname "naughty finger" is identical with the imperfection of physical organs.

Life is not always like this. But I have to accept this condition, ... even though I have a life with economic disabilities, but I am sure that one day I will be given a better life than today (Ambo Asse).

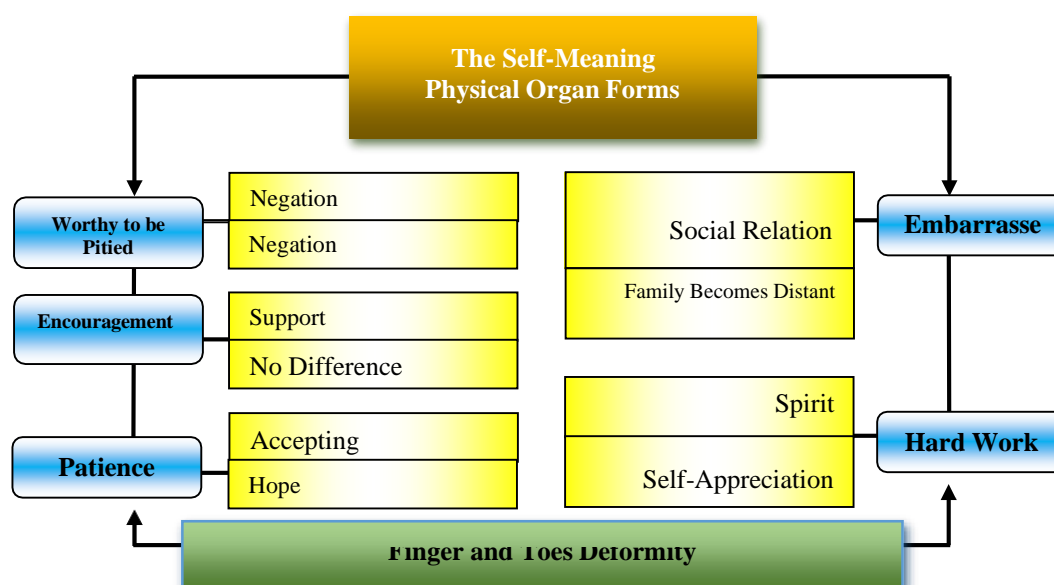
The same action was made by Goffman that "stigmatization for people with disabilities is related to individual disabilities" (1973: 14). Stigma as an act of discrimination "expulsion" to do activities together with others, as what Goffman stated that "Discrimination action is one of the self-images of stigma" (1973). Stigmatization as an act of discrimination is experienced when communicating with the surrounding environment.

### Encouragement of the Self-Meaning

The limitations of the physical organ forms were not interpreted negatively. It is given a meaning of "encouragement" which has the context of "hope" of life in the future. They have a particular group that accepts themselves as a support and not as an obstacle to having a "hope" of future life.

*Rahmat* as an informant said that "*it is not a hindrance, a hope for livelihood in the future, not feeling ashamed of physical organs like this.*" This situation did not make him feel inferior to friends in the village or at school and had to limit his activities. The hope of future livelihoods is reflected in his ideals. The drive shows that there is no difference between them to demand formal education.

With their ability, they conduct themselves in accordance with the group in their interaction and existence, not feeling embarrassed to limit themselves to do an activity. Finally, having an open attitude of placing themselves is a high value of an activity which is carried out to achieve the expected goals in accordance with the capabilities and conditions of his livelihood (Goffman in Muzaham, 1995:195). With the limitations, there is no difference compared to other people, never lose hopes and spirit to improve their lives for a better future.

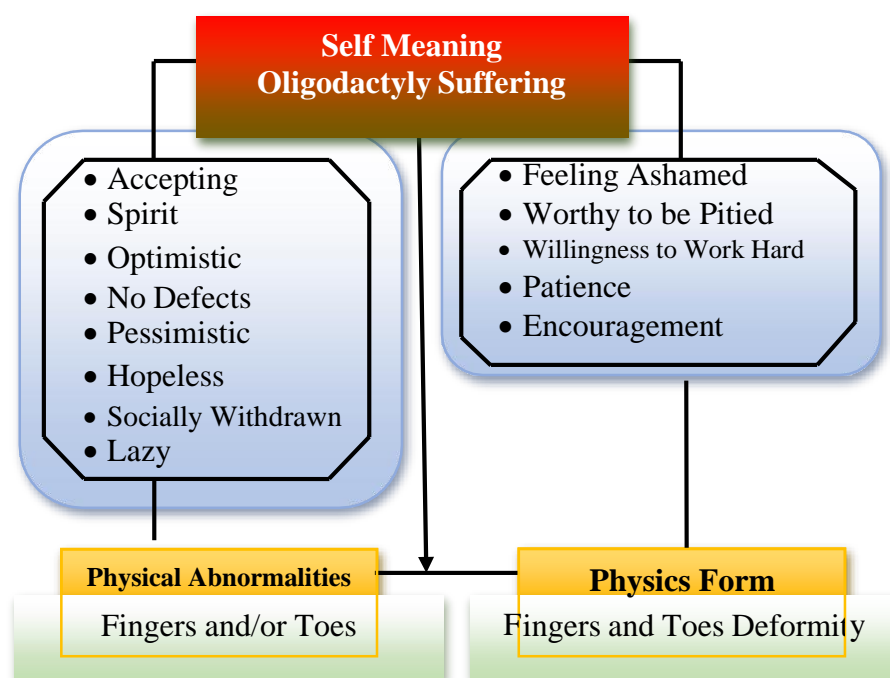


Picture 4  
The Self-Meaning on Physical Organ Forms

With the understanding and meaning of the form of physical organ, it can be seen that the self-meaning is shaped by the experience and knowledge of fingers and/ or toes deformity by which can change with the process of space and time changing, in line with Cooley's theory on the concept of "*the looking-glass self*" that is "the ability to see themselves through the reflection of the view of other people.

The social reality is characterized by physical deformity from birth, fostering a subjective interpretation for those who experience it. The subjective interpretation of the oligodactyly sufferers about themselves will diverse depend on their communication. Given the interpretation are an active process of thought and creative action in clarifying personal experiences (Littlejohn and Foss, 2009: 58).

The meaning of an oligodactyly sufferers has physical abnormalities and the shape of a physical organ from birth that is different from other people in the surrounding environment interpreted based on individual consciousness with subjective self-interpretation. In the principle of phenomenology and social action are focused on the subjective meaning of individuals. Therefore, Schutz in Mulyana (2018) explains the reality of the world to be intersubjective in the sense that community members share basic perceptions about the world that they internalize through socialization and enable them to interact or communicate. The actions of oligodactyly sufferers are part of their position in the surrounding environment so that their actions can only be camouflage or imitation of the actions of others in their environment.



Picture 5

### The Self-Meaning of the Oligodactyly Suffering

Phenomenology theory explains that phenomenology is a science that can be found external experiences, but more to the subjective awareness of oligodactyly sufferers, the self-meaning of oligodactyly sufferers comes from their life experiences, so self-meaning will be interpreted differently by everyone who suffers oligodactyly, depending on the life experience someone in their daily lives that can change over time, because changes in the situation are found in social interactions in the environment.

For Schutz, the social world must be seen from a historical point of view. Social action is oriented toward individual actions in the past, present, and future. In a phenomenological context, an oligodactyly sufferer is seen as an agent of communication actions who interpret his environment in a free will and desires to suit himself with a different meaning from others.

### Concluding Remarks

Some researchers explained to the oligodactyly sufferers have their own positive self-meaning of physical abnormalities in accepting, spirit, optimism, no defects, and negative self-meaning of physical abnormalities such as pessimistic, hopeless, socially withdrawn, and lazy by having physical deformity that causes feeling ashamed, worthy to be pitied, willingness to work hard, patience, and encouragement. Especially the self-meaning of the oligodactyly sufferers in the village of Ulutaue, Sulawesi, Indonesia based on experience and knowledge through communication with the surroundings environment.

This research has discussed some aspects of the life experiences of the oligodactyly sufferers. Further research needs to be conducted to investigate other aspects, one of which is how the oligodactyly sufferers communicated with the surrounding environment. It has been found, for example, that they receive the nickname "*jemari bertangkai* (finger stalked), *manusia jari kepiting* (crab finger man), and or *keluarga bertangan kepiting* (crab hand family)" that can weaken the oligodactyly sufferers. So by using the social

construction perspective, we can explore the communication with the physical abnormalities as a symbol that becomes the identity of the oligodactyly sufferers. Indeed, this topic is beyond our current discussion.

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Table 1. Research Subject Identification

No.	Pseudonym	Age/Year	Gender	Education	Work	Population Status
1.	Ambo Asse	78	Man	Never attended school	Does not work	Married
2.	Kaharuddin	52	Man	Primary school	Fisherman	Married
3.	Gambur	32	Man	Never attended school	Fisherman	Single
4.	Ulhadi	38	Man	Never attended school	Cattle rancher	Single
5.	Cahaya	56	Woman	Never attended school	Sea scavenger	Married
6.	Hafid	23	Man	College	College student	Single
7.	Abditiro	40	Man	Never attended school	Farmer farm worker	Single
8.	Matahari	35	Woman	Never attended school	Sea scavenger	Married
9.	Antokaseng	15	Man	Never attended school	Cattle rancher	Single
10.	Nahriah	32	Woman	Never attended school	Sea scavenger	Married
11.	Renita	40	Woman	Never attended school	Fisherman	Single
12.	Ihwanullah	15	Man	Never attended school	Sea scavenger	Single
13.	Subaco	18	Man	Junior high school	Learn	Single
14.	Rahmat	15	Man	Junior high school	Learn	Single
15.	Nurhalijah	18	Woman	Junior high school	Learn	Single

**Source:** processed from various sources.