Self-Meaning of Oligodactyly: Health Communication Study of People with Oligodactyly in the Village of Ulutaue, South Sulawesi, Indonesia

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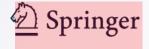
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REGULAR ARTICLE



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Abstract

A health communication of the people with oligodactyly aims at exploring the meanings associated with deformities of physical gans in fingers and/or toes from birth. This study discusses how fifteen people with oligodactyly in the village *Ulutaue*, South Sulawesi, Indonesia, construct themselves having physical abnormalities and physical organs different from those of other people through communicating with the surrounding environment. This research uses a subjective interpretive method with a health communication approach. The results explain that the people with oligodactyly are as the subjects and are considered to have their self-meaning, including the meaning of the physical abnormalities with the positive and negative self, the physical organ limitations with the self-meaning of feel ashamed, worthy to be pitied, will to work hard, 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 · Self-meaning · Physical abnormalities · Physical organ forms

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Introduction

The phenomenon of a social reality experienced by people with disabilities shows that some private companies do not accept employees (etc. Henry et al. 2014, 237-248; Saunders and Nedelec 2014, 100–110). Not to mention the existence of the political rights of people with disabilities (Dawkins 2012, 146; Spratt 2019) that is less been maximally protected and be ignored. Other people with disabilities often accept stigma (Endelstein and Louses 2013, 249-264; etc. Ali et al. 2012, 2123) as a discriminatory act (Zäske 2017, 147; etc. Adam et al. 2018, 27-34) 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 cannot interact with them (Stransky et al. 2018, 2147-2155). 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 (etc. Ali et al. 2012, 2123), related to the social role and social conditions of people who see people with physical disabilities as a social community. Those who suffer from bodily abnormalities have attracted little attention, especially people afflicted with leprosy and oligodactyly.

By definition, oligodactyly is the condition of fewer than five fingers or toes on a hand or foot (Chiang 2006, 137–145). Biomedical specialists such as etc. Robinow et al. (1986, 295–297) and etc. Turnpenny (1992, 659–667) have investigated those deformities from a clinical and genetic perspective. 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. 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 a 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 includes biomedical, personalistic, and naturalistic. The biomedical paradigm, including the people with oligodactyly, 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 people with oligodactyly.

However, fewer investigations on the social implications of this ailment have been carried out, let alone in Indonesia. This research is aimed to fill in this wide research gap. From a social perspective, people with oligodactyly is not merely a disease, but it is also an illness that may affect the psychological condition with oligodactyly and their interaction with people around them. This does not mean that due to the closed communication between individuals with oligodactyly, they carry out life activities like humans without physical disabilities, but people with oligodactyly seem to be isolated from the patterns of livelihoods of the rural poor. The people with oligodactyly, is like a vicious circle, partly dependent on how nondisabled people treat them. The worse the treatment, the worse their psychological condition. By understanding people with oligodactyly and subjective experiences, we can empathize more with them, so that they are more motivated to enhance their lives.



The people with oligodactyly in the self-meaning is unique; it is physical limitations and can provide knowledge to interpret him, so that the crisis of public awareness, especially normal people, the importance of understanding the sociological awareness competence of the oligodactyly 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. Another factor is the limitation of normal people to understand and know about what and how people with oligodactyly who are not contagious and disgusting, but who have physical disabilities. 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.

There has been a lot of research on healthcare based on the social construction theory (often associated with phenomenological and the symbolic interactionist theory). This overwhelming research includes the following works: Davis (1990), Musgrove (1977, Chapters 5 & 6), Vittoria (2011), Nguyen (2006), etc. Kovarsky et al. (2007), etc. Hinojosa and Craig (2011), and etc. 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 investiga 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 with 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 (2007) 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 (2011) found that the with 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. The people with filariasis interpreted their ailments as self humiliating and to be pitied, but in some cases as a driving spirit. Meanwhile, Hafiar (2012) discovered that the excelled disabled athletes had special identities that 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 people with oligodactyly who lived in the *Ulutaue* village 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 *Ulutaue* village was constructed by the media as "the village of crab human", causing resistance from some communities in the village, including from the with oligodactyly. Some of them realized that the television media constructed the village solely due to the profit-oriented aspect regardless of the physical, psychological, and economic conditions of the people with oligodactyly.

Abnormalities of physical organs are experienced as a symbol of "personal identity" of the people with oligodactyly 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 the people with oligodactyly as subjects rather than as



objects with the health communication approaches through transactional communication, such as their psychological, beliefs, behavior, social norms, traditions, and lifestyles.

Theoretical Perspective

Merleau (2007) states that phenomenology is the study of the essence in which all problems are the same as finding out the definition of essence. However, phenomenology is also a philosophy that returns essence to life and does not expect to reach a human understanding and the world from any starting point other than their "facticity" (etc. Tasleem et al. 2020, 241–251). However, today Goldthorpe (2014, 81–84) is known as the most prominent phenomenological theorist as he can make Husserl's abstract ideas easy to understand. Also, he introduced phenomenology into the social sciences and made phenomenology as a characteristic of social science to the present. He claims that phenomenology functions to connect scientific knowledge and where the knowledge comes from. In other words, it is based on social action on experience, meaning, and awareness (Goldthorpe 2014, 81–84).

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" (Goldthorpe 2014, 81–84). The meaning is the result of construction, develops along with the subject's life experience. The meaning of people with oligodactyly 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 oligodact 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 Mead have the concept of "self", as well as Cooley (1990, 184) defines it as "a process originating from the social interaction of individuals with others" (Mulyana 2018, 73) and for Mead and Cooley (1990, 184), "self" arises because of communication. The self-meaning 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 people with oligodactyly determines his or her meaning and then builds meaning about others around him.

The assumption of this theory, how the people with oligodactyly explore themselves with the self-meaning of having physical abnormalities and physical organ deformities that are different from other people through communication with at er people around their environment in daily life. As etc. Marks (2000, 6) point out, "people's accounts of health and illness are interesting and illuminating topics of study in their own right". The with 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 this



research, people with oligodactyly should be considered an illness rather than the sease. Etc. Kleinman (in Mulyana and Sulaeman 2016, 136–144) 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 a disease or ill health" (Scharf in Vanderford 2003, 14).

Through the health communication approach, communication as a symbolic act, then the health communication for the people with oligodactyly aims to explore the meaning through transactional communication related to physical abnormalities and physical organ deformities since birth. As a compact son, it can be seen from the extended idea of Goldthorpe (2014, 81–84) that "... is a certain way of directing one's gaze at an item of one's own experience". The meaning as the result of 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 people with oligodactyly related to the elements which become the parts of the meaning construction. The meaning possessed by the people with oligodactyly is formed form their judgment and action by using an interpretative perspective. 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 more appropriate and holistic to examine the uniqueness of the individual experience.

The individual experience deals with an understanding of how everyday intersubjective world are formed and aims to find out how individuals can interpret their social actions as meaningful and to reconstruct the derivative of meaning in individual inter-subjective communication in the world footnote footnote for social life (Goldthorpe 2014, 81–84). It means how to interpret social actions with others as meaningful (to be interpreted) and to reconstruct the derivation of meaning (meaning used next time) from meaningful actions in individual inter-subjective communication in the social life of the people with oligodactyly in phenomenological studies. This research focuses on the essence of the experience of the people with oligodactyly about the process of interaction and communication, meaning that they have physical abnormalities and physical organ shapes on the fingers and or toes.

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 2018, 73). Formation of meaning is a production process in which the people with oligodactyly tries to understand something and convey it to others based on experience as part of their daily lives in the social process.

Methods

This research uses qualitative research (etc. Sulaeman et al. 2020, 1–19; Sulaeman 2018, 662–674) with the method of the phenomenology of communication (Mulyana and Sulaeman 2016, 136–144) to explore individual by using a distinctive construction process (etc. Tasleem et al. 2020, 241–251), then give the meaning to the people with oligodactyly by using an "interpretative" perspective or more specifically, the perspective of social construction and symbolic interaction. To use Berger and Thomas perspective (1966), the social construction of reality is a symbolic interplay between



an actor's 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).

Preliminary information on oligodactyly as informants was obtained from peers and looked back at broadcast television coverage of the media constructing *Ulutaue* village as "the crab finger human village". In the field, researchers used location mediators and mediators with oligodactyly. Initially, for a month the researchers experienced relations with informants and researchers themselves psychology. Then establishing more close relations with informants, researchers entered the inner world of people with oligodactyly, such as providing educational scholarships, facilitating social support, facilitating building materials by with oligodactyly, and learning the process of empowering with oligodactyly in government offices. The relation of researchers is well established, even though researchers have finished conducting research, they often communicate to researchers through cellular media and vice versa.

In this study, the concern and applied of the researcher are maintaining the confidentiality of informant. The confidentiality of informant through not being given his real name, but pseudonyms as an of with oligodactyly. The inclusion of a pseudonym emphasizes the principle of volunteerism to provide the information needed by researchers. Volunteering is in the form of his conscious experience as an with oligodactyly. The ethics of the researchers' agreement with the informants to keep their identities confidential, without feeling afraid of interventions to express their experiences, despite telling of their ugliness. They hinted that the identity of his name is unknown so that it is more open and comfortable to tell the situation and whereabouts.

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

The researcher's experience in the *Ulutaue* village includes various data collection activities, such as interview techniques, especially in-depth interviews, and models, even though they have various risks, such as long nostalgic responses of joy and sorrow (Creswell and Poth 2017; Bogdan and Steven 1998). This technique allows the researcher to observe the informant activities and to listen or ask questions of the informants and the surrounding people in an actual situation that is not systematically controlled or regulated by study parameters. Researchers make observations when interviewing and informants doing activities. Researchers observe their homes, verbal



Table 1 Research informants identification of the people with oligodactyly

No.	Name are pseudonyms	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	Leam	Single
14.	Rahmat	15	Man	Junior high school	Leam	Single
15.	Nurhalijah	18	Woman	Junior high school	Leam	Single

Source: Field observations and interviews

and nonverbal actions, places where they work, including markets where they sell their catch, where they play and or entertain themselves. Researchers conducted this research for ten months from on date May 02th, 2018 to February 01th, 2019.

The researcher observed participation to reveal the informant self-meaning when interviewing. The researcher not only observes but joins the people with oligodactyly 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 himself 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 people with oligodactyly 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 sign of subjects using media such as notes, cameras, and tape recorders. The aim is to obtain a complete and complete picture of meaning the people with oligodactyly.

Researchers interviewed each informant between three to five times, so four times on average, with the duration of each interview between 50 to 90 min. Initially, making the interviews was not as easy as the people with Oligodactyly regarded us as journalists who would take advantage of them by reporting their life stories to readers. Even when they will be interviewed, the people with oligodactyly seemed uneasy, especially at the beginning. However, we could gather data from them, as we always showed our patience and empathy toward them. Most times, the interviews flowed smoothly. It facilitated the interviews because one researcher knew and used their local



language, enabling the interviews to be conducted intimately. We asked each of people with oligodactyly similar questions, although the sequence of the questions was not always the same.

The results of data collection obtained from the field are then analyzed through the flow of qualitative data processing activities carried out simultaneously (Rossman and Rallis 1998; Creswell and Poth 2017), 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 (Wolcott 1994; Creswell and Poth 2017). This verification is obtained conclusions to answer the meaning of person with oligodactyly. Then verified with other data or with the research informants.

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The People with Oligodactyly in Doing Activity

The people with oligodactyly interpret physical 47 ormalities as symbolically. The meaning of the symbol does not appear by itself but through a process of interaction with the environment. The meaning of physical abnormalities depends on the culture and social processes carried out when interacting with their environment. The meaning of the owned physical disorder will change along with the increase in their life experience. Individual experiences in carrying out activities of daily life have different meanings and are important for individuals. This individual has a difficult life economically, socially, and psychologically in everyday life as illustrated in Fig. 1.

- Eating rice with bare hands; rice continuously fell through their fingers.
- Holding small objects such as glasses and plates; people with oligodactyly often dropped these utensils unintentionally and broke them.
- Drinking a glass of water with trembling fingers.
- Going outside just to get in the sun. Even though when they were in the sun, some
 of them got sick easily.
- Working as sea pickers; due to their deformed hands and feet, it was difficult for them to pick small shrimps, small sisters, and seaweeds, and to work as assistants to fishermen.
- Selling the products in markets. Nondisabled people were reluctant to buy products from people whom they considered frightening and worried that the products were contaminated.

The limitations of the form of the fingers of the people with oligodactyly feel physically different from the physical self of others. This condition is felt there are differences with others, such as eating rice with bare hands; rice continuously fell through their fingers.





Fig. 1 The people with oligodactyly in the village of Ulutaue, South Sulawesi, Indonesia

This incident has been experienced since was a child, three years old and still feels. I see when my wife and child raise a glass to drink it does not always drop the glass, how come it feels different, they lift the glass well, whereas I do not and often the glass falls and broke, well there I just realized myself, oh my fingers are different from others because only have three fingers. (Interview with Kaharuddin at *Ulutaue* village, July 15th, 2018).

They understand that they have physical limitations, only three fingers compared to others with five fingers. This knowledge gave rise to their experiences with physical conditions on the fingers different from others. The people with oligodactyly feel physically different from others born with physical limitations, holding small objects such as glasses and plates; people with oligodactyly often dropped these utensils unintentionally and broke them.

Since I was a child when I was able to hold something. I observed my brother with normal physical condition doing drinking water in a glass with his hands not trembling, gradually giving rise to an experience in me that I could not do the same activity because the physical form of his fingers was different from the fingers of his sister's hands. This experience provides physical knowledge about the different fingers. (Interview with Rahmat at *Ulutaue* village, October 19th, 2018).

Physical comparison experienced by people with oligodactyly with other people's physical experiences. They cannot do the same activity "drinking a glass of water with trembling fingers". This experience, the physical form of the fingers, is differs from the physical form of others. This experience provides physical knowledge related to different fingers. Physical limitations give rise to the experience in themselves that they cannot carry out the same activities because the physicality in their fingers differs from the physical fingers of another person.

The social reality encountered can lead to a certain thought in oligodactyly. Like the experience to carry out activities in a way that is generally done by those around him. Raises questions in themselves that gradually give birth to an experience, such as going outside just to get in the sun. Even though when they were in the sun, some of them got sick easily. The people with oligodactyly have difficulty doing sunbathing in the moming sun and this experience has different physical abnormalities experienced with



other people in doing sunbathing, except bathing in the sea, so basking in the sun, direct headaches.

The people with oligodactyly women realize there is something different between themselves compared to others in working as sea pickers; due to their deformed hands and feet, it was difficult for them to pick small shrimps, small systems and seaweeds, and to work as assistants to fishermen difficulties experienced, made them realize their work as sea scavengers ware not the same as the work of other women. This experience is felt ashamed to carry out this work continuously which is different from other jobs in the village, only to do the work of drying small shrimp and the work of sea scavengers is only done by women oligodactyly.

The experience of women the people with oligodactyly there is something different between themselves compared to others when selling in the market, such as selling the products in markets. Nondisabled people are related to buying products from people whom they considered frightening and worried that the products were contaminated. Women's people with oligodactyly selling in markets where other people do not want to buy the sale, making themselves realize that the ability to sell is not the same as the ability of other people's sellers.

The people with oligodactyly feel helpless and need to be pitied (Phelan et al. 2001, 366). They need empathy from normal people, even though they not refuse assistance given to them, especially from the authorities responsible for people with disabilities and the poor in general. The people with oligodactyly, poorly educated have never even gone to school, due to conditions of economic disability. Low education possessed causes their interaction and communication is limited with others, especially normal people, and with limited job choices. When they interact and communicate with others, sometimes they are humiliated who nonverbally feel ashamed, bowed their heads, and offended.

Self-Meaning Physical Abnormalities of the People with Oligodactyly

The reality experience of people with oligodactyly through the self-meaning who has a physical deformity "fingers and/or toes" from birth with self-positivity (accepting, spirit, optimistic, no defects) and self-negativity (pessimistic, hopeless, socially withdrawn, and lazy) as illustrated in Fig. 2.



Fig. 2 The people with oligodactyly in the village of Ulutaue, South Sulawesi, Indonesia



Accepting

The people with oligodactyly accept themselves of the physical abnormalities they experience. Self-acceptance is the will of God, 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" (Interview with Ambo Asse at *Ulutaue* village, June 09th, 2018). 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.

Many of my trials as an ordinary human, sir, myself see myself in a blind state, unable to see, ... everything has become destiny as a weak human. (Interview with Ambo Asse at *Ulutaue* village, June 09th, 2018).

Self-acceptance of physical abnormalities does not interfere with the activities of daily life and does not feel it will burden his life and is only considered as a trial. Not only physical abnormalities are experienced, but they also experience blindness, all of which are considered destiny, meaning self resignation. What they are experiencing now is something given from God and must be accepted as a trial in the face of life.

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. (Interview with Abditiro at *Ulutaue* village, November 22th, 2018).

The people with oligodactyly give meaning to themselves with "self-acceptance." The self-meaning of "accepting" is supported by Purwanti research (2011, 300–302), "With filariasis sufferer reconciled themselves by accepting the condition. ... affecting their development to be not optimal, their illness conditions make them resigned." The self-acceptance with oligodactyly toward their physical deformity the fingers and/or toes is the will and the test from God 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 Joan 1990, 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

The self has a physical disorder with enthusiasm in living life, is part of the life process like other people, does not prevent communication by fostering good relations in the environment. The people with oligodactyly 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 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, God 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. (Interview with Kaharuddin at *Ulutaue* village, December 07th, 2018).

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 2018, 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

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 with 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 self have to go to school as long as parents can still pay for it, but I also hope for others, ... can provide school assistance. (Interview with Rahmat at *Ulutaue* village, January 05th, 2019).

The meaning physical abnormalities from an "optimistic" self-perspective in the context of the "ideal-self" with an understanding of having an expecting of the ability



of his potential and shortcoming, as Rogers explains "the individual has the hopefulness for himself. This expectation is self-ideal" (Calhoun and Joan 1990, 71). The hopefulness of self-ideal of the people with oligodactyly 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 Karen 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

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.

Physical abnormalities are not felt, giving rise to self-confidence and the self does not have physical abnormalities. Every day in the village can interact and communicate in the surrounding environment, make friends with anyone and assume everything in him is the same as other people. (Interview with Hafid at *Ulutaue* village, August 11th, 2018).

Physical abnormalities are not felt, give rise to self-confidence, have hope in life with enthusiasm. Although I still need encouragement and enthusiasm for life to improve his life in the future, so that the life of economic incapacity experienced now will be different in a better future. (Interview with Ihwanullah at *Ulutaue* village, January 10th, 2019).

The self-confidence of the people with oligodactyly shows that humans are all the same, there is no distinction from each other, so that they can eliminate negative feelings toward themselves and always see themselves and others alike. Finally, they can adapt to friends, both in the village and in the environment outside the village. Adaptation carried out with the surrounding environment shows their life expectancy with enthusiasm even though they have physical abnormalities.

The people with oligodactyly assume that self-perfection, not just from the physical, we must respect each other's shortcomings. Feel yourself the same as what is in other people who do not have physical deficiencies and live this life as it is, not burdened, not thinking about physical abnormalities. His daily life is carried out with passion and enthusiasm to fight for himself and his family so that he is not considered a beggar, even though he currently has an economic incapacity as illustrated in Table 2.



Table 2 The positive self-meaning based on physical abnormalities the people with oligodactyly

No.	Physical abnormalities	Meaning
1.	Accepting Accepting yourself	The will of God that has happened as fate, exam or trial that must be accepted, and grateful for the sincerity of the heart.
2.	Spirit Live the life	Self-introspection and not be silent, not as an obstacle to life, the spirit of life, help family activities, and fight unyielding and do not regret living in conditions of physical deprivation experienced by carrying out life activities.
3.	Optimistic Ideal-self	Difficulties faced must be able to overcome and not easily give up.
4.	No Defect Hasn't physical abnormalities	Self-confidence through adaptation, the same as other people, as it is, is not burdened, and does not think of physical abnormalities experienced, not visible when communicating and the fingers and toes only stick with other fingers.

Source: Field observations and interviews

Pessimistic

The rejection from the surroundings and the low self-esteem of the oligodactyly sufferers are the determinants of what they can 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" (Syam 2012, 56). Being pessimistic, unable to interact and communicate well socially and feel like the inferior actor compared to others, eventually, they will feel insecure, afraid, and embarrassed to do social interaction and communication with the surrounding environment.

Self-pessimistic, always blaming himself has physical abnormalities. Minder and unable to do anything. Always aloof, assuming others reject him. (Interview with Nurhalijah at *Ulutaue* village, December 04th, 2018).

Self pessimistic for life. Self as an orphan has physical abnormalities. The self is unable to arouse itself for the better because it is poor, inferior, and ashamed. Lifelike this is regrettable and friends stay away from him. Every day, only cow herding activities belong to other people and sea scavengers. The results of sea scavengers are used for snacks, independent living. (Interview with Antokaseng at *Ulutaue* village, October 21th, 2018).

The people with oligodactyly interpret themselves with pessimism, can not be separated from the experience in their lives as individuals who have physical disorders and always blame themselves for the physical abnormalities experienced. Lack of self makes them insecure and does not try to develop themselves. The people with oligodactyly consider themselves to not have the ability to hope to reach hope, do not have high fighting power, do not dare to hope to achieve their hopes in the future, not apart from other people's



rejection of the physical abnormalities experienced. Experiences like this, they are always alone thinking about themselves, other people do not accept him.

Hopeless

Being born with a physical disorder is not something that people want with oligodactyly, moreover this disorder has to suffer a lifetime and is a rare physical disorder and one of the characteristics of them in *Ulutaue* village. This physical disorder, there is no solution given medically. Hopeless physical disorder is interpreted as having no hope of the ability to face the spirit of life full of trials because life is a gift that must remain grateful.

This physical deficiency hurts oneself and discourages me as a wife with this physique. (Interview with Matahari at *Ulutaue* village, December 22th, 2018). 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. (Interview with Nahriah at *Ulutaue* village, October 07th, 2018).

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 have 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 people with oligodactyly.

Socially Withdrawn

As "socially withdrawn" 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. (Interview with Renita at *Ulutaue* village, January 17th, 2019).

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. I always scold my brother "do not meet new people, and I often expel these people to go from the village. (Interview with Ulhadi at *Ulutaue* village, November 29th, 2018).

The people with oligodactyly interacted in many different ways of communication with people around them, although most of them indicated a similar tendency, that is, a withdrawal from others' presence and their preference to be left alone. They were aware that they were people to be avoided by people without disabilities in the daily social intercourse. The research has found that the dominant negative messages the sufferers received and internalized from their immediate family members, relatives and nonfamily members have weakened their spirit to survive.

If they are communicating with their environment, they tend to disguise themselves as a result of low confidence, as Maltz (1984, 55) pointed out "to increase self-confidence, cultivating a positive perspective becomes necessary" it creates avoidance of self-exposure, such as hiding, anti-social behavior, apathy, inferiority, fear of their physical abnormalities.

Lazy

This self-meaning of "lazy" is related to "life uncertainty", in the future. The meaning conforms 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 ways which neglect and lack of attention, quick-tempered, and abusive to the people with oligodactyly.

Feeling disappointed and regretting this physical deficiency. ... 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 feel bored doing it because it is considered this job can not change life as a person with physical disabilities. (Interview with Subaco at *Ulutaue* village, July 22th, 2018).

This way of parenting is inappropriate and gives negative self-meaning as an individual who is useless and has no hope for the future, such as the story from Alex Phiri (in 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 as illustrated in Table 3.



Table 3 The negative self-meaning based on physical abnormalities the people with oligodactyly

No.	Physical abnormalities	Meaning
1.	Pessimistic Not capable	Blaming themselves that others reject and consider themselves worthless with others who ultimately make themselves inferior, afraid, and ashamed to communicate with their environment.
2.	Hopeless Have no hope	Humiliated thoughts, discouraged, unable to live, bored life as individuals who experience physical abnormalities, self-regret, hurt, discouraged, insecure, disgusting, and no self-esteem.
3.	Socially Withdrawn Avoid interacting	Hiding, confining themselves, inferior, afraid of the state of physical abnormalities experienced not to interact with the surrounding environment.
4.	Lazy Uncertainty of life	Always depressed, self-pity constantly, do not have hope for the future, and the passion for life is not there to work.

Source: Field observations and interviews

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 with oligodactyly related to the elements that are part of the construction of meaning. The meaning of oligogactyly 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 people with oligodactyly is formed from the judgment and the actions of themselves having physical abnormalities in fingers or toes since birth.

Using Cooley's view of the meaning of physical abnormalities in fingers and or toes will facilitate the understanding of how the people with oligodactyly define their self-meaning and then build the meaning of others around them. Through communication with the surrounding environment, individuals think to modify and give meaning or change meaning based on the interpretation of the situation encountered (Mulyana 2018, 86). The formation of the meaning of physical abnormalities is a production process in which the with oligodactyly seek to understand something and to communicate it to others based on the experience as part of their daily life in the social process.

Self-Meaning Physical Organ Forms of the People with Oligodactyly

The form of physical organs of the people with oligodactyly 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 sees themselves as a 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 as illustrated in Fig. 3.

Feel Ashamed

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. (Interview with Cahaya at *Ulutaue* village, December 16th, 2018).

The feeling ashamed affects their behavior when they are away from home or when they walk on the street, they will walk quickly and ignore other people in their surrounding environment as the statement said: "...hiding from the views of others" (West and Lynn 2007, 103) see themselves through the ability to take a role, such as wearing "pumped sandals" to cover the toes which are different to the other people's toes, indicating 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 2018, 74). The people with oligodactyly can reflect the judgment of others, such as the fearsome and frightening toes that eventually are covered by "pumped sandals".

Worthy to Be Pitied

The self-meaning of "worthy to be pitied" is expressed in the physical organ form as "concern" have different forms of physical organs, when compared to others.



Fig. 3 The people with oligodactyly in the village of Ulutaue, South Sulawesi, Indonesia



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. (Interview with Ulhadi at *Ulutaue* village, December 18th, 2018).

They accept the stigma of family and community treatment for themselves. This treatment is similar to Goffman 2009, 11) expressed "stigma is often occurred on the skin and physically defect", the acceptance of stigma as 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, and negative attitudes toward others.

Some individuals, even parents, siblings, in-laws, grandparents, and other relatives reject or not accept the conditions of the people with oligodactyly, as if they do not exist. The people around his neighborhood did not communicate much, looked away, and left without saying a word with oligodactyly and often experienced discrimination. With oligodactyly considered as a "beggar". because of the strange physical form organs with dirty and dirty appearance. As an individual is useless with a distorted treatment. The consequence people oligodactyly avoid interaction and communication with others. Thinking of others has weakened the will to survive.

Will to Work Hard

For of the people with oligodactyly, 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 and Stacy 2012).

Work, ... not discouraged, don't give up, ... but why do 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. (Interview with Kaharuddin at *Ulutaue* village, August 20th, 2018).

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

The people with oligodactyly accepts his situation with the meaning of "patience" with the act of "surrender" to God. Accepting life and hope in his life will change someday if God wants a change in his life. The physical form of the organ is not their will, everything has become the destiny of God, 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. (Interview with Ambo Asse at *Ulutaue* village, August 03th, 2018).

The same action was made by Goffman that "stigmatization for people with disabilities is related to individual disabilities" (2009, 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" (2009). Stigmatization as an act of discrimination is experienced when communicating with the surrounding environment.

Encouragement

The limitations of physical organ forms were not interpreted negatively. It is given the 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". (Interview with Rahmat at *Ulutaue* village, January 11th, 2018). 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 (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 as illustrated in Table 4.

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 charge 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.



Table 4 The self-meaning on physical organ forms the people with oligodactyly

No.	Physical organ forms	Meaning
1.	Feel ashamed Uncomfortable	Relationships with the opposite sex always end for no apparent reason, stigmatization as an act of discrimination in the household (away from the family), and the impact on lack of self-confidence, inferiority, and patience.
2.	Worthy to be pitied Concern	Obtain stigmatization as an act of discrimination in work that is considered disgusting, get stigmatization as an act of denial of descent, and economic inability.
3.	Will to work hard Live the life	The spirit of life, and the hope of a better future life, the ability to respect oneself as a necessity for life fulfillment.
4.	Patience Surrender yourself	Surrender, the will of God, hope of facing future lives, get stigmatization as an act of labeling which becomes the destiny of God.
5.	Encouragement Hope	Acceptance as family support and not as a hindrance, the announcement of which is considered no difference.

Source: Field observations and interviews

The social reality is characterized by physical deformity from birth, fostering a subjective interpretation for those who experience it. The subjective interpretation of the people with oligodactyly 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 Karen 2009, 58).

The meaning of people with oligodactyly 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. The principle of phenomenology and social action is focused subjective meaning of individuals. Therefore, Mulyana (2018, 132) 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 people oligodactyly 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.

Phenomenology theory explains that phenomenology is a science that can be found external experiences, but more to the subjective awareness of with oligodactyly, the self-meaning of people oligodactyly comes from their life experiences, so self-meaning will be interpreted differently by everyone who 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 Mulyana (2018, 146), 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, the people with oligodactyly 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.



Bodily Defects of the People with Oligodactyly

The people with oligodactyly of this research, there are three field findings regarding the condition of physical abnormalities experienced, including different physical organs, curse as a cause of physical abnormalities, and physical disorders as a gift. Differences in their perception should not be considered exclusive. Instead, they just have a different attitude as illustrated in Fig. 4.

Different Physical Organs

Their view of the physical abnormalities experienced has existed from an early age and claims to be different from the physical organs of normal people. Some with oligodactyly say that their physical organs are different from other normal physical organs in general. This understanding is obtained from parents, for example, buying certain sandals (pumped) to cover the toe disorders. The subject felt fortunate that he still had a deformity of the fingers and toes from birth, feeling he could not change forever. They realize that their physical condition makes normal people feel sorry, afraid, and disgusting for people who see it and or avoid meeting with them.

I am poor. Work is uncertain, sometimes as a seaweed scallop and scallop. Sell seaweed at the market and buy cigarettes, and bring home clams to eat. Often feel hungry, because there is nothing to eat, ... want to catch fish in the sea, but don't have a boat. I wanted to be a fisherman's aide but was ignored. I am with them. Even if could catch fish, people would not buy my catch because was considered disgusting. (Interview with Ulhadi at *Ulutaue* village, August 01th, 2018).

The people with oligodactyly have experienced negative feelings in the past, even though those negative feelings have been interpreted as pessimistic, hopeless, closed, and lazy to work. They blame themselves, they have no life expectancy. Realizing such bad luck, shame in front of normal people, especially the opposite sex. Feelings of shame encourage them to always walk with quick steps when outside the home and/or on the highway and ignore the people in the surrounding environment.



Fig. 4 The people with oligodactyly in the village of Ulutaue, South Sulawesi, Indonesia



Why live like this? Life does not change. Life is tiring and disappointing because have a physical disorder. Cannot make life and family's life better. (Interview with Kaharuddin at *Ulutaue* village, January 13th, 2019).

I am embarrassed. Friends shouted, "Don't get close, because you have naughty fingers. What they mean naughty fingers are the fingers that are not normal. They asked me to leave and not play with them. I have to accept this situation with the hope that one day they will not treat me like that anymore. (Interview with Subaco at *Ulutaue* village, December 17th, 2018).

The people with oligodactyly know that normal people will not approach them, let alone interact and communicate intimately. Beyond their imagination, normal people will marry her, except in the event, some special expertise, for example as a shaman. In relationships with the opposite sex, they feel disappointed when their partners reject the relationship, leaving it just like that, for no apparent reason.

I once approached women but always failed. A woman once liked me at first, but left me like that, she knew that I had a disfigurement of my fingers and toes. I feel humiliated and ashamed. I have to try again to find someone who can accept me as I am. (Interview with Abditiro at *Ulutaue* village, November 12th, 2018). I feel inferior. Have been abandoned by the husband since the second child was born. As a wife, I have a heavy responsibility. The child also has the same condition as having physical abnormalities in the fingers and feet. (Interview with Cahaya at *Ulutaue* village, January 18th, 2019).

In terms of gender, the female oligodactyly seemed to psychologically more than the male people oligodactyly because of the stigma attributed by nondisabled people. Women in the *Ulutaue* village were more dependent on men and on the family, rather than the other way around. Men people with oligodactyly were more likely to marry nondisabled women, especially if the men had expertise that could be used to maintain the family. In terms of age, the younger oligodactyly seem to be more depressed than the older ones. This tendency is partly due to the fact that the younger oligodactyly had greater needs to be accepted by their peers, and if possible, as prospective spouses. It is our assumption that if the people oligodactyly had received optimal psychological and emotional support from their immediate families and relatives, they would have had more positive self-concepts and less negative reactions toward nondisabled people.

The comparison process is carried out by the people with oligodactyly through differences in the physical form they have between themselves and others, which can form a certain identity within the people oligodactyly as explained by Erikson, that: "... identities are self-created, forms through identity conflicts and crises, through identities diffusion and confusion" (Martin and Thomas 2003, 49). The experience of self-identity as the people with oligodactyly can arise after going through the stages of crisis and confusion he experiences in connection with the difference between the physical form and function of the fingers and or toes possessed between himself and others.

The experience of the people with oligodactyly arising through the process of comparing physical forms and functions held between themselves and others is what drives human crab fingers to influence the concept of self-owned from the perspective



of differences with others, namely the fingers and or toes, the way to move, and different abilities.

Curse as a Cause of Physical Abnormalities

Some people with oligodactyly interviewed stated that this physical disorder was caused by a curse from God. Physical disorder experienced is an act and/or sin committed by their family, parents, grandparents, or even their ancestors. The with oligodactyly assume that these physical abnormalities are caused by negative attitudes from their ancestors who consider themselves to have a higher degree compared to others in the surrounding environment, such as condescension, humiliation, arrogance, and ridicule others..

When pregnant, mothers like to demean other women in the village, consider themselves higher degrees compared to other women. (Interview with Ambo Asse at *Ulutaue* village, November 19th, 2018).

My grandmother used to insult other people. (Interview with Gambur at *Ulutaue* village, July 16th, 2018).

My grandmother is arrogant and arrogant towards others who feel she is more beautiful than other women. (Interview with Renita at *Ulutaue* village, December 30th, 2018).

My grandmother likes to mock others, considers herself to have royal blood. (Interview with Nahriah at *Ulutaue* village, January 06th, 2019).

The people with oligodactyly perception of their illness are similar to the perception of people with leprosy in Tangerang as found by Teja (2006). Teja delineated that the dominant factor causing leprosy as perceived by the sufferers was God's curse of them, although they hardly ever associated the curse with the faults of their parents or their ancestors.

Physical Disorders as a Gift

Most people with oligodactyly admit that in the past they were hopeless and depressed who wanted to commit suicide. Over time, some of them sincerely accepted their physical condition. They try to be patient, strong, determined, hardworking, and optimistic about their lives. They tend to accept themselves and not as obstacles to living everyday life, has the potential to develop relationships with others. They believe that physical abnormalities in the fingers and toes and economic inability are gifts as gifts from God. They say that the abnormalities brings blessings in disguise, including:

- Physical strength. The oligodactyly seemed stronger than people without disabilities. They were continually working; they never looked tired in working.
- Physical immunity. They seldom suffered from other diseases, except for their deformed hands and feet. One oligodactyly, Ambo Asse, claimed that when he was



a child and fell down from a high tree, he was all right. He also claimed that sharp tools could not hurt him.

- Ability to read other people's minds. The sufferers knew what would happen through their dreams.
- Having spouses who pere physically normal, having durable households.
- Having the ability to work as Paraji, that is, traditional heapers as in the case with Ambo Asse, Renita, and Kaharuddin. They inherited the expertise to cure people from their parents. These people were considered as having supernatural powers with which to give favors to the environment, for example, by leading the ritual Mappare lise tasi in the village. In this ritual people feed the sea by bringing tuli (food) composed of colorful rice, eggs, banana leaves as the cover of the food, sirih leaves and a money (Rp. 1000,-) folded with the sirih leaves. Through this ritual, it is expected that the fishermen were given safety and much sustenance by pajjagatasi (the sea god).

Based on the people oligodactyly accounts, it is clear that their past illness experiences have been reinterpreted in terms of the present reality, although despite the fact that they were still with from the same illness. Indeed, Goldthorpe (2014, 81–84) confirms the significance of temporality in the social construction of reality: individuals give meaning to an event only after it has occurred; the meaning of an event is primarily retrospective. Based on the present perspective, the sufferers' past experiences are explicable.

My husband married me when I was 19. He was good looking, a virgin and physically normal. How come I got a husband like that. It was a gift for a physically handicapped woman like me. (Interview with Matahari at *Ulutaue* village, January 09th, 2019).

Physical condition is not perfect like others'. But have been granted a mind to complement my weakness. Finally able to predict and to find out what other people are thinking. In addition, body is strong. Never feel tired to work. Although have a physical handicap, it is a gift from God. Accept it sincerely. Have been given a long span of life. Have been granted several children and grandchildren. They often visit me to entertain. (Interview with Ambo Asse at *Ulutaue* village, November 12th, 2018).

I often cure people suffering from illness in this village. People think that I have a kind of superiority due to my deformed hands. I usually cure people on Friday. (Interview with Kaharuddin at Ulutaue vilage, August 12th, 2018).

Body as God's bounty as the wisdom possessed by the people oligodactyly is given to them to try to be stronger in facing their social reality. As Gilson and Stacy (2012) states that "... people with disabilities are self-motivated and always try to be stronger, ... without fear of disability, they feel they have extraordinary determination and courage, far more powerful than people normal people". The gift is felt with the limitations of the fingers and or toes that are not like that experienced by other people having normal fingers and toes as a "complement" lack of the people with oligodactyly.



The people with oligodactyly feel that despite having physical abnormalities, they still have a respectable status in the eyes of others, at least others in the surrounding environment need the help of a shaman for treatment. This research found that people with oligodactyly have the ability of non-medical treatment for sick people who are not only famous in their villages, but also other villages. They are considered by some villagers to have more trustworthy abilities than medical services. Other people who normally view oligodactyly have expertise because physical abnormalities are experienced in the fingers and toes.

Conclusion

The people with oligodactyly construct themselves with self-meaning that has physical abnormalities and different forms of physical organs from others. They give a certain meaning to what is experienced based on communication experiences in social interactions in their daily lives that have shaped the social world that they believe and developed into reality in social life. Some people with oligodactyly viewed their defected body just as a different body, while others considered their deformed hands and feet as God's curse, and still others regarded their ailments as God's bounty.

Some findings explain that people with oligodactyly have self-meaning physical abnormalities and physical form limitations. People with oligodactyly are treated differently from others in the surrounding environment, although most of them show the same tendency to avoid others from communicating in social interactions in the surrounding environment, such as self-despair and closed self are negative self-meaning discouraging to survive. The treatment of acceptance of discrimination raises social anxiety and communication barriers. This research found positive messages that tend to be accepted and internalized, such as resigned self, self-spirit and optimistic self as positive self-meaning with self-confidence, no distinction, life as it is, not burdened and not thinking about physical abnormalities experienced.

Then the shape of the owned physical organ is different from other people in the surrounding environment, some of them still regret their fate, and others interpret it as a gift from God behind the physical deformity and the shape of the physical organ experienced. As a human being wants to have a perfect physical and not as individual physical limitations but does not try to seek treatment, he feels ashamed to be insulted, ridiculed, and ridiculed as receiving treatment in the surrounding environment.

In this research the social construction theory and the theory of symbolic interaction has been useful in exploring the experiences of the people with oligodactyly. To some degree, the way the people with oligodactyly have defined their physical condition and the way they looked at themselves have been molded by the way others have treated them, although some of the people with oligodactyly have redefined their illness and their self-meaning in a more creative way, especially those who have considered their illness as God's bounty.

This research has discussed several aspects of the life experience of people with oligodactyly communicating with the surrounding environment. It has been found, for example, that they receive the nickname "finger stalked, crab finger man, and or crab hand family" that can weaken the oligodactyly. Further research needs to be carried out to investigate other aspects, one of which is how to explore forms of communication



behaviors with oligodactyly with fellow oligodactyly, families, communities, governments and television media. From a methodological perspective, it is hoped that this research can be continued with the same research methods and approaches, such as phenomenological methods and qualitative approaches to study the communication behavior of the people with oligodactyly. Indeed, this topic is beyond our current discussion.

A qualitative approach can be a method for understanding and knowing the communication psychology with oligodactyly. Through this research, it is hoped that related parties, especially the Ministry of Social Affairs, Ministry of Education and Sports support and socialize about the people with oligodactyly so that there is no more stigmatization as an act of discrimination and labeling for them. Socialization can be done in the form of seminars on disabilities so that the public knows that people with oligodactyly are not a contagious disease but rather a physical disorder in the fingers and toes.

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