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The values of family and social sources resilience of disability children: a phenomenology study

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ABSTRACT

This study was Aiming to describe how the values of the family resilience of children with hearing loss in the Bengkala, Bali. The study of participants included the parents of children with hearing loss, and community in Bengkala, Bali, Indonesia. In this study, values are understood as a crucial concept to explain the underlying motivations of resilience attitudes and behaviors demonstrated by the members of the family of children with hearing impairment. The data analysis technique using coding that is open coding, axial coding and selective coding, There are three themes related to the values that underlie the family resilience of parents of the children with hearing impairment in Bengkala, the which include: (1) the value of tradition and religious; respect, commitment and acceptance of traditional cultural customs and ideas or religion given, (2) The value of the policy; the which is the value of keeping and giving happiness, prosperity with the people who Often interaction in their group and (3) the value of universalism; that is the value of understanding, appreciation, tolerance, and protection for the welfare of all people and the environment.



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Introduction

The disability condition as a disaster and ordeals. The condition is often one of the obstacles for individuals who experience the disabilities on discrimination conditions in the community and experience barriers to achieving goals in life (Raghavan, 2015; Spencer, Erting, & Marschark, 1999), So also for families, where children with disabilities tend to be perceived as a burden of economic, social and moral (Heiman, 2002).

In Village of Bengkala, Buleleng Regency, Bali, Indonesia, were traditional village which view of unique tradition community. One of the traditional values of this village community is regarding the acceptance of hearing loss children who are believed to be the will of God and their ancestors (Suranata, Atmoko, Rangka, & Ifdil, 2017). Contrary to the families of children with disabilities conditions in general, in the village of Bengkala, presence of children with the condition of disability especially children with hearing loss is not perceived as something that actually dropped the family. Residents of hearing loss in this village had been there for generations. Uniquely sometimes the children with hearing impairment not always is from parents with hearing impaired, or even one or all of their parents was hearing impairment, but the children grow to be a normal child (not with hearing impairment). The children with hearing loss do social interact well in society

without discrimination. Many marriages also occur among normal people (not with hearing impairment) with some people with hearing impairment.

The amount of attention to the existence of rural communities of children with hearing impairment children in the village Bengkala evidenced either by the pioneering inclusive school in this village in years of 2007's. Before the inclusion of the school was founded, the hearing impairment children in this village are difficult to gain access to formal education. This inclusive schools accept children with special needs (especially with hearing impairment) and provide educational services system that is tailored to the needs of children without special needs through curriculum adaptation, learning, assessment, and infrastructure facilities.

Based on the results of the initial study through interviews with some of the figures in the village Bengkala, noted that people have the belief that the phenomenon of children born deaf and dumb in this village not just a question of the real world, but also about the natural balance of intangible (noetic). Some people in the community believe that the existence of hearing impairment person cannot be separated from the many spirits deaf in nature no real effect on the real world so that people born in Bengkala hearing loss. Historically, based on records of documents in this village, a hearing impairment childbirth in this village for generations have existed for more than 70 years ago (about the years of 1940). The results of this preliminary study indicate that there are certain values are adhered to and provide support.

The values in the appointment of the individual or group of individuals can be moving the individuals or groups of individuals to believe, behave and act (Schwartz, 2012), This value can be formed from the norms, traditions, beliefs prevailing in a particular community group. Schwartz (2012) suggested based on the theories of value, there are ten values that apply wide (universal) in accordance with the underlying motif respectively, which include (1) Self-Direction is value in thinking and acting independently; choose, create, explore; (2) Stimulation. The values concerning the spirit, novelty, and challenge in life. (3) Hedonism, concerning the value of sensual pleasure and satisfaction for yourself. (4) Achievement, concerning the value of personal success through demonstrating competence according to social standards. (5) Power, values concerning the social status and prestige, control or dominance over people and resources. (6) Security (security), the value of which concerns about safety, harmony, and stability in social life, interact, and security of person. (7) Conformity regarding the values in controlling the actions, inclinations, and impulses that may harm others and violate social norms or social expectations. (8) Tradition, concerning the value of respect, commitment, and acceptance of the customs and ideas of cultural or religious and tradition have given, (9). Policies, and provide value to maintain the happiness, well-being of the people you interact in the group. (10) Universalism, the value of which involves understanding, appreciation, tolerance, and protection for the welfare of all people and the environment. and stability in social life, interact, and security of person. (7) Conformity regarding the values in controlling the actions, inclinations, and impulses that may harm others and violate social norms or social expectations. (8) Tradition, concerning the value of respect, commitment, and acceptance of the customs and ideas of cultural or religious tradition given. (9). Policies, and provide value to maintain the happiness, well-being of the people you interact in the group. (10) Universalism, the value of which involves understanding, appreciation, tolerance, and protection for the welfare of all people and the environment. and the impulse that may harm others and violate social norms or social expectations. (8) Tradition, concerning the value of respect, commitment, and acceptance of the customs and ideas of cultural or religious tradition given. (9). Policies, and provide value to maintain the happiness, well-being of the people you interact in the group. (10) Universalism, the value of which involves understanding, appreciation, tolerance, and protection for the welfare of all people and the environment. and the impulse that may harm others and violate social norms or social expectations. (8) Tradition, concerning the value of respect, commitment, and acceptance of the customs and ideas of cultural or religious tradition given. (9). Policies, and provide value to maintain the happiness, well-being of the people you interact in the group. (10) Universalism, the value of which involves understanding, appreciation, tolerance, and protection for the welfare of all people and the environment. the welfare of the people who interact frequently within the group. (10) Universalism, the value of which involves understanding, appreciation, tolerance, and protection for the welfare of all people and the environment. the welfare of the people who interact frequently within the group. (10) Universalisme, the value of which involves understanding, appreciation, tolerance, and protection for the welfare of all people and the social environment.

Several studies have already discussed that the social value system in an environment of particular groups of people associated with psychological resilience, individual and family unit (Berkes, Folke, & Colding, 2000; Cote & Nightingale, 2012). Children with disabilities who are more vulnerable to discrimination in the social environment and society (Adair, 2015; Girli, Sari, Kırkı, & Narin, 2016). The values that develop in society are significant assets for the mental and social development of children with disabilities (Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014; Hart, 2013).

Parents or families merupakan unit sosial yang merepresentati masyarakat. In a family environment (Walsh, 2016). In the family environment unit, children with disabilities have the potential to get support so that they become resistant in carrying out their developmental tasks even though they have limitations (Anaby, et al., 2013; Coster, et al., 2012; Gibson, et al., 2012). This condition is generally referred to as family resilience. Family resilience Refers to the capacity of the family system to survive and rise from adversity, by strengthening and developing resourcefulness (Walsh, 2016). Families that are resilient in dealing with developing resources and managing disturbing experiences, stress buffers, and effective management that affect adaptation for all family members and the kin system (McConnell & Savage, 2015; Peer & Hillman, 2014; Walsh, 2016).

Interesting attention to this can be found in the families or parents of deaf children in Bengkala Village. they provide excellent care for their disabled children without distinguishing them from other normal children. Even in low economic conditions, they are trying to meet their children's need for ongoing medical care. There is no despair, anger, disappointment they show with these conditions. They are still working hard, enduring, moving from one difficulty to another. They can achieve their hopes and dreams so that their children who are deaf can live a normal or healthy life like other people. So that an in-depth study of what values are believed by the family or the social environment of the community in Bengkala Village regarding the existence of children with disabilities is interesting to study. Related to this, this study aims to describe the values used by families and communities in Bengkala Village in supporting development and gaining access to schools for deaf children.

Method

This study is a phenomenological study, with a qualitative approach (Gall, Borg, & Gall, 1996; Sokolowski, 2017). This phenomenological tradition-oriented research on the phenomenon of direct human experience, such as how they are thinking and feeling.

Respondents were selected by using purposive (Ames, Glenton, & Lewin, 2019; Rai & Thapa, 2015). Respondents on this study is four pairs of parents (the father and mother) children with hearing loss who were studying in Inclusion elementary School Bengkala, Buleleng, Bali, Indonesia. Interview with a pair of parents carried out simultaneously.

Study data was obtained through semi-structured in-depth interviews (Mears, 2012; Scanlan, 2020), as well as the use-field record. The interview lasted for 1-2 times with a duration 1-1.5 hours. The interviews focused on parents' views of the values they hold and use as well as the views of the community in the village to support the development and education of deaf children.

All data are from transcripts and recorded using an audio tape recorder to obtain the complete recorded data. Data analysis techniques use coding, namely open coding, axial coding and selective coding (Creswell, 2003). Data analysis takes place in line with the data collection process. Schwartz's value theory (Schwartz, 2012) is used to explain the meaning of each respondent's statement. Efforts to maintain data credibility are carried out through long engagement, data triangulation, peer debriefing, member checks and audit trails.

Results and Discussions

Based on the analysis of three respondents' pair of parents of children with hearing loss through coding, in Table 1 are described a narrative summary of the values that are believed by the families of children with hearing impairment.

Based on table 1, it can be seen that there are three dominant values that form the resilience of four parents who repress the families of children with hearing impairment in Bengkala Village. The first value is tradition and religiosity (Gunnestad & Thwala, 2011). This value involves belief and respect, commitment, and acceptance of traditional cultural or cultural practices and habits. all parents of children with hearing impairment who become participants of this study revealed that basically destined to have a child with hearing loss is a sadness or a disaster. But their belief on the tradition, culture and customs (Harry, 2002; Wright &

Masten, 2005), beliefs and values of religiosity that flourished in the village of Bengkala for generations encouraged them to become stronger, and to rise to accept that reality and do better for a brighter future expectation for the family and their children.

Table 1 <The Summary Narrative Values Parents Children Experiencing Hearing Loss>

Values	Parents DL	Parents PS	Parents WK	Parents DD
Tradition and Religious	The first time you find out one of her children with hearing loss at age 3, parents DL very sad and upset. But they started to wake up and accept these conditions when considering that one of the ancestors they also with hearing impairment, so assume this is part of a legacy that should they receive. They believe that by accepting and caring for a child with hearing loss is part of honoring ancestors.	Accept and thank the Lord even though endowed with a child with hearing loss. They believe that this is God's decision to be grateful.	Guessed when newly married, that one of his future there must be a hearing impairment because generations of legacy the blood of his parents had always some dumb deaf-born child in the family.	Feeling depressed and sad in a very long time (many years) with the birth of one of her children with hearing loss. In fact, they are the spouse is normal (without hearing impairment). But eventually, realize they must accept and believe in the birth of children with hearing impairment is a tradition in the village.
Policy	Attempting to meet the needs of food, clothing, and education and strive for children to receive medical care at least once a month.	Attempting to give happiness to their children both physically and psychologically.	Although on low economic conditions, giving priority to buy what is needed children with hearing impairment in order not to be sad.	Meeting the needs of children, their conditions care of the medical experts on a regular basis, and pay attention to its development.
universalism	With good care for their children with a hearing impairment means has fulfilled its obligations as a human being to keep the other.	Care for and raise children who are hearing impairment is a humanitarian duty.	Happy and deliver a hearing impairment son can live well in the community is a noble thing as a human being.	It is a duty as human beings to keep and receive, especially as he is our son.

The second value is the value of the policy (Fine & Glendinning, 2005; Resch, et al., 2010), which encourages efforts to safeguard and provide happiness, prosperity with people who often interact in groups. In this value domain, all participants revealed that they developed a belief that by trying to provide physical and psychological needs, the well-being of their hearing-impaired children made them more enthusiastic to continue the hope they had with their child.

The last value they show is about understanding, appreciation, tolerance, and protection for the well-being of other human beings or universalism. All participants illustrate that by treating and nurturing their children with hearing impairment as well as possible, they have carried out to other and be a good human being.

The above findings show that traditional and religious values are the main values that encourage families and communities to accept well, pay attention and encourage children with disabilities in Bengkala village to grow up, and get the same education as normal children.

Conclusions

Value is a crucial concept to explain social and individual systems and its amendments. The concept of value not only have an important role in the study of sociology, even in psychology, anthropology and other disciplines related to it. Values are the beliefs associated with emotions and feelings. When values are infused, that value will seep into the feelings.

The findings of this study described that behind the resilience shown by the families of children with hearing loss, there are the values they believe in and hold firmly. Those values include: (1) the value of tradition and religiosity, ie the value of involving honor, commitment, and acceptance of the customs and ideas of cultural or religious tradition given. (2). The policy value, that value to maintain and provide happiness, well-being with the people you interact in a group and (3) the value of universalism, namely concerning the value of understanding, appreciation, tolerance, and protection for the welfare of all people and the environment.

The implications of these findings are in terms of family interventions, in particular, families of children with disability. In line with the opinions Walsh (2016a) that a particular system of beliefs and values that can positively develop resistance or resilience in the family when it is experiencing a particular hardship or calamity. The results of this study add that the values and religious traditions, values and universalism policies need to be developed in the family

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