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Social support to improve self-care ability of people with mental disabilities

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ABSTRACT

The objectives of this research are to describe and explain types of social support provided by families and residents of surrounding communities to individuals with mental disabilities in Ponorogo Regency. This research used a qualitative descriptive approach along with its case study design. The data collection was undertaken through in-depth interviews, documentation, and passive observation. The sources of data were derived from main informants, events or activities that provided the social support to improve the ability of people with mental disabilities, and documents in the form of background data on the people with mental disabilities and other pertinent documents. The research subjects were 27 people with mental disabilities. To determine the research subjects and informants, a purposive sampling technique was used, and the data analysis used an interactive analysis model. The results show that families, normal citizens, and village government in Jambon district, Ponorogo Regency provide the social support to people with mental disabilities through the provision of self-care skills training, information and assistance in taking care of family members with mental disabilities. Likewise, the much-needed skills training is set to produce works worth considering.



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Introduction

The World Health Organization's International Classification of Diseases (ICD-10) defines mental retardation as a mental disorder that simultaneously refers to people of below average intellectual capability marked by the limitation of two or more skills, namely communication, self-care, social skills, safety, and personal health (Regan & Willatt, 2010). The overall prevalence of people with mental disabilities is publicly less-exposed. The Pusdatin data of the Ministry of Social Affairs showed 11.580.117 people with disabilities, and 1.389.614 people with mental disabilities (Maftuhin, 2016) in Indonesia in 2010. Another research by the National Socio-Economic Survey (Susenas) revealed that the population of people with disabilities in Indonesia in 2012 was 2.45% (6.515.500 people) out of 244.919.000 of the estimated population of Indonesia including people with mental disabilities. This prevalence has increased 2.45% out of the total population in Indonesia based on the data from 2009 to 2012 (Diono, Mujaddid, & Budijanto, 2014).

Jambon Sub-District, Ponorogo Regency is one of the areas whose citizens have many mental disabilities and people with disabilities (ODK), so that it is often called the mentally disabled village. Data on the total population of people with disabilities and people with mental disabilities in the mentally disabled village are presented in the table 1.

Table 1. The population of people with mental disabilities and people with disabilities

No	Village, Sub-district, Ponorogo Regency	Number of Population (people)	Number of People with Disabilities (ODK)	Number of People with Mental Disabilities	Percentage of People with Mental Disabilities
1	Sidoharjo, Jambon	6.263	301	285	4.55%
2	Krebet, Jambon	8.119	105	66	0.52%

Source: (Hanif & Asri, 2016)

Table 1 shows that many people with mental disabilities in the two villages in Jambon District, Ponorogo Regency, live in remote areas with barren and arid soil conditions and plains surrounded by limestone mountains. As the large number of people with mental disabilities emerges in the area, it is necessary to highlight in-depth factors resulting in mental disabilities. Internal or genetic factors are often the main factors due to mistakes of community members who do inbreeding, chromosomal abnormalities (Murry & Pu, 2011; Siew, Tan, Abbaspour Babaei, Cheah, & Ling, 2013) lack of nutrition during pregnancy (Armatas, 2009; Asri & Afifah, 2017), prenatal problems such as infections and herpes viruses, rubella, syphilis, and pregnant women's alcohol consumption (Iqbal, Baig, Bhinder, & Zahoor, 2016; Strømme & Hagberg, 2000).

Environmental factors are also a threatening cause, along with the presence of heavy metal content such as Pb (lead), Hg (mercury), Cd (cadmium) and Cr (a high toxic power of heavy metal) although it relatively has harmed the human brain. Heavy metals are regarded as inorganic so as to cause damages to the thyroid or thyroid gland. The presence of heavy metals in the Jambon District connects to the iodine in the ground water in that the drinking water in the area has the lowest level of iodine (Sunarto & Fitriawan, 2015).

Psychosocial factors can result in the mental disability inseparable from the lack of community education and low socioeconomic levels. Citizens have experienced periods whereas they have only consumed food of poor nutritional values for decades. The geographical conditions of remote areas lead to the lack of proper education and health services (Asri & Afifah, 2017). In addition, parents with stress conditions and lack of social support can cause the low stimulation of child development (Hanif & Asri, 2016).

Mental disability is defined as a symptom possessed by an individual who has a below average of intellectual functioning, and the limitation of two or more skills such as communication, self-care, social skills, safety, and personal health. Mental delays can either be known or diagnosed prior to the age of 18 years old (Danuta, Robert, Danuta, & Marek, 2015; Lianou & Siamaga, 2011; Sadock & Sadock, 2011). Mental disabilities are divided into four groups, namely (1) mild retardation (IQ of 50-75). This category is the largest part of the population with mental disabilities. As adults, their IQ is equivalent to children of 8-11 years old. Their social adjustment is almost similar to those of other normal adolescents, but they have weaknesses in terms of imagination, creativity, and the ability to make judgments; (2) moderate retardation (IQ of 35-49). After adulthood, individuals in this group have an IQ equivalent to children of 4-7 years old. Physically they look strange because that usually have a number of physical disabilities. Poor motor coordination is another weakness resulting in the slow movement; (3) severe retardation (IQ of 20-34). Severe mental disability is often referred to as "dependently retarded" in which individuals are severely retarded in motor and speech development and are often accompanied by sensing and motor disorders. They can be trained to help themselves on a limited basis. They can also be trained to do simple tasks, but for other more complex jobs they are still very dependent on others; and (4) profound retardation (IQ <20). This category of severe mental disability is also called "life support retarded", which fully requires the support of others to be able to survive, and their ability to adapt and speak is very limited.

Viewed from the aspect of physical and psychosocial development, individuals with mental disabilities look different from those of normal individuals in general. Therefore, people with mental disabilities need special attention from family and social environment because of their inability to take care of themselves in daily life and other adaptive skills. The ability to care for oneself is called self-care ability, which includes eating, drinking, bathing, brushing teeth, urinating, defecating, dressing, wearing shoes, buttoning clothes, and body health care (Ardiç & Cavkaytar, 2014). Self-care for people with mental disabilities consists of six components, namely mental stability, regulation of daily life, ability to receive support, development of relationships with others, empowerment, and motivation for life (Yamashita, 2018). This research more focused on self-care abilities in daily activities, such as eating, bathing, brushing teeth, washing cloth, and life skill training. This is caused that most of the individual with mental disabilities are in the moderate and severe categories so they need social support in their self-care abilities.

The ability of self-care is an important and supportive ability in daily life because it deals with the ability to develop oneself for people with mental disabilities urgently grabbed attention, family assistance, and social support from both the surrounding community and the government, so that individual with mental disabilities have a minimum ability to self-care (Ghaneh, Saeed-Banadaky, Rahaei, Rezaeipandari, & Mohiti Ardakani, 2016). Individuals with mental disabilities, especially the ones who belong to moderate and severe categories certainly need support from others (Hanif & Asri, 2016). Individual with severe mental disabilities have essential disorders of cognitive processes, disorders of sensory and motor functions that cannot function optimally so the self-care abilities is needed (Akhmetzyanova, 2014). Self-care is defined as the activities that people recognize and perform individually to maintain their life and health (Ghaneh et al., 2016).

In an individual's life, social support is a crucial need. Social support is multi-dimensional concept that describes emotional and physical comfort provided to individuals by other people (Campbell & Gilmore, 2014). Social support can derive from family, friends, teachers, communities, partners, colleagues, surrounding community, and various affiliated groups (Yasin & Dzulkifli, 2010). However, parent support is the strongest predictor of all symptoms of mental health (Campbell & Gilmore, 2014). In daily life, social support often plays a pivotal role in helping individuals to deal with the pressures of life, and promote mental health. Social support occurs because of extensive social networks that provide positive experiences for someone who is committed to sustaining love, respect, and care. Therefore, social support is crucial for individuals' lives. The low social support received by an individual is correlated with a variety of psychological problems, such as depression, loneliness, and anxiety. Conversely, the high social support obtained is positively connected to physical and mental health (Eskin, 2003; Yasin & Dzulkifli, 2010). Social support is a form of social modality that individual draw upon to help them cope daily stressors (Cheng et al., 2014). Social support is referring to a social assistance in the provision of psychological and material helps in order to enhance individual coping ability against any stress or ailment. Even though social support as one of the social factors of health, plays significant role in humanizing and enhancing psychological well-being in ones lives, included individual with mental disabilities. Social support is very important for disabled people to interact with other people and the environment (Sultan, Malik, & Atta, 2016).

The role of social support is very influential for the development of people with mental disabilities, especially in the mentally retarded village of Ponorogo Regency. Individuals with mental disabilities manifest social needs through emotional ties with family and people without disabilities. The family is a very important environment for the lives of individuals with disabilities (Danuta et al., 2015). Social support is very important to improve the ability of self-care for people with mental disabilities. To realize this, normal citizens show acceptance, create conditions for people with mental disabilities to play a full role in the activities held in the village, make fun activities, assume responsibilities according to their abilities, instill confidence and motivate them to live respectfully. To support this notion, (Danuta et al., 2015) point out that normal individuals must understand individuals with mental disabilities as they are very sensitive to what others say and what attitudes other show.

Many researchers have conducted research on people with mental disabilities associated with several psychosocial variables. However, this research obviously focuses on their ability to develop themselves with mental disabilities that must require social support, both from families and members of the surrounding community. Although people with mental disabilities have limitations in carrying out daily activities, the surrounding community provides opportunities for them to develop themselves and generate income economically. Thus, this research aims to describe and explain about forms of social support provided by families and surrounding community members to increase the ability of self-care for individual with mental disabilities.

Method

This research was undertaken with a time frame of 5 months. The research locations are two villages, Kreet Village and Sidoharjo Village, Jambon District, Ponorogo Regency, East Java, which is often referred to as the mentally disabled villages. The research design used a qualitative descriptive approach. This research was conducted to emphasize more on the observation of researchers toward interactions and daily activities of research subjects. In addition, it used in-depth interviews along with selected informants.

The data in this research are a number of information relating to efforts to carry out social support to improve the capacity of people with mental disabilities. Types of data sources include (1) 6 main informants, namely 2 village officials, 3 people who have family members with mental disabilities, 1 administrators and cadres of the Kasih Kasih Social Organization in Ponorogo Regency, (2) events or activities of providing

social support to improve the capacity of self-care of people with mental disabilities, and (3) documents of background data on the lives of people with mental disabilities and other pertinent documents. The research subject were 27 people with mental disabilities. To determine the research subjects, a purposive sampling technique was used, because it was adjusted to the objectives and research problems. In terms of the characteristics and types of data needed, data collection techniques used in this research include (1) in-depth interviews, (2) documentation, and (3) passive observations.

The data analysis was performed using an interactive analysis model (Miles & Huberman, 2002) carried out in two stages, namely during the data collection and after the data collection. More clearly, the data analysis was carried out through 3 (three) activities that took place simultaneously, namely (1) data reduction, (2) data presentation, and (3) drawing conclusions / verification. The techniques were selected by researchers to check the validity of the data, namely (1) extending the participation of researchers, (2) making observations diligently and carefully, (3) triangulation of data sources by comparing results of observations and the results of interviews, and the contents of documents used as a source of research data, and (4) check the findings through group discussions (focus group discussions).

Results and Discussion

Based on observation of the activities individual with mental disabilities show that the ability to self-care is still poor, such as eating, drinking, bathing, dress and undress, buttoning clothes, washing clothes, and brushing teeth. This situation is caused by disabilities especially the moderate and severe levels of having motoric coordination so that it looks less flexible in carrying out activities. This is supported by Yamasita's research that people with mental disabilities often impairment of self-care abilities because of disease characteristics such as cognitive dysfunction that might include inability to sustain attention and deficit in executive function. However, it is important to realize that family's support or the significant others are important to create or increase the ability of self-care for individual with mental disabilities (Yamashita, 2018). Ghaneh's research show that disability is common problem in a majority of the elderly and their self-care level is poor. Consequently, the role of parent and social support is needed to provide education on healthy behavior, as well as providing emotional, psychological, and financial support. This is very influential to increase their autonomy and confidence (Ghaneh et al., 2016).

The result show that even though their socioeconomic status is low, parents of individual with mental disabilities love and pay attention to their children's needs, especially in conducting self-care behavior in daily activities. The result of such research show that individual with mental disabilities need help with self-care abilities (Ghaneh et al., 2016; Lianou & Siamaga, 2011; Miyahara, 2008; Yamashita, 2018; Yasin & Dzulkifli, 2010). The ability to develop oneself, including the ability to dress and undress, use the toilet, take food independently, bathe, wash, and so forth directly affect the self-measurement of mental disabilities and it is an important stage in socializing themselves (Akhmetzyanova, 2014).

Despite their weaknesses, parents of individuals with mental disabilities are very loving and considerate of their children's needs. The results of in-depth interviews with parents' informants of people with mental disabilities indicate that parents and family members of people with mental disabilities claim to be unburdened and not feel ashamed with a glaring fact that they have such family members. Parents claimed to be resigned and were still grateful for the circumstances. They accept their disabled children sincerely; they do not complain, and declare that the conditions are a destiny from God. As can be viewed from the observations, parents' attitudes toward their children with mental disabilities are very good; parents do not differentiate between children with mental disabilities and normal children. Parents can actually learn many positive things from their lives, such as practicing patience, valuing time, and learning to appreciate every effort made by their mentally retarded children. As seen in daily behaviors, parents love them and prioritize the needs of their disabled children. All of this is a form of social support that important increases the capacity of self-care of family members who experience mental retardation. The most visible form is the parents' attitude to guide and educate children to carry out daily activities such as eating, drinking, bathing, urinating and defecating, and wearing clothes independently. Miyahara's research (2008) supports this research result by putting forward viewpoints on families who have family members with mental disabilities (Miyahara, 2008). They can provide social encouragement in the form of instrumental, informational, and emotional support. Instrumental support is mainly concerned with self-care or self-care, and delivery of therapy. In addition, families provide informational support to obtain information about disability, provide care and services, and solutions to problems faced by people with disabilities. While emotional support in the form of love from family, friends, or people around them.

Social support provided for people with disabilities is not only obtained from parents or families, but also from the community, Rumah Kasih Sayang Social Organization, and government of Ponorogo Regency. The form of social support from the community to improve the self-care abilities for individual with mental disabilities is to provide life skills training. The purpose of this training activity, in addition to training hand skills, is also an empowerment effort to improve their economic level, namely training to produce things that have market values. The products include doormatss made of patchwork, brooches from corn husk, feather duster, catfish farming, angkrang as an ant cultivation, and goat livestock. The products are marketed to offices at the sub-district level and surrounding communities, with assistance from the Rumah Kasih Sayang Social Organization.

The direct observation in the research setting indicates that a person with mental disability has multiple disabilities; though deaf and impaired in terms of speech productions, they are very skillful in making patchwork rugs. The products look elegant and neat due to a patchwork color composition that is very artistic and is not inferior to products made by normal crafters. This is one proof that intense attention and training can improve the life skills of people with mental retardation. In addition to training, administrators and cadres of the Rumah Kasih Sayang Social Organization (RKS) and the Kreet Village Government visited the homes of people with disabilities to provide knowledge, practices and simple actions in self-care such as how to brush their teeth properly, wash their hands using soap, wear their own clothes, bathe, and clean the house by themselves. The village apparatus and administrators of the Rumah Kasih Sayang Social Organization periodically invite normal community members to provide counseling on healthy living for people with mental disabilities and their families, such as health education by providing guidance on clean-healthy knowledge, attitudes and behaviors about hygiene and self-care, such as washing hands using soap, dental hygiene, home hygiene, and home sanitation. Much assistance has been provided by various parties both from the government, private institutions and individuals through the social organization Rumah Kasih Sayang. One form of assistance received was daily medical equipment such as toothpaste, toothbrushes, bath soap and laundry soap. Of course, this assistance is very useful in maintaining the physical health of people with disabilities who mostly come from economically disadvantaged families. The other side, health service officers of the Ponorogo District Health Office pay attention to people with mental disabilities by providing the counseling on the importance of cleanliness of the surrounding houses and consuming iodized salt as an effort to overcome Iodine Deficiency Disorders (IDD). Health centers at the sub-district level provide health services in the form of care for people with mental disabilities who have panic attacks. According to data obtained from some documents under research, most people with mental disabilities have had panic attacks and are treated at the district health center. Other research conducted by (Fasihi Harandi, Mohammad Taghinasab, & Dehghan Nayeri, 2017) mentions that social support from families and community benefits for individuals who face events that trigger stress both physically and psychologically.

The social support from normal residents in the surrounding areas is the social acceptance of the condition of people with mental disabilities by involving them in community activities without exception. This support is crucial because it will impact on the quality and life satisfaction of people with mental disabilities. This is in line with what (Kapıkıran, 2013) highlights, social support shown to people with disabilities is a factor that mediates the development of life satisfaction. It is also a major predictor in adapting to the environment (Campbell & Gilmore, 2014; Miyahara, 2008; Rueger, Malecki, & Demaray, 2010).

The social support is an important factor in daily life in establishing self-care abilities of people with mental disabilities so as to improve the psychological well-being of individuals with disabilities. This is supported by the statement that individuals with mental disabilities have a twice-higher prevalence of mental health problems compared to normal individuals in the general population so that social support can improve the psychological well-being of people with disabilities (Einfeld, Ellis, & Emerson, 2011). Social and financial support from family, community, and government are important for individual with mental disabilities because they have many social, economic, and psychological challenges. These include stress, worries, sadness, and bitterness (Ambikile & Outwater, 2012).

Conclusion

The community needs to realize that self-care abilities for individual with mental disabilities is very important in survival. This result show that social support from family, environment, and government are important to enhance the self-care abilities of individual with mental disabilities in their daily activities, and

providing life skills training so that the individual with mental disabilities can remain useful with all their weakness.

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