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## Relationship of Family Function to the Quality of Life of Persons with Disabilities

Budi Susanti<sup>1</sup>, Mora Claramita<sup>2</sup>, Wahyudi Istiono<sup>2</sup>

<sup>1</sup> Seborokrapyak Primary Health Care; Indonesia

<sup>2</sup> Department of Family Medicine and Community; Faculty of Medicine, Public Health and Nursing; Universitas Gadjah Mada; Yogyakarta; Indonesia

### Corresponding Author:

Budi Susanti: Seborokrapyak Primary Health Care; Purworejo; Central Java. Dusun II, Seborokrapyak, Banyuurip, Purworejo, Jawa Tengah 54171.

E-mail: [santiajipwr@gmail.com](mailto:santiajipwr@gmail.com)

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### ABSTRACT

**Background:** People with disabilities are often referred to as disabled people, and regarded as unproductive members of society, unable to perform their duties and responsibilities so that their rights are sometimes not protected and violated. The number of persons with disabilities is about 15% of the world population, with 2.45% in Central Java and 0.75% in Purworejo Regency. Many people with disabilities need family attention. As a direct result, family has an important role in improving the quality of life of persons with disabilities. Assessment of family function using the family APGAR score and the quality of life of persons with disabilities using the WHOQOL-BREF instrument can be performed by most family doctors. **Objective:** This research aimed to determine the relationship of family function in people with disabilities using Family APGAR scores and quality of life using the WHOQOL-BREF instrument. **Methods:** This research was a quantitative analytical study with a cross-sectional design. Out of a total of 535 people with disabilities as research subjects and respondents, 190 people were excluded and 345 respondents were included. Statistical analysis used Spearman correlation tests to determine the relationship between the quality of family function and quality of life. Data processing used the Syntax program with significance set as  $p < 0.05$ . **Results:** Data collection in 29 villages that became the locations of the study obtained 345 samples. Statistical analysis results showed significant associations of APGAR score, sex and age with WHOQOL-BREF measurement ( $p = 0.00$ ). The family function had a significant relationship with the quality of life in the domain of social and environmental relations. **Conclusion:** There is a relationship between family function and the quality of life of persons with disabilities in the domain of social and environmental relations.

**Keyword:** Family APGAR, WHOQOL-BREF instrument, people with disability

### INTRODUCTION

People with disabilities refers to those who are disabled, and often regarded as unproductive citizens, unable to perform their duties and responsibilities so that their rights are not protected and they are neglected. According to the World Health Organization (WHO), disability is damage of body function or structure, limitation of activities or difficulties encountered by individuals in carrying out a task or action and limitation of participation and involvement in life situations<sup>1</sup>.

The number of people with disabilities is about 15% of the world population and 80% of them are in developing countries<sup>2</sup>. According to the results of the National Socioeconomic Survey (*Susenas*) in 2012, the number of people with disabilities in Indonesia was 6,008,661 people (2.45%)<sup>3</sup>. The prevalence of people with disabilities in Purworejo Regency was 0.75%<sup>4</sup>.

Such considerable numbers of people with disabilities need attention from their family. Family plays an important role in improving the quality of life of people with disabilities. Recognizing dysfunction in a family can help family doctors in improving the quality of life of people with disabilities<sup>5</sup>. Family function can be measured by a family APGAR questionnaire consisting of five main social function aspects: Adaptation, Partnership, Growth, Affection and Resolve.<sup>6</sup> In addition to having good reliability and validity, this questionnaire is practicable and workable so that it is widely used in primary health care services.

Family is a group that plays a very important role in developing, preventing, adapting, and/or solving health problems found in the family. All potentials owned by people with disabilities can be maintained, or developed and even actualized to achieve the optimal quality of life of people with disabilities<sup>7</sup>.

The WHO defines a person's quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.<sup>2</sup>

The quality of life of persons with disabilities can be measured using the WHOQOL-BREF instrument, consisting of 4 domains and 26 items, namely Physical, Psychological, Social, and Environmental, with excellent validity and reliability<sup>1</sup>. Recently, mental health researchers have studied the association of family function with the quality of life of people with disabilities. This research aimed to determine the relationship of family function in people with disabilities using Family APGAR scores and quality of life using the WHOQOL-BREF instrument.

## RESEARCH METHODS

This research was a quantitative analytical study with a cross-sectional design. The subjects of this research were all persons with disabilities in the Banyuurip subdistrict, Purworejo Regency in Indonesia. Samples were taken using total sampling totaling 535 people with disabilities, consisting of 10 people with hearing impairment, 30 people with mental retardation, 11 people with visual impairment (blindness), 7 people with cerebral palsy, 441 people with physical disabilities, 10 double-disabled people and 26 former psychotic persons.

The inclusion criteria were the following: 1) people with disabilities, 2) living in Banyuurip Subdistrict, Purworejo Regency, 3) able to speak Indonesian language, 4) willing to participate in the research, and 5) aged  $\geq 18$  years old. Deaf people who could not communicate, people with Cerebral Palsy (CP), and people with disabilities who were not willing to be respondents were excluded from this research

This research analysis examined two variables, namely the independent variable, i.e. family APGAR score ranging from 0 until 10, and the dependent variable, WHOQOL-BREF instrument with a scale of 0-100. The confounding variable that was not measured was regulation concerning rights and obligations of people with disabilities in Law No. 8 of 2016.

Data were collected through interviews. Questions in the questionnaire were read by the data collectors, specifically researchers and research assistants from the Universitas Gadjah Mada undergraduate nursing program and NURSE specialist program who had received explanation concerning the data collection procedures before the research began.

The Family APGAR questionnaire and the WHOQOL-BREF instrument employed in this research had undergone cross-cultural adaptation to maintain the validity of the concepts after it was translated. The assessment of a trial of the Family APGAR questionnaire and Indonesian translation of WHOQOL-BREF in 30 respondents indicated that both questionnaires were valid and reliable to be used in the research in the Indonesian context. These results were consistent with pre-existing studies.

Data were analyzed using quantitative analysis methods through Spearman's statistical tests to determine the correlation between quality of family function and quality of life. The data used were primary data with ordinal and interval data scales. The research data were processed using the software Syntax program with significant value set as  $p < 0.05$ .

## RESULTS

This research involved 345 respondents and excluded 190 respondents, consisting of 41 who were not willing to participate as respondents in the research because they were ashamed of their physical condition, 25 who died, 27 moved to other subdistricts following their children or relatives, 10 people not considered people with disabilities in the village, 44 psychotic persons from the data of social services agency of Purworejo Regency recorded as former psychotics, 10 heavily deaf, 7 double disabled and 16 persons with CP. The number of people with disabilities in Banyuurip was 525 people, while the number of the entire population is 45,212 people so that the prevalence of people with disabilities in Banyuurip District Purworejo was 1.16%. The results are presented in the following some tables and images.

**Table 1. Varieties of disabilities in Banyuurip district Purworejo district**

No	Various	Amount	Percentage
1	Physically disabled	247	47
2	Deaf	31	5.9
3	Blind	33	6.3
4	Mute	15	2.9
5	Double disabled	33	6.3
6	Expsychotic	127	24.2
7	Mentally Retarded	23	4.4
8	Cerebral Palsy	16	3

Data source of PMKS sub district Banyuurip Purworejo district.

Table 1 shows most of the people with disabilities in Banyuurip district, Purworejo district are physically disabled, while speech impairments and CP are only a few of the total disabilities.

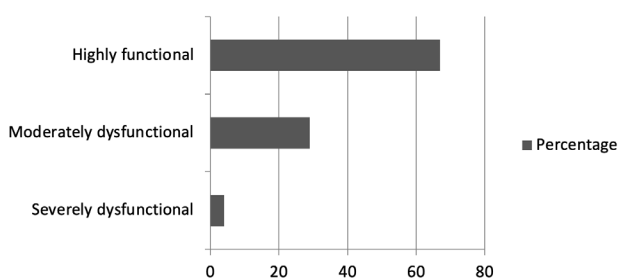
**Table 2. Distribution according to the basic characteristics of respondents**

No	Characteristics of respondents	Frequency	Percentage*
1	Gender		
	Male	197	57.1
	Female	148	42.9
2	Profession		
	Farmer	109	31.6
	Entrepreneur	24	7
	Unemployment	187	54.2
	Laborer	25	7.3
3	Marital status		
	Married	155	44.9
	Not married	190	55.1
4	Level of education		
	Not finished primary school	141	40.9
	Primary school / SLB	113	32.8
	SLTP	49	14.2
	SLTA	39	11.3
	College	1	0.3
No	Characteristics of respondents	Frequency	Percentage*
5	Income level		
	Stable	8	2.3
	Unstable	337	97.7
6	Age	49.4 years old (SD 17.5)	
9	Type of disabilities		
	Deaf	21	6.1
	Limb defects	181	52.5
	Blind	33	9.6
	Expsychotic	46	13.3
	Speech impaired	15	4.3
	Multiple flaws	26	7.5
	Mental Retardation	23	6.7

\* amount divided by total research subjects.

Table 2 shows most of the respondents are physically disabled, and most of them men, with the education level of most respondents in primary school, and more than half of respondents do not work, while most types of income are not fixed, the average age of respondents is 49.4 years and more than half of the respondents are not married.

The functional scores of respondents' family are shown in Figure 1. As many as 67% of respondents have highly functional family function, whereas respondents with the most functional family scores are mostly from physically disabled, and respondents with severe family dysfunction are expsychotic, as seen in Figure 1.



**Figure 1. The distribution of respondents based on APGAR scores**

Figure 2 shows a functional family distribution that is highly functional in the physically disabled, double disabled and mute groups, whereas the family function includes the most severe dysfunctional in the expsychotic and mental retardation group.

Most of the respondents had good quality of life (99%), with there was only 1% who had poor quality of life from the people with physical disabilities as shown in Figure 3.

Figure 4 shows almost all persons with disabilities have good quality of life, while very few have bad quality of life from disability.

APGAR score relation to characteristics and WHOQOL-BREF scores is shown in Table 3.

Table 3 shows gender, age and scores of APGAR have significant correlations with quality of life based on the WHOQOL-BREF instrument, while employment, marital status, education level and income level do not have any significant association with quality of life for persons with disabilities in this study.

In testing the relationship of family function with APGAR score and quality of life with the WHOQOL-BREF instrument, APGAR scoring data and WHOQOL\_BREF in normality test data, the results were not normally distributed based on the Kolmogorov Smirnov test scores. Because the data were not normally distributed then they were analyzed with Spearman correlation statistical tests. Spearman test results obtained significant results with  $p = 007$  ( $p < 0.05$ ), so it can be concluded that there is a significant relationship between APGAR scores with scores for the measurement of subjects' QoL with the WHOQOL-BREF.

Table 4 shows the family function has no significant relationship with quality of life of the physical health and psychological health domains ( $p > 0.05$ ) with Spearman correlation tests. The family function has a significant relationship with the quality of life of social relations and the environmental domain ( $p < 0.05$ ).

**DISCUSSION**

The results of statistical analysis show the relation of family function with APGAR score and quality of life with WHOQOL-BREF instrument. The relationship of family function and quality of life is shown in domains 3 and 4, which suggests that family function is related to quality of life in the health domain of social and environmental relations. In this study, the results show the relationship between family function and quality of life is mainly in the domains of physical and psychological health. Another study about the relationship of family function with the quality of life of elderly also had similar results<sup>8</sup>.

People with disabilities who have a very functional family will have a better quality of life, physical health domain, psychological health, social relations and environment. As found in a study in China, social support plays an important role in improving the quality of life of patients with leukemia in China which was measured using APGAR scores that included psychological, social and environmental domains<sup>9</sup>.

Another study in Spain showed that the higher the APGAR score of the family is, the higher the quality of life of the schizophrenic family. Burden of care, social support and

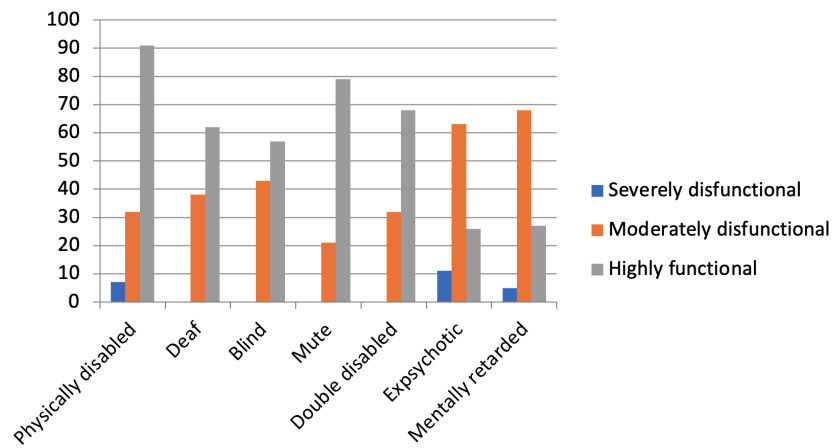


Figure 2. Distribution according to the disability based on APGAR scores

**Distribution by WHOQOL-BREF classification**

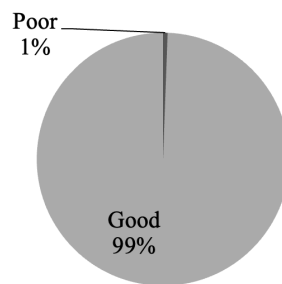


Figure 4. Distribution of disabilities based on WHOQOL-BREF scores

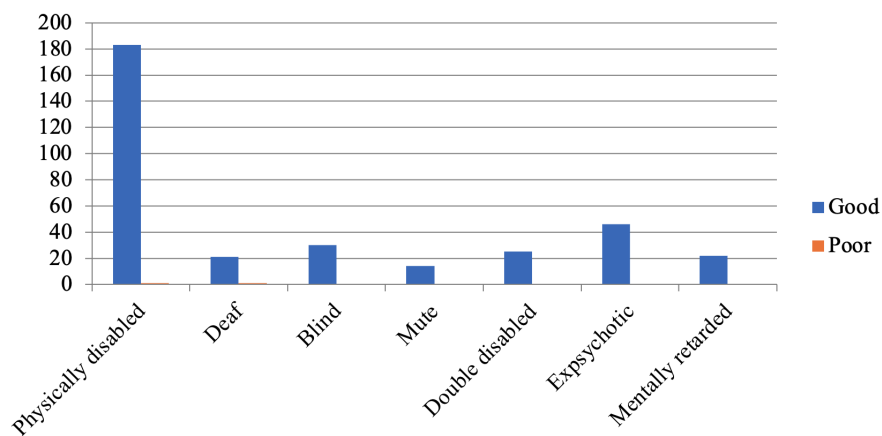


Figure 4. Distribution of disabilities based on WHOQOL-BREF scores

professional support to a good schizophrenic family affect the quality of life<sup>10</sup>. The results of multiple regression show that there are 8 predictors including religion, drug use, occupational status, work stress, work passion, fatigue, quality of life and family function which have an effect on overall quality of life in 34.2% of flight attendants<sup>11</sup>. Family support as measured using APGAR score and occupational support affects the quality of the life of transvestites before conducting transgender surgery in Spain<sup>12</sup>. Good family support positively affects the quality of life in the environmental domain of people with heroin addiction in Taiwan<sup>13</sup>. The results of research of associations between social activity, social interaction and family function with quality of life of the elderly in the working area of Community Health Center I, North Denpasar of Denpasar

City showed significant correlation between family function and the quality of life of the elderly. Considering the odds ratio, the quality of life of respondents with good family function was better than that of respondents with poor family function<sup>14</sup>.

In this research, age, sex and family function (APGAR score) had a significant correlation with quality of life (WHOQOL-BREF score). Meanwhile, occupation, marital status, education level, and income level had no significant correlation with quality of life. Most of the people with disabilities did not work, did not attend school, were unmarried and had unfixed income. In another study, the results of Chi-square and Fisher Exact tests showed the significance of the correlation between education and family function, main breadwinner's occupation and family

**Table 3. Relationship of characteristics with WHOQOL-BREF scores and APGAR scores with WHOQOL-BREF scores**

No	Characteristics of respondents	Frequency	Percentage*	p value**
1	Gender			
	Male	197	57.1	<b>0.000</b>
	Female	148	42.9	
2	Profession			0.489
	Farmer	109	31.6	
	Entrepreneur	24	7	
	Unemployment	187	54.2	
	Laborer	25	7.3	
3	Marital status			0.500
	Married	155	44.9	
	Not married	190	55.1	
4	Level of education			0.568
	Not finished primary school	141	40.9	
	Primary School /SLB	113	32.8	
	SLTP	49	14.2	
	SLTA	39	11.3	
	College	1	0.3	
5	Income level			0.96
	Stable	8	2.3	
	Unstable	337	97.7	
6	Age			<b>0.000</b>
	Average	49.4 years old (SD 17.5)		
7	APGAR score			<b>0.000</b>
	Average	7.53 (SD 2.29)		
No	Characteristics of respondents	Frequency	Percentage*	p value**
8	WHOQOL-BREF score			
	Average	76.7 (SD 13.07)		
9	Type of disables			
	Deaf	21	6.1	
	Limb defects	181	52.5	
	Blind	33	9.6	
	Expsychotic	46	13.3	
	Speech impaired	15	4.3	
	Multiple flaws	26	7.5	
	Mental retardation	23	6.7	

**Table 4. Relationship of Family Function with the WHOQOL-BREF**

Domain of WHOQOL-BREF	p Value
Domain 1 Physical Health	0.063
Domain 2 Health Psychology	0.0564
Domain 3 Social Relations	0.011
Domain 4 Environmental Functions	0.035

function as well as correlation between family function and quality of life of the elderly in Wirobrajan, Yogyakarta<sup>15</sup>. The results of Kendal tau test indicated a significant value, meaning there was a correlation between the level of independence and the quality of life of the elderly in Karang Tengah Hamlet, Nogotirto Village, Gamping Subdistrict, Sleman Regency, Yogyakarta. The value of correlation coefficient was 0.288, which indicated that both variables had correlational strength<sup>16</sup>.

The family function clearly affects the quality of life of people with disabilities, where generally the better the family function, the better the quality of life of people with

disabilities. The quality of life of people with disabilities is affected by several factors, namely ability to adapt and accept such abnormalities, appreciation and fair treatment from the environment of people with disabilities<sup>8</sup>.

Family APGAR assesses the level of satisfaction of people with disabilities that includes *adaptation* in terms of receiving necessary assistance from family members, *partnership* to communication, deliberation in making a decision and or solving a problem that is being encountered, *growth* in terms of freedom given by the family in maturing the growth or maturity of each family member, *affection* in terms of affection and emotional interactions that take place in the family, and *resolve* in terms of togetherness in dividing time, wealth and space between families. High APGAR results in which each member of the family supports each other show that the family function is healthy. Family support and healthy family environment are closely correlated to the quality of life of people with disabilities<sup>8</sup>.

Family function is also affected by economic factors, where if the economy is low, the family function also will often not be healthy, because family members will find it difficult to obtain a healthy residence, nutritious food, adequate

education and maximum health services that will result in poor quality of life of the family members. Health greatly affects the family function, so that if there is difficulty to obtain adequate health services, the family function will be unhealthy because unhealthy family members will increase the morbidity rate of the family and result in poor quality of life<sup>8</sup>.

The measurement of quality of life in people with disabilities consists of four main domains, namely physical, psychological, social relation and environmental health correlated with family function and affected by SCREEM variables (social, culture, religious, education, economic, and medical factors). There are at least several other factors that increase the quality of people with disabilities, namely ability to adapt and accept all changes and setbacks experienced, along with the appreciation and fair treatment from the environment of people with disabilities<sup>8</sup>.

Handling of disabled persons should involve holistic care, comprehensive care and continuity of care with primary care physicians as the spearhead of services that can be done collaboratively with the health service offices as well as related parties such as Social Service, Education Office, *Kesra Setda* and third-party equipment providers all of which are required by persons with disabilities to improve their quality of life.

## CONCLUSIONS AND SUGGESTIONS

From this research, it can be concluded that the prevalence of people with disabilities in Banyuwangi sub-district of Purworejo district is 1.16%, while the *difabel* range includes disabled, blind, speech, hearing impaired, expsychotic, mental retardation and double defects. The functioning of disabled, deaf, blind, blind and dual disabled families are largely highly functional and in patients with mental impairments and retardation, most families have moderate dysfunctional functionalities. The persons with disabilities mostly have good quality of life for the disabled, deaf, blind, speechless, expsychotic and a small number of people with multiple disabilities and mental retardation have poor quality of life. There is a relationship between family function (assessed by APGAR score of the family) and the quality of life of persons with disabilities (assessed with WHOQOL-BREF instrument). Quality of life measurements consist of four domains. In this study, the function of the family is proven to be particularly affected by two domains of the four domains of quality of life, i.e. the domains of social and environmental relations.

Primary care physicians are expected to coordinate with relevant agencies (social department, Hospital, Section of Setda Purworejo District and third party providers of tools for disabled persons) to provide services to persons with disabilities, and further encourage research on factors that affect the quality of life of persons with disabilities, especially in terms of handling persons with disabilities with holistic care, comprehensive care and continuity of care to improve the quality of life of persons with disabilities.

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