

Independence in activities of daily living and quality of life of community-dwelling persons with paraplegia in Indonesia

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Abstract

Spinal cord injury can affect independence in activities of daily living. Independence is a significant factor that influences the quality of life of people with spinal cord injury. Objective: study the association of independence in daily activities and quality of life of community-dwelling persons with paraplegia living in Indonesia. Methods: This is a descriptive cross-sectional study. People with spinal cord injury aged 18-64 without communication problems (deafness, severe mental disorder) living in Bantul, Kulonprogo and Sleman Districts, Yogyakarta Province were recruited with purposive sampling. The Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) were used to measure independence, and the World Health Organization BREF (WHOQOL-BREF) to assess quality of life. Correlation test was used to assess the association between independence in activities in daily living and quality of life with age and sex included as covariates. Results: A total of 30 respondents participated in this study. They had dependence in activities of daily living. Data showed significant correlation of independence in ADL with the physical health ($r = .579$, $p = .001$), psychological ($r = .436$, $p = .021$), and environment ($r = .565$, $p = .002$) domains of WHOQOL-BREF and no significant correlation with the social relationships domain. Independence in IADL showed significant correlation with physical health ($r = .541$, $p = .003$) and environment ($r = .508$, $p = .006$) domains of WHOQOL-BREF but no significant correlation with psychological and social relationships domains. Conclusions: Independence in daily activities is associated with quality of life in people with spinal cord injury.

Keywords: Independence, quality of life, disability, spinal cord injury, Indonesia

Introduction

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The Global Burden of Disease Study 2016 reported on global, regional, and national burden of traumatic brain injury and spinal cord injury during 1990-2016 and reported that both the incidence and prevalence of spinal cord injury in Indonesia increased (1). The age-standardized incidence rate of spinal cord injury per 100,000 Indonesian population in 2016 was 7 and the incidence rate from 1990 to 2016 increased by 14.1%. The prevalence rate per 100,000 Indonesian population in 2016 was 205, and the prevalence increase from 1990-2016 was 33.2% (1). Despite this fact, attention to the treatment of people with spinal cord injury is still far from sufficient. There are only two hospitals with special spinal cord injury unit in Indonesia: Professor Dr R Soeharso Orthopedic Hospital in Solo and Fatmawati General Hospital in Jakarta (2).

Tulaar et al. (2) described the journey that one with spinal cord injury goes through the chain of medical care. When one suffers from a spinal cord injury, one will be admitted and cared for in a hospital. Usually one will have a neuro or orthopedic surgery, a transfer to the intensive care unit for stabilization, and another transfer to the acute care. Usually, a person with spinal cord injury will stay in the hospital for about 1-2 weeks. Following discharge, one has rehabilitation service. Most patients in Indonesia access healthcare service using the national health insurance. The number of rehabilitation services, orthosis or other types of assistive device that is covered by the national health insurance is limited (2). The number of medical staff with specialization in spinal cord injury care is also limited and usually those specialized staff are concentrated in the big cities. The availability of medical facilities and staff vary quite widely in Indonesia. Thus the medical services delivered to a person with spinal cord injury differ from place to place, especially between the most advanced and the least developed areas in Indonesia.

Spinal cord injury affects quality of life. There are numerous studies on the quality of life of people with spinal cord injury, although most are from developed countries (3-6). There are fewer studies on the quality of life of people with spinal cord injury in developing countries (7, 8).

There are a few publications on the quality of life of people with spinal cord injury in Indonesia. Ferdiana et al. (9) interviewed 12 people with spinal cord injury to investigate the meaning of quality of life and

classified 13 components of it into five domains: participation, social support, relationship with God, independence and psychological resources (9). Another study assessed the quality of life of hospital outpatients who had spinal cord injury and neurogenic bladder problem (10).

According to the World Health Organization, quality of life is affected by one's physical health, psychological state, level of independence, social relationships and relationship to salient features of the environment (11). Spinal cord injuries cause physical disability that reduces one's level of independence (12). The independence of people with spinal cord injury in Indonesia has not been reported before.

This study aimed to assess independence in activities of daily living, depressive symptoms and quality of life of people with paraplegia, and to assess the correlation between those variables. The correlation between depression and quality of life has been reported elsewhere (13). This paper reported the correlation between independence in daily activities and quality of life.

Methods

This study was conducted in collaboration with Pusat Rehabilitasi YAKKUM (PRY), a non-governmental organization that empowers people with disability. PRY provided a list of people with paraplegia who used to be their program beneficiaries. One of the researchers paid home visits to the research participants to collect data in person.

Independence in activities of daily living was measured using Barthel Activities of Daily Living (ADL) and Lawton Instrumental Activity of Daily Living (IADL) which have been widely used in studies involving people with spinal cord injury (14-16). ADL assesses independence in bathing, dressing, grooming, toileting, transferring, walking, going up and down the stairs, continence, and feeding. The ADL score ranges from 0-20, a score of zero indicates total dependence, and a score of 20 shows that the person is able to do activities daily living independently. IADL measures ability to use the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medication and ability to handle finances. The score range of IADL is

from 0-16, in which a higher score implies higher independence.

Assessment of quality of life was conducted using WHOQOL-BREF that has been validated for people with spinal cord injury (17). WHOQOL-BREF has four domains: physical health, psychological, social relationships and environment. The score ranges from 0-100, a higher score indicates a higher quality of life.

Partial correlation was conducted to determine the relationship between independence in the activities of daily living and quality of life with age and sex as covariates. Studies of people with spinal cord injury have reported differences in quality of life related to age and gender (18, 19). Ethical clearance was obtained from the Ethics Committee of Faculty of Medicine, Duta Wacana Christian University.

Results

This research collected data from 30 people with paraplegia living in Bantul, Kulonprogo, and Gunungkidul Districts of Yogyakarta Province, Indonesia in November 2017. Most (83.3%) of them were victims of an earthquake that hit Java in 2006. There were more female respondents in this study. The earthquake caused houses to collapse that afflicted the respondents. As most women in the area were homemakers who stayed at home, they were more adversely affected by the earthquake. The age of the respondents ranged from 26 to 63 years, the mean age and standard deviation were 44.7 ± 9.78 years.

The most common complication found in this study was decubitus ulcers. Those with decubitus ulcers said that they had no one to remind or help them change positions to accelerate wound healing. Their families were busy working or doing housework. The individuals with urinary tract infections tended to not change the catheter on a regular basis because of financial difficulty to replace their catheter. The respondents in this study were mostly married. Most of them were already married before they suffered from spinal cord injury.

Most of the study participants were unemployed because of their physical limitations, especially those with pressure sores. Only five (16.67%) individuals had some income not from formal works. They had established some economically productive activities,

such as making handicrafts, breeding chickens and sewing.

Table 1. Characteristics data of the respondents

Variable		N	%
Sex	Male	11	36.7
	Female	19	63.3
Age	20-29	2	6.7
	30-39	6	20
	40-49	12	40
	50-59	9	30
	60+	1	3.3
Injury degree	Complete	5	16.67
	Incomplete	25	83.33
Complication	Pressure ulcer	6	20
	Urinary Tract Infection (UTI)	1	3.33
	Pressure ulcer and UTI	4	13.33
	No complication	19	63.33
Marital status	Single	6	20
	Married	22	73.33
	Divorced	2	6.67
Employment status	Employed	5	16.67
	Unemployed	25	83.33
Bathroom accessibility	Yes	26	86.67
	No	4	13.33
Kitchen accessibility	Yes	24	80
	No	6	20
Public toilet accessibility	Yes	1	3.33
	No	29	96.67
Public transport accessibility	Yes	1	3.33
	No	29	96.67

All respondents were holders of 'Kartu Indonesia Sehat' (Healthy Indonesian Card), so they could receive health services for free. However, they had difficulty in accessing the healthcare facilities, because the community health centers' buildings were not wheelchair friendly, and the health insurance did not cover home visits by healthcare workers.

Most of the study participants were able to access the bedroom, kitchen and bathroom, as during post-earthquake reconstruction and rehabilitation phase, they received assistance to rebuild their houses and the design was accessible for wheelchair users. However, they could not access public toilets and public transport

because those facilities were not accessible to wheelchair-bound people. Respondents who were able to access public facilities were those who used crutches as mobility assistive devices. The characteristics of the respondents are presented in Table 1.

Independence in activities of daily living

The ADL scores of the study participants ranged from 10 to 20. One respondent could do her activities of daily living independently, while 29 had some level of dependency. The activities in which most individuals needed help were using stairs (86.7% respondents), walking (83.3% respondents) and bladder control (83.3% respondents). The mean and standard deviation of ADL scores were 14.17 ± 2.379 .

The IADL scores of the respondents varied from three to 16. Five individuals were independent in their instrumental activities of daily living. The activity that half of the study participants needed help was mode of transportation. They did not own a vehicle to take them around, while public transportation was not accessible or friendly to wheelchair users. Six people (20%) needed help to do their shopping.

Quality of life

WHOQOL-BREF has four domains. There are seven questions in the WHOQOL-BREF physical health domain. The question with the lowest score was the one that asked the extent that the respondents felt that physical pain prevented them from doing what they wanted to do. This result suggested that they still had pain that limited their activities. The question about how much they needed medical treatment to function in daily life had the highest score. They used to have medical rehabilitation that enabled them to make modifications in their lives to accommodate the spinal cord injury, and this made them think that they did not need medical treatment to be able to function in daily life.

Of six questions in the WHOQOL-BREF psychological domain, the question on the respondents' ability to concentrate had the lowest score, while the highest score was found in the answer

to the question about their ability to accept their bodily appearance.

In the WHOQOL-BREF social relationships domain, the question on the satisfaction with sexual life had the lowest score. Twenty-two (73.33%) study participants were married and they felt that they could not satisfy their spouses in their sexual life. The question about satisfaction with the support from friends had the highest score. All respondents joined a local disabled people's organization (DPO) and they were happy with the solidarity they received from their peer people with disability.

The WHOQOL-BREF environment domain had eight questions. The question of whether the respondents had enough money to meet their needs had the lowest score. Among 30 respondents, 25 (83.3%) were unemployed and had no income. They relied on their family and social assistance from the government or social organizations. The second-lowest score in this domain was the question about their satisfaction with their transportation. The question about the availability of information that they needed in their daily life obtained the highest score. They felt that the information they received from the other members of the disabled people organization was sufficient. The data of quality of life of the study respondents were presented in Table 2.

Table 2. Data of quality of life

	Mean \pm SD	Minimum	Maximum
Overall quality of life	3.40 \pm 0.675	2	5
General health	2.97 \pm 1.159	1	5
Domain 1 (physical health)	57.53 \pm 13.756	25	81
Domain 2 (psychological)	62.30 \pm 14.186	25	94
Domain 3 (social relationships)	61.10 \pm 13.082	31	94
Domain 4 (environment)	59.63 \pm 13.171	25	81

Correlation between independence in activities of daily living and quality of life

Partial correlation was performed to identify the association between independence in activities of daily living (ADL and IADL) and quality of life with age and sex as covariates. The results of statistical analysis were presented in Table 3. There was significant correlation between ADL and quality of life physical domain ($r = .579$, $p = .001$), psychological domain ($r = .436$, $p = .021$) and environment domain ($r = .565$, $p = .002$). No significant correlation between ADL and social relationships domain was found. Analysis between IADL and quality of life revealed significant correlation with physical healthy domain ($r = .541$, $p = .003$) and environment domain ($r = .508$, $p = .006$). There was no significant difference between IADL and the psychological and environment domains of quality of life. ADL and IADL had positive correlation with quality of life, higher independence in daily activities was associated with higher quality of life.

Table 3. Correlation between independence in activities of daily living and quality of life

	ADL		IADL	
	r	p	r	p
Physical health domain	.514	.004	.436	.016
Psychological domain	.366	.047	.342	.065
Social relationships domain	.232	.217	.136	.475
Environment domain	.521	.003	.651	<.001

Discussion

This research studied people with paraplegia. Decubitus ulcer and urinary tract infection are common complications found in people with spinal cord injury (20, 21). Although all respondents had access to healthcare service because the government paid their health insurance premiums, they did not receive wound care because the healthcare facilities were not accessible to wheelchair users and home visits were not covered by the national health insurance. Decubitus ulcer or urinary tract infection are two of the reasons for hospital admission of people with spinal cord injury (22).

Most respondents did not have income at all. This is a common finding in research on people with disability in other parts of the world. The percentage of

people with disability working is lower than that of people without disability and the majority of them work in informal sectors (23, 24). People with spinal cord injury have greater difficulty in accessing labor market, more than 60% were unemployed globally (3, 25).

Accessibility to public facilities was still a problem for wheelchair-bound people in Indonesia. This is a common problem found in developing countries. One study has reported that public facilities in Nigeria were not accessible to wheelchair users, because there were no ramps (26). Another study reported social discrimination in Croatia as there were areas in Zagreb that were inaccessible for people on wheelchairs (27). A study from Thailand also found a lack of accessible public transportation and public buildings in Bangkok and almost everywhere in Thailand, and reported that enabling environment is one of five factors that support the quality of life of people with spinal cord injury (28). This finding may explain the low score to the question in WHOQOL-BREF environment domain about the respondents' satisfaction with transportation.

Independence in activities of daily living

The activities that most of the study participants needed help were using stairs, walking and controlling their bladder. In the instrumental daily living, the biggest problem was transportation. Public transportation in Indonesia was not accessible to people with mobility disability in general, and worse for wheelchair-bound people (29, 30).

Quality of life

The respondents of this study had lower quality of life than the Indonesia general population in overall quality of life, general health, physical health, psychological and social participation domains (31). The quality of life in the environment domain of the study participants was comparable to the general population.

Compared to the quality of life of people with spinal cord injury from other countries, the results of this study were a little different. The individuals in this study had comparable quality of life in the physical and psychological domains, lower quality of life social

relationships domain and higher quality of life environmental domain.

The lowest score was found in the answers to the question about having enough money to meet their needs. A recent study on the quality of life of people with spinal cord injury in Thailand found that the most important factor for them to have a good life is to have a paid job that will secure their financial situation (28).

The second-lowest score was satisfaction with sexual life. A study on the sexual function and quality of life of 30 males with spinal cord injury in Tunisia revealed a significant correlation between the two variables (32). Another study comparing the sexual function and quality of life of women with and without spinal cord injury found women with spinal cord injury had sexual dysfunction and it was associated with poorer quality of life (33). Lee et al. (34) studied 299 males and females with spinal cord injury and reported that sexual activity was one of the factors affecting quality of life. The finding of this study implies that sexual function has a significant implication on quality of life.

Correlation between independence in activities of daily living and quality of life

There was a significant correlation between independence in activities of daily living (ADL and IADL) and quality of life physical. It has been reported that the first component of quality of life of people with spinal cord injury is physical function and independence (35). Tramonti et al. (36) reported a positive correlation between the independence and health-related quality of life of 40 people with spinal cord injury using Spinal Cord Independence Measurement III (SCIM-III) to assess independence and the Short Form-36 (SF-36) to assess health-related quality of life. Goulet et al. (37) found an association between independence, particularly in mobility and health-related quality of life of people with spinal cord injury. Li et al. (38) studied 200 individuals with spinal cord injury and reported that better physical function can have positive effect on the quality of life.

Half of the participants did not own a vehicle as their mode of transportation. They relied on their families or friends to take them around because the existing public transportation was not friendly to

people with disability, especially those who were wheelchair-bound. This fact provides evidence that advocacy for accessible public transportation needs to continue.

Most study participants were unemployed and they considered themselves not having enough money. A study reported (39) that in 2016 the Indonesian workforce participation rate was 56.72 for people with mild disability and 20.27 for people with severe disability. The workforce participation rate for people without disability was 70.40. The data showed that there is still unequal opportunity for people with disability to enter labor market. The Indonesian Act no 8 year from 2016 on People with Disability stated that people with disability have the same right to employment as people without disability (40). However, law enforcement needs to be strengthened. Programs that improve the opportunity of people with disability, including people with spinal cord injury, are expected to improve their quality of life.

Research limitations

The study has limitations in the small sample size and selection suggesting caution in drawing conclusions from this study's results. Quality of life is an individual's subjective perception in the cultural and value systems' context where one lives and it may or may not depend on time and place.

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