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Meaning and components of quality of life among individuals with spinal cord injury in Yogyakarta Province, Indonesia

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ABSTRACT

Purpose: Knowledge on the meaning of quality of life in individuals with spinal cord injury in developing countries is limited. This study aims to explore the meaning and components of quality of life for individuals with spinal cord injury in a rural area in Indonesia.

Method: Data were obtained through semi-structured interviews with 12 individuals with paraplegia (8 males, 4 females) aged 24–67 years. Thematic analysis was used to identify themes that constitute meaning and components of quality of life.

Results: Quality of life was not an easily understood concept, while “life satisfaction” and “happiness” were. Life satisfaction was associated with a person’s feeling when achieving goals or dreams and related to fulfillment of needs. Thirteen components of life satisfaction were identified and categorized into five domains as follows: (1) participation: earning income and work, being useful to others, community participation, and having skills and knowledge, (2) social support: social support, social relationship, (3) relationship with God: injury is God’s will, praying, (4) independence: being independent, mobility and accessibility, and health, and (5) psychological resources: accepting the condition, maintaining goals and motivation.

Conclusions: Social, cultural and religious influences were prominent in the perception of life satisfaction. The measurement of quality of life for individuals with spinal cord injury in Indonesia needs to consider locally perceived meaning and components of quality of life.

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Quality of life; spinal cord injury; disabled persons; developing countries

► IMPLICATIONS FOR REHABILITATION

- Financial, social and health needs of individuals with spinal cord injury in Indonesia must be immediately addressed.
- To increase financial independence, rehabilitation professionals should equip individuals with spinal cord injury with adequate self-employment skills.
- Sociocultural and religious aspects should be considered in the measurement of quality of life.

Introduction

The significance of sociocultural values in shaping the individual’s perception on quality of life (QOL) has been emphasized in the following definition of World Health Organization Quality of Life Assessment (WHOQOL) [1]: “Individuals’ perceptions 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. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment.” It implies that the meaning of QOL and the value placed by individuals to different aspects of it is subject to sociocultural differences [2].

For many years, researchers have attempted to obtain better understanding of sociocultural differences in QOL from cross-

cultural studies using internationally-recognized QOL measures which have undergone extensive adaptations into many languages [3]. However, the concept of QOL was originally evolved in the Western setting particularly in high-income, English-speaking countries, which values are inherently incorporated in the development of QOL instruments [2,4]. Despite thorough psychometric evaluations, these instruments remain insensitive to different sociocultural perspectives of QOL [3,5]. Areas of QOL important for the target cultures may be irrelevant for the cultures where the instruments were originally developed [6]. More importantly, the concept of QOL is not widely understood or used in non-Western cultures [2]. For example, in Asian countries such as Japan and South Korea, the term QOL is not easily translated and has no equivalent concept within the local language [5]. To gain a better knowledge of the cross-cultural differences associated with QOL interpretations, perception of the individuals from the culture

of interest should be sought [7]. Moreover, intervention to improve QOL will be more successful if it is culturally relevant and addressing the components of QOL expressed by the population.

Despite the recognized importance of understanding different perception of QOL within its social and cultural context, knowledge about QOL in people with spinal cord injury (SCI) – a neurological condition characterized by diminished sensory and motor functions [8] resulting in significant disability – predominantly originates from studies in Western, developed countries. These studies showed that although the level of QOL diminish within the first 5–10 years after the injury, individuals with SCI will eventually adjust to their body and lifestyle and achieve relatively good QOL with supportive social and physical environment [9,10].

Several comparative studies showed that individuals with SCI living in Eastern countries reported much lower QOL than their counterparts in Western countries [11,12]. Poor socioeconomic condition, limited access to medical and rehabilitation care and huge environmental barriers experienced by individuals with SCI in most developing countries in the Eastern hemisphere can be obstacles to achieving good QOL [13,14]. In addition to the gaps in socioeconomic situation and provision of health services including rehabilitation [15], differences in life values between Western and Eastern culture might play a role in individual's assessment of their QOL. Some qualitative studies in Eastern culture identified several unique QOL components not available in the existing QOL instruments such as relationship with family and neighbors, government support, and peace [16]. These findings highlighted the need to first assess the meaning of QOL and its components from the perspectives of individuals with SCI if a reliable measurement of QOL is to be conducted.

In Indonesia, information about QOL in individuals with SCI is non-existent. Even in general population or other chronic diseases, studies on QOL are very limited. There are only very few QOL questionnaires that have been translated into Indonesian and validated, for example the SF-36 [17,18]. During the validation study, it was found that some questions were not relevant to Indonesian settings and item responses were not easily understood by respondents. In addition, most validation studies were done in specific patient groups such as cancer, hypertensive or pediatric patients [18,19].

The present study aims to explore the meaning of QOL for individuals with SCI in Indonesia and to identify components perceived important for their QOL.

Methods

Setting

This study was conducted in the Yogyakarta province in the central region of Java Island, Indonesia. Indonesia is a developing country in South-East Asia with a population of 240 million [20], of which 60% reside on the Java Island. Almost 90% of the population is Muslim [21]. The Yogyakarta province is home to 3.5 million people, of which about 34% live in rural areas with farming as major occupation [22].

Only a few hospitals provide acute and rehabilitation care for SCI. At the time of the study, Health care costs are mainly paid out-of-pocket. Public health insurance is provided only to the poor and civil servants, while some formal sector workers are covered by employer health insurance. Individuals can also purchase private health insurance. However, these health insurance schemes often provide limited coverage for rehabilitation treatment. In 2014, a universal health care insurance scheme was introduced, aiming to cover the whole population with comprehensive care including medical rehabilitation by 2019.

The study was conducted at Pundong Vocational Rehabilitation (VR) Center, which was established in 2008 by the provincial government in response to the severe earthquake in 2006. A 9-month inpatient VR training is provided for free. Today, the center enrolls all people with disability residing in the province, provided that their medical condition is stabilized.

Ethical considerations

Ethical clearance was obtained from the ethical committee of the Faculty of Medicine, Gadjah Mada University, Indonesia. Each respondent received 10 Euro for participation. Written consent was obtained prior to data collection.

Respondents

Potential respondents were identified from the list of patients with paralysis enrolled in the VR program between 2009 and 2012. Maximum variation sampling was used to ensure representation of both sexes, younger and older age (<40 and ≥40 years), and living in the community or in the center. Eligible respondents were contacted at the center or visited at their home by a research assistant. If respondents expressed interest to participate after explanation of the study purposes, the research assistant scheduled an interview and neurological examination to confirm the SCI diagnosis.

Data collection

Semi-structured interviews were conducted between March and July 2012 using an interview guide. The interview guide was developed based on a literature review and piloted among three wheelchair-user individuals. The interviewing research assistant had a sociology background and was experienced in conducting interviews with patients with chronic conditions. The interviews were conducted in Indonesian and/or Javanese language and digitally recorded. On average, interviews lasted for 1 h. The first section of the interview guide elicited socio-demographic and injury-related information i.e. age, sex, highest educational level (primary school/junior high school/senior high school), income (<50 Euro/month vs ≥50 Euro/month), onset of injury, cause of injury, and treatment after injury. The second section of the interview guide pertained to QOL: (1) How do you define quality of life and (2) Can you mention five important things that are important for your quality of life?

The neurological examination was conducted by a resident in neurology from the local university hospital. The level of neurological lesion was classified using the American Spinal Cord Injury Association (ASIA) scale as paraplegia (paralysis of the lower body) or tetraplegia (paralysis below the neck). Completeness of the injury was classified as complete (no sensory and motoric functions remain below the level of the lesion) or incomplete (some of the sensory and motoric functions are retained). The level of functional independence was assessed by the 10-item Barthel index, measuring independence in 10 self-care and mobility domains. Scores range from 0 to 20 with higher scores indicating greater independence [23].

Data analysis

First, the digital recordings of all interviews were transcribed verbatim in Indonesian or Javanese or mixed by the research

assistant. Transcripts were checked by the first author and any errors were corrected. The first author, who is fluent in Indonesian, Javanese and English read the whole transcripts and translated the responses relevant to the study aims into English. It has been recommended that translation in cross-cultural qualitative research should be conducted by a bilingual researcher or staff member who is familiar with the context and content of the research [24]. The translations were discussed with the research assistant to ensure the correct meaning. Translation during the analysis has been recommended because it ensures the authenticity of the findings [25]. Forward-backward translation was not performed as this is not common in qualitative research [26,27].

Thematic analysis was then performed on the English translations. Four coauthors (AF, UB, MP, JvdK) independently read the transcripts line-by-line and assigned codes to meaningful responses. Codes were compared, discussed and ambiguities resolved. Recurrent codes were grouped into categories and categories were grouped into themes that together reflected the meaning and components of QOL according to the respondents. After it became clear that no new themes emerged and no new information came up within the themes that had been identified, it was decided that saturation was reached and recruitment of new respondents was terminated. The final analysis was reviewed by all investigators. ATLAS.ti software [28] was used to support the data analysis.

Results and analysis

Sixteen people were interviewed. Neurological examination showed that two respondents did not have SCI. In two other respondents, the interviews could not be completed because of health reasons. Finally, 12 respondents with paraplegia were included in the analysis (Table 1). Two respondents were injured for more than 10 years, while the rest was mostly injured for 5–10 years because of the earthquake which occurred 6 years prior to the study. Two respondents were injured for less than 5 years. Seven respondents were living in the community, while five were undergoing training at the VR center. All respondents were paraplegic, wheelchair-user and of Javanese ethnicity. All but one respondent were Muslim. Seven respondents were self-employed after injury. Of these, six respondents had small home-businesses, e.g. computer rental, grocery shop, selling food, electronic services, handmade bags etcetera, while one respondent had both formal employment and home business. Table 2 provides information on each individual respondent.

Meaning of QOL

There is no direct translation of “quality of life” into Javanese and the Indonesian term for “quality of life” was not easily understood by the respondents. The interviewer had to repeat the question or use prompts and examples to explain the term. Instead, the terms “life satisfaction” or “happiness” proved more useful and these were used during the subsequent interviews. Both terms will be used interchangeably in this study.

When being asked to define what life satisfaction or happiness meant, most respondents described circumstances or things important as means to achieve those situations. Only a few respondents described life satisfaction as a global state or final value. Among these respondents, life satisfaction was mostly associated with a person’s feeling when achieving goals or dreams, “When we learn to achieve something that we want, that’s what we call satisfaction.” (Karti). Life satisfaction was also associated with

Table 1. Demographic and clinical characteristics of the respondents.

Variables	N (%) / Mean (SD)
Age, in years median (IQR)	35.7 (12.05)
Gender, N (%)	
Male	8 (66.7)
Female	4 (33.3)
Education, N (%)	
No school/primary school	2 (16.7)
Junior secondary school	3 (25)
Senior secondary school	7 (58.3)
Family income, N (%)	
< 50 euro	5 (41.7)
≥ 50 euro	7 (58.3)
Working, N (%)	
No	5 (41.7)
Yes	7 (58.3)
Duration of injury	
≤ 5 years	2 (16.7)
6–10 years	8 (66.7)
> 10 years	2 (16.7)
Cause of the injury, N (%)	
Earthquake	8 (66.7)
Traffic accident	3 (25.0)
Fall	1 (8.3)
Neurological level of injury, N (%)	
Paraplegia	12 (100)
Tetraplegia	0 (0)
Motor completeness of injury, N (%)	
Complete (A and B)	11 (91.6)
Incomplete (C and D)	1 (8.3)
Barthel index, median (range)	12–16

the fulfillment of needs, but some respondents mentioned that human beings by nature can never be fully satisfied. “I think not everybody can feel satisfaction. Human beings, mostly cannot be satisfied. Personally, I feel satisfied when my life is complete, when everything (all my needs) is fulfilled then I feel satisfied” (Hari).

Other respondents characterized life satisfaction as a subjective experience that varies from person to person. It was also mentioned that life satisfaction is something that cannot be quantified in terms of material resources. When a person’s need of or desire for a material thing is fulfilled, it will not last long.

“If satisfaction is measured with material satisfaction, you know when pursuing material things, I think our body will kind of measure the portion that we want. For example, when we like a type of food, eating it one time will taste good, but if you eat it every day then it will taste not so good anymore. There is a kind of limit.” (Dodi).

For a few respondents, life satisfaction was a different entity than happiness. One respondent mentioned that happiness will come after people feel satisfied with their life. Another respondent stated that people can be happy without being satisfied. “If it is about happiness then I am happy, I’m happy because I can be with my family. But if it is about satisfaction, I’m not satisfied.” (Irwan).

Respondents believed that God would ultimately give them happiness, which implied that happiness is not something that should be actively pursued. “... the things (for happiness) I mentioned before are difficult to realize, but there is still God. God says, ask and you will receive. You will receive it immediately or after some time, you don’t know. But you will receive it, it’s just a matter of time.” (Karti).

Happiness was associated with after-life happiness, i.e. happiness does not only prevail to this world, but after-life happiness may finally be granted. “For us, the world seems to be unfair, but there will be justice hereafter. With this expectation, if heaven exists,

Table 2. Characteristics of each respondent.

No	Alias	Location	Age	Gender	Education	Income	Duration of injury (years)	Cause of injury
1	Ali	Community	31	M	Senior high school	≥50 Euro	6	Earthquake
2	Bibi	Center	26	F	Senior high school	<50 Euro	3	Traffic accident
3	Cak	Center	27	M	Primary school	<50 Euro	3	Fall
4	Dodi	Center	42	M	Senior high school	≥50 Euro	22	Disease
5	Eka	Center	46	M	Junior high school	<50 Euro	6	Earthquake
6	Feni	Community	22	F	Senior high school	≥50 Euro	6	Earthquake
7	Gus	Community	67	M	Primary school	≥50 Euro	6	Earthquake
8	Hari	Community	40	M	Junior high school	<50 Euro	6	Earthquake
9	Irwan	Community	35	M	Junior high school	<50 Euro	6	Earthquake
10	Jumi	Community	31	F	Senior high school	≥50 Euro	6	Earthquake
11	Karti	Community	30	F	Senior high school	≥50 Euro	6	Earthquake
12	Lalu	Center	38	M	Senior high school	≥50 Euro	18	Traffic accident

then I hope (after I die) I will be happy in there, although I'm not happy in this world." (Dodi).

Components of life satisfaction

Thirteen components of life satisfaction were identified, which were grouped into 5 domains: participation, social support and relationship, independence, relationship with God, and psychological resources.

Participation

Earning income and work. The majority of respondents mentioned that earning an income is a central component of life satisfaction. Most respondents reported that their financial situation had deteriorated after the injury and thus earning income is vital for survival. "If I am able to earn money; that is happiness for me. Although it is not enough but at least it is sufficient for everyday meals." (Hari). Male respondents who had family emphasized that they wanted to resume their responsibility as breadwinner.

By earning income, respondents hoped to reduce their dependency on other people to support their needs. This was more frequently mentioned by younger respondents. "Being productive, I mean having your own income, although just a small amount, but as best as we can. It's impossible for human beings not to work; you cannot be dependent on other people forever." (Karti). Having money would also enable respondents to help others. "Sometimes when I have money, I will invite children around here to help me with something, then I will give them money." (Eka).

Being able to work itself was viewed a source of happiness. "For me, (life) satisfaction is about working. Working (in an occupation) that makes you happy. Although it doesn't result in a lot of money, but if I can work, I'm happy." (Gus).

Being useful to others. Respondents felt satisfied when they were able to do something that is useful to other people. "What would be my (source of) satisfaction or happiness is to be independent and to be useful to others." (Ali). Respondents described doing household chores, taking care of children, or helping with the family business as examples of being useful for the family. Male respondents who previously worked outside home felt satisfied when they could help their spouses with domestic work. They also felt satisfied when they could help and support their friends. "Happiness for me is when I can be useful for other people despite of my limitation. If there are people in difficulties then I will try to help as best as I can. For example, if people need to borrow money or ask for money, I want to be able to help, as best as I can, whenever I can help then I will help." (Karti). Other respondents mentioned that they have an obligation to contribute to society. "Being useful.

We have to be useful as a human being; our ideas, our thoughts are useful, for ourselves or for our surroundings." (Dodi)

Community participation. Community activities were important, especially in rural areas where contribution to community activities was expected from each village member. "For people in the village, contributing to each other is very important. If I am not able to do that then I cannot feel happy." (Gus). Respondents also articulated the importance of being accepted by community members. For example, being invited to celebrations such as wedding ceremonies or being asked to contribute in communal events, made them feel respected and accepted by the community.

Having skills and knowledge. Having skills and knowledge were perceived as important to life satisfaction, especially among respondents who were undergoing VR training. "Here I can learn new skills, I meet new friends, and that makes me happy. At home I only do what I can do, work and then sleep, but here I can join classes, and there are many friends." (Cak). Respondents who had worked prior to joining VR expected to gain more knowledge and practical skills to expand their employment opportunities. "I was thinking that if there is an opportunity to increase my knowledge, to have personal development and everything, then why not? If we want to get more knowledge, there is no limit, as long as there is an opportunity. But if we look only for money, it is kind of static, it does not necessarily increase your knowledge. For me, the more I learn, the happier I am." (Eka). One respondent reported higher life satisfaction after the injury because he can provide services to other people using his new skills. "I feel unlimited, I feel more useful to other people. When I was normal, I didn't know how to do this (screen-printing)." (Ali).

Social support and relationship

Having social support. Almost all respondents identified family as important source of life satisfaction. Family was regarded as an important source of moral support, peacefulness, understanding, and love. They felt happy when they could be with their family, to see them healthy and to make them happy. "To be with my family, having a harmonious life with my family, that makes me happy. If you are with them but you argue all the time, it is not happiness. Happiness comes from a harmonious life, understanding each other." (Eka). Often the family had a double function as caregiver and financial supporter for the respondents.

Friends provided strength, comfort, and motivation especially in the first few years after the injury. "Support from people whom we love. Support from my surroundings, from people who love us, friends, best friends, they do not see me differently. They still see me as I was before, they don't discriminate." (Feni). Many respondents also referred to peers as an important source of support and

motivation. Peers can be patients at the center, or other individuals with SCI that they knew through patient organizations. With peers, respondents often felt more comfortable to share their stories because peers were better able to understand.

Acceptance and understanding of their condition from family, friends and peers were especially valued by respondents. *"I want to get more attention from my family, I feel that I am not getting enough attention from them. Sometimes I feel there is not enough care (for me). Here (in the center) I am using a wheelchair, and I am using diapers, sometimes it leaks and smells bad, so my friend (roommate) does not like it, and that makes you mentally down. I want to be understood, we are all disabled anyway."* (Bibi)

Maintaining social relationship. Keeping good relationships and doing activities with friends and peers were important, particularly for younger respondents. Visits from friends or being able to visit friends were important to keep them happy. *"I want to buy a motorcycle, and then go around visiting my friends. When I have been out from here (the center) I will visit them (peers) at home"* (Cak). Some respondents also received practical support from their friends and peers such as transportation to go to places or events.

Relationship with God

SCI is Gods will. SCI was perceived by most respondents as a kind of test or punishment from God. In the first few years after the SCI, respondents felt down and angry towards God for giving them such a condition.

"At first, I was like blaming God for my condition. I asked God, 'why did You give me such condition?' But then after reading and studying Koran, I often cried in the night, asking for forgiveness for everything I have done. I repented; maybe it's kind of late because I did those things in the past, and one might say that why I didn't do it when I was healthy. Maybe this is a kind of reminder from God that I should be more thankful, that I'm still alive." (Eka).

However, respondents realized that they were not supposed to feel dissatisfied or unhappy, because their current condition was God's will that they had to accept. Instead, they expressed their gratitude to God for being alive and to be able to return to people they loved.

"I'm trying to be happy, that is what I can do, because (this injury) is a punishment for me. So I just try to be happy. I'm happy, because I am granted life by The Almighty. Although I'm punished like this, but I have been rewarded life, so I should be happy. Whatever it might be like, I am happy because I have been granted (life)" (Gus)

Praying. After the injury, praying and sholat (obligatory prayers for 5 times a day in Islam) were intensified and seen as a way to seek God's forgiveness, to strengthen their relationship with God, to ask for help, and to express their thankfulness for being alive. It was also a source of spiritual strength. Some respondents studied religion more intensively after the injury. *"Praying, that is the only thing I can do. With praying, we can be close to God, it will give us peace, resignation."* (Irwan).

Independence

Being independent. Most respondents expressed that they wanted to be *mandiri* (meaning: can live independently) so as not to be a burden to others. *"I'm trying to be independent, so I will not bother people."* (Lalu).

Being independent was also described in terms of functional independence in doing daily activities, especially among respondents who were injured less than 10 years. *"At first I wasn't able to do anything, I was learning to wear my pants, it took me 2 h. I was*

very distressed and angry to myself. How could I not be able to wear pants on my own. But after trying for so many times, I was able to. I was very happy, because I knew that I could do it. That's a small example. Also when I was able to take a shower on my own, I was very happy." (Jumi). Several respondents seemed to retain the expectation that they would resume their functional independence. *"Being able to walk again. That is what most important."* (Gus). Respondents who were injured less than 5 years often found themselves in adjustment process. *"I want to be better than I am now, being independent, being useful. Until now I still need help from others."* (Bibi).

Mobility and accessibility. Mobility was recurrently mentioned as an important factor in supporting life satisfaction. *"I think I was more satisfied, happier before the injury, because now I cannot go anywhere. I'm healthy, my body is healthy, but I cannot go anywhere."* (Irwan).

Mobility was also an important modality to maintain social relationships. *"I want to buy a motorcycle, and then go around visiting my friends. Here (the VR center) I also learn that there are actually many organizations (for people with disability). People often ask me, 'which organization do you join?' And I said that I haven't joined any because I cannot walk and there is no one to pick me up."* (Cak). Many respondents were dependent on their family, friends or peers for transportation. *"I'm not able to do anything by myself, I can't. Everywhere I go there should be someone to accompany me, anywhere, so I'm not independent."* (Feni).

Although most respondents did not explicitly mention that physical accessibility of the environment was important for life satisfaction, it was indicated that their mobility and ability to participate was much impeded by physical barriers in their environments. *"I could not enter the mosque, so I sat in my wheelchair outside."* (Hari). Only one respondent mentioned the lack of accessibility of public buildings and infrastructure and related it to the lack of attention from the government to people with disabilities. This respondent was an activist in a local SCI patient organization.

Health. Only a few respondents explicitly mentioned health as a component of life satisfaction. Health was seen as modality to perform daily activities including working.

Many respondents had more health problems after the injury such as tiredness, feeling feverish, muscle spasms, pressure ulcers and pain. After the injury, they became aware that being healthy is very important. *"Because I'm no longer able to do anything, I can only ask for being healthy in the long term."* (Gus). Respondents were also more careful with their health because of their perceived vulnerability to health problems. One respondent mentioned that health is important because it is a modality to earn income. For male respondents, resumption of sexual ability to satisfy their spouse's sexual needs was important for life satisfaction.

Psychological resources

Accepting the condition. Respondents emphasized that trying to accept the condition is an important factor to begin with, because then they can control their body and optimize their remaining capabilities. In that way, they can gain more self-confidence.

"You should have self-awareness. It means that you should know about your condition, can accept the current condition. By knowing and accepting the condition then you will know what you can do and what you cannot do. Self-confidence, so you have to be aware that you have the same rights and responsibilities as other people. If you don't believe

in yourself then how can you expect people to believe in you?" (Ali).

Maintaining self-esteem and self-confidence as ingredients of life satisfaction was more frequently expressed by young respondents or respondents who were active in community or disability organizations.

Maintaining goals and motivation. Respondents mentioned that to be satisfied or happy, a strong internal motivation was necessary. Having internal motivation and personal goals were important to keep them optimistic. *"It is very important to stay motivated, to give spirit to myself. The most difficult person (to deal with) is yourself, how you can keep yourself spirited and motivated."* (Feni). *"We need to have a personal goal to motivate ourselves. If we do not have goals, then we will think that life is worthless and we feel desperate."* (Jumi). Lack of internal motivation may lead to worsening physical health and even survival. *"You know if a person wants to die he would have died long ago, if you are sick, then it's not time for you to die, if you are sick you have to try no matter what. As a living person you are not supposed to give up, if you give up you will not survive. I have some friends who had the same condition, but they were mentally down, and they died after 1 year, even 1 month."* (Cak).

Differences in perception of QOL between respondents' groups

There were few differences in the perception of QOL and components of QOL according to respondent characteristics. The differences in what was important for QOL and its components seemed to be associated with the respondents' social position. For example, the importance of earning income in fulfilling primary needs was especially expressed by male respondents, perhaps due to the expected role of males as breadwinner. The importance of social support from friends was more frequently uttered by single, young respondents, while married respondents emphasized the family as component of life satisfaction. Functional independence as components of QOL was more often cited by respondents who were injured less than 10 years before the study. It was also apparent that respondents who were younger than 40 years of age or active in patient organizations were more aware of the importance of psychological resources in life satisfaction. We did not find substantial differences in the perception of QOL and QOL components between respondents residing in the community and those undergoing VR, except in terms of expectation towards VR training.

Discussion

This is the first study to explore the perspectives of QOL and components among individuals with SCI in Indonesia. QOL was not widely recognized or easily defined by individuals with SCI in Indonesia. The terms "life satisfaction" or "happiness" were more familiar to the respondents. In defining life satisfaction, it was mostly framed in terms of components instrumental to achieve the state of being satisfied in life.

Studies in the US and China also found that QOL was mainly described as life satisfaction by the respondents [16,29]. Post et al. [30] conceptualized QOL using three approaches, i.e. health, well-being and superordinate construct. Life satisfaction is a construct closely related to the conceptualization of QOL as wellbeing, i.e. cognitive and emotional reactions experienced by people when evaluating their achievements in life against their aspiration, needs and expectations [31]. The cognitive reactions to the gap

between expectations and reality are reflected as life satisfaction, while the emotional reactions are reflected as mood or affect [31].

Life satisfaction in the present study was not defined as a final value or a state; instead it was described as components which constituted life satisfaction. This finding is in accordance with other studies [29]. Only a few respondents described life satisfaction as a state or feeling, probably because Javanese people are not used to expressing their feelings [32]. Life satisfaction was mostly described as related to their reactions concerning achievements of goals, needs and dreams, which is in line with the definition of life satisfaction described above by Dijkers [31].

Many components of life satisfaction found in the present study such as earning income and work, social support and community participation have been reported previously [33], but it was apparent that the differences in social and economic context explained the extent to which some of these components were valued [16]. For example, respondents in studies from developed countries reported that limited income made it difficult to meet secondary or tertiary needs such as home equipment, caregivers, medical insurance, leisure and sports etc., whereas respondents in our study stated that income was vital for primary or even survival needs [16,29,33,34].

The role of religion was prominent in this study, as shown by the frequent expressions of gratitude to God and the belief that SCI is a destiny. Gratitude to God after experiencing SCI was also reported by Christian respondents in the US [35]. The accepting attitude that SCI is God's will reflected the Islamic pillars of faith i.e. "qada" and "qadar" (belief that everything in the universe happens by the will and decree of God). Praying was the main religious coping strategy among the respondents, which is also a common practice among people with chronic conditions [36,37]. Evidence on the relationship between religious spirituality and QOL or life satisfaction in SCI in Western individuals is ambiguous [38,39], which warrants further research.

Our findings might also reflect Javanese sociocultural values in the perspectives of life satisfaction. The way respondents perceived their situation, no matter how unsatisfying, is probably influenced by Javanese life value called "nrimo", i.e. "accepting whatever is given to them by the Creator" or "resignation" (Koentjaraningrat, 1975). The importance of being useful to other human beings and independent i.e. not burdening other people, probably reflects the Javanese values of always placing the interest of other people over one's own interest. The significance of community participation also reflects the collectivistic nature of the Indonesian culture. In the Javanese culture, mutual relationships, communal work and helping each other, referred to as the "gotong-royong" principle, is highly valued especially in rural areas [40]. The Javanese society attempts to attain and preserve the notion of "rukun", which signifies living in harmony and helpfulness without conflicts [41].

The importance of psychosocial factors in life satisfaction was shown by the significance of positive gain and experience after SCI, such as hope, which have been reported previously in Western countries [42,43]. More research is needed into whether psychosocial factors can be targeted in interventions to improve life satisfaction in individuals with SCI in low income settings.

In contrast to previous studies [10,44], external factors such as accessibility of the environment and institutional support were not frequently mentioned, maybe because we asked for the definition of life satisfaction, not for hindrances in daily life. It cannot be excluded that low life satisfaction in this study is related to environmental barriers, as has been well-established in earlier studies.

It is interesting to note, that many of the components found in the present study are broader than health domains and not

incorporated in the most frequently used QOL instruments in SCI, such as the Medical Outcomes Study Short Form 36 Item (SF-36) [45,46]. For example, the components within the participation domain (earning income and work, being useful to others, community participation, and having skills and knowledge) are not measured by the SF-36. The SF-36 assesses the influence of health problems and services to QOL domains, yet these domains are limited to health status and functioning [47]. Our study highlighted that a chronic and debilitating health condition can impact broader aspects facets of life beyond these domains.

The WHOQOL is another frequently used QOL instrument, developed at the end of the 1990s and consisting of 100 items (WHOQOL-100). This instrument was developed cross-culturally [4,48], thus it will probably be more relevant to context-specific settings as our study. However, one major weakness of this instrument is its length. A short version, the WHOQOL-BREF is available, which consist of 26 items within 4 domains: physical health, psychological, social relations and environment [49]. The WHOQOL-BREF has been advised as the best QOL instrument to use in SCI research [50]. However, unlike the WHOQOL-100, the current version of the WHOQOL-BREF has not adequately incorporated spirituality and religious aspects [51]. Further research is needed to examine whether the WHOQOL-BREF supplemented with spirituality and religious aspects is a valid, reliable and acceptable measure of QOL in SCI in Indonesia.

As QOL in the present study was mostly defined and identified with life satisfaction, the existing life satisfaction scales might also be useful to assess QOL in people with SCI in Indonesia. Several life satisfaction scales that have been validated in SCI populations include the Satisfaction With Life Scale (SWLS) and Life Satisfaction Questionnaire (LiSat-9) [52,53]. Again, several components identified in the present study are not sufficiently included in these life satisfaction instruments, especially those within the domains of independence and religiosity. The Personal Wellbeing Index (PWI) [54] is less commonly used in SCI research, but the 8 domains of this measure seem to reflect most of the domains of life satisfaction identified in our study. The PWI showed good cross-cultural validity in SCI [55] as well as in the general population in Asia [56,57]. This may be a promising focus for a further research.

Study limitations

This is the first study to explore the meaning of QOL among people with SCI in Indonesia. It should be noted that the respondents only represented the Javanese ethnic group and their conceptualization of QOL or life satisfaction may not be generalizable to the other 200 ethnicities in Indonesia. Moreover, the respondents were recruited from a VR center with voluntary enrollment; therefore, the respondents may have different characteristics than those who did not come into contact with the VR center.

Although the saturation in this study was reached after the 10th respondents, our findings would be enriched by a more heterogeneous sample. For example, there were few female respondents recruited in this study due to the limited number of female patients enrolled at the VR center. In general, SCI occurred more often in males than in females [58]. In addition, we did not interview any tetraplegic respondents because none of the SCI patients joining the VR center had tetraplegia. This might be due to the smaller overall proportion of tetraplegia in earthquake-affected areas [59,60] or poorer survival rate of individuals with tetraplegia [61,62]. Tetraplegia is also associated

with more medical complications and limited mobility [63] which may prevent them from accessing VR services. Previous studies indicated that individuals with tetraplegia reported lower QOL than those with paraplegia [44,64] and different perception on important components constituting QOL [44]. Moreover, most respondents were injured between 5–10 years, after which adjustment process is taking place and this might affect QOL perspectives.

Implication for research, policy and practice

The present study suggests that it is very important to seek the locally perceived meaning of the QOL concept and interpret the results with respect to the social, economic and cultural characteristics of the population. Although some of the domains identified in the present study can be found in existing QOL and life satisfaction instruments such as the WHOQOL-100 and the PWI, subsequent research is needed to examine and validate whether these instruments are appropriate for individuals with SCI in Indonesia, in particular when compared to other countries. Our findings also show the need for a locally specific QoL instrument to reveal information useful to develop appropriate interventions.

Our findings also highlight urgent financial, social and health needs of individuals with SCI in Indonesia. Provision of disability benefits as supplementary income should be initiated to ensure stable income for these individuals and their caregivers. VR programs should ensure long-term programmatic impact to help individuals with SCI maintain financial independence after completing the program. For example, VR programs can provide vocational skills that are aligned with job market needs. For those who seek livelihood by self-employment, VR programs should not only provide capital investment or tools to start the business but also marketing skills.

A system of regular medical follow-ups including home visits should be established to overcome the transportation barriers. The new universal health insurance scheme was launched in 2014 and will cover medical rehabilitation costs indicated by the physician. Individuals with severe disability are exempted from the premium. However, the full implementation of this scheme and its impact to individuals with SCI is yet to be seen in the coming years. Health education to prevent complications should be delivered to the individuals and their caregivers. Finally, in such a limited resource setting, health providers should target components of life satisfaction that can be addressed with low-cost interventions, such as psychological and religious interventions by involving the community. Educating the community and family to provide positive social environment and to actively engage individuals with SCI in community activities might allow these individuals to achieve greater life satisfaction.




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Disclosure statement

All authors declare no conflict of interest.

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