



Barriers and facilitators for work and social participation among individuals with spinal cord injury in Indonesia

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Abstract

Study design Qualitative study using in-depth interviews.

Objectives To describe experienced barriers and facilitators for work and social participation among individuals with spinal cord injury (SCI).

Setting Vocational rehabilitation (VR) center in Yogyakarta Province, Indonesia.

Methods Semi-structured interviews were conducted with 12 participants (8 males, 4 females) aged 24–67 years. Five participants still underwent vocational rehabilitation, while seven participants lived in the community. Thematic analysis was used.

Results None of the participants who worked before the injury returned to her/his previous occupation, most participants became self-employed. The frequency of participation in social activities decreased substantially. Barriers for work and social participation included health conditions and environmental barriers, including inaccessibility, stigma and discrimination and limited institutional support and services. Identified facilitators for work and social participation were perceived importance of work and social participation, adaptations to disability condition, and social support.

Conclusion Barriers to engage in work and social activities for individuals with SCI in Indonesia are combination of physical limitations, lack of accessibility, stigma, and institutional barriers. The capacity of social networks such as family in facilitating participation should be strengthened during the VR processes. VR should provide marketing skills and link self-employed clients with the market, in collaboration with the private sector and industries. Immediate policy and programmatic action is needed to enable these individuals to enhance sustainable work and social participation.

Introduction

Active community participation, especially in economically productive activities such as employment [1] and social activities, is positively associated with quality of life (QOL) in individuals with spinal cord injury (SCI) [2]. However, only a few studies focused on participation in individuals with SCI living in developing countries [3]. It is important to conduct such a study in developing countries because firstly, the labor market in developing countries is largely structured around informal employment, and unemployment rates are high, even for people without disability [4]. This may present different barriers to individuals with SCI compared to their counterparts in economically developed countries. Secondly, the importance of having paid work is high in developing countries, since there is no formal or well developed welfare systems available to unemployed and disabled people [5]. Consequently, individuals with SCI might be more motivated to overcome barriers to survive.

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Further, social participation is strongly influenced by the sociocultural context [6]. Therefore, the extent to which participation in certain social activities is regarded desirable or acceptable by the individual and society differs significantly between cultures. In Indonesia, social participation is highly valued, which is typical for country with collectivist culture. Communal work and helping each other, or often called as “*gotong-royong*”, is integral in the daily life especially in rural areas [7]. Such culture-specific norms may influence the type and nature of participation by individuals with SCI. It is important to understand how social participation is defined within such a collectivist sociocultural context to conduct an adequate assessment of social participation and its determinants.

Our previous study showed that paid work and social participation are perceived as important components of QOL among individuals with SCI in Indonesia [8], yet no study has specifically assessed challenges in resuming work and social participation after the onset of SCI in this country. The present study aims to describe experienced barriers and facilitators to work and social participation in individuals with SCI in Indonesia. This knowledge may potentially provide policy makers and service providers a better understanding of challenges in everyday lives and coping and thereby helping to determine the focus of future policy and practice measures to enhance participation.

Methods

Setting

Since there was no hospital with spinal unit or rehabilitation hospital in the study location, this study was conducted in a vocational rehabilitation (VR) center in Yogyakarta province, Indonesia. In 2006, the province was hit by an earthquake causing 300–400 individuals affected by SCI. The VR center was established to provide a 9-month inpatient program to medically stable earthquake victims and residents with permanent disabilities. VR clients were able to choose skills that they wanted to learn, for example computer or handicraft skills and equipped with tools and equipment to start-up their business.

Participants

Participants were individuals with SCI who had completed VR and returned to the community or were undergoing VR training at the time of the data collection. Potential participants were identified by the first author and interviewer from the record of VR center clients who had paralysis between 2009 and 2012. Participants were purposively selected to ensure representation of both sexes, age groups

<40 and \geq 40 years, living in the community or in the VR center. Fourteen eligible participants were identified and were contacted by the interviewer with the assistance of the VR center staff to participate in the study.

Data collection

Data collection was performed by the first author and/or trained interviewer with background in sociology. To achieve similar understanding, the first author and the interviewer performed the three first interviews together. After being informed by the VR center staff regarding the study, eligible participants were visited in their room at the VR center or at home by the first author and the interviewer. The aim and procedure of the study were explained prior to asking participants for their willingness and consent to participate in the interviews.

Since no medical record was available for the VR clients, a neurological examination was performed by a neurology resident to verify the diagnosis of SCI. All examination was also attended by the first author. Level of neurological lesion was classified using the International Standards for Neurological Classification of Spinal Cord Injury into paraplegia and tetraplegia. Completeness of injury was classified as complete (no sensory and motoric functions below the level of the lesion) or incomplete (some of the sensory and motoric functions are present) [9]. The level of functional independence was assessed using the Barthel Index. Scores range between 0 (completely dependent) to 20 (completely independent) [10].

In-depth interviews were conducted using an interview guide developed based on previous studies [2, 11]. Work participation was defined as performing any work, employment, or income-generating activities. Social participation was defined as taking part in any activity that involved interaction with others, such as social events. Participants were asked to describe what prevented them to return to or start with work and to take part in appropriate social activities. The interview guide is presented in Table 1. Interviews were conducted in mixed Indonesian and Javanese language by the interviewer. The first author and the interviewer are fluent in both languages. All interviews were digitally recorded.

Ethical clearance was obtained from the Faculty of Medicine Universitas Gadjah Mada, Yogyakarta, Indonesia. Written informed consent was obtained from all participants prior to the neurological examination and interviews. All interviews and examination were conducted in the private room of the participants in the VR center or at home at times convenient for them. The duration of interviews varied, but ranged from 1 to 2 h. Some interviews were conducted in 2–3 sessions considering the availability of participants and their stamina to endure the interviews.

Table 1 Interview guide.

(A) Work and participation

(1) Mention 5 activities that are most important to you in your life.

(2) For each of these 5 activities, are you able to do this activity without assistance?
What are barriers to perform these activities?
What could help you to perform these activities?

(3) Is there anything else important to you that you would like to do or participate in, that you cannot do now?
What are barriers to perform them?
What assistance would be needed to perform these things?

(4) Can you tell me your source of income after the injury?
Did you work before your injury?

(5) Are you working right now?
(a) If yes, describe the nature of your work.
(Proceed to question 6)

(b) If not, would you like to work?
Why and why not?

(6) What kind of work do you desire?

(7) What are the things that enable you to work?
What are the things that prevent you to work?
How do you cope with the barriers, if any?

(B) Social participation

(1) How is your relationship with other people surrounding you (e.g., family, friends, neighbors etc.). What are their roles in your life?

(2) Has any change occurred in your relationship with other people surrounding you (e.g. family, friends, neighbors etc.) after your (SCI) condition?
How?
(3) What are the activities in your neighborhood that you participated in before the injury?

(4) What are the activities in your neighborhood that you participate in right now?

(5) Do you think participation in social activities is important in your life?
Why or why not?

(6) What are the things that enable you to participate in social activities?
What are the things that prevent you to do so?

(7) Are there any neighborhood or social activities that you would like to participate in, that you cannot do now?
What are barriers to perform them?
What assistance would be needed to realize this participation?

Data analysis

The digital recordings of all interviews were transcribed verbatim into Indonesian or Javanese by the interviewer. The first author translated the responses into English and discussed the translations with the interviewer to ensure the correct meaning. Thematic analysis was performed on the

English translations of the responses. All authors read the transcripts line-by-line independently and assigned codes to meaningful responses. Codes were developed and assigned labels. Recurrent codes were grouped and categorized into subthemes such as injury factors, environmental barrier or social support etc based on discussions among all authors and relevant literature. Subthemes were categorized as barriers or facilitators for work and social participation. The first author reviewed the fit of the themes and subthemes with the original Indonesian/Javanese responses in the text. When no new subthemes under each theme emerged from the subsequent interviews, data saturation was considered present and no new participants were recruited. Data analysis was conducted using ATLAS.ti 7.0 software.

Results

Interviews with two participants were not completed because of illness. Table 2 shows characteristics of the 12 participants completing the interviews. All participants had paraplegia, 11 of which had an incomplete injury, and used a wheelchair for their everyday mobility.

Changes in work and social participation after injury

Before the injury, four participants worked in formal employment, four worked in informal or self-employment and four were university and high school students. After the injury, none of the participants who worked before returned to her/his previous occupation. Only one individual had part-time formal employment and seven participants were self-employed in small home industries in various area of business. These home industries were of small-scale and the customers were limited to individuals such as neighbors.

Substantial changes in the frequency and nature of social participation were reported among participants who still participated in social activities. A few participants reported that they rarely or never participated in any social activity after injury. New social networks were formed, for example with peers or other persons with disabilities in the hospital, rehabilitation centers, or disability person organizations. These networks became a gateway to social participation after the injury.

Barriers for work and social participation

We identified that barriers for work and social participation were largely similar among participants and included physical limitations, environmental barriers, and limited institutional support and services, stigma and discrimination and limited financial resources.

Table 2 Characteristics of participants.

Participants	Gender	Age (years)	Duration of injury (years)	Work status at the time of injury	Work status at the time of the study	Residential status	Barthel index
1	M	32	18	University student	Self-employed (family-shop keeper)	Home	14
2	F	26	9	Student	Not employed	Home	13
3	M	28	3	Driver	Not employed	VR center	14
4	M	41	22	Employee	Self-employed (trade)	VR center	14
5	M	44	6	Employee	Self-employed (electronic repair)	Home	14
6	F	21	6	Student	Not employed	Home	14
7	M	67	6	Farmer	Not employed	Home	12
8	M	41	6	Handyman	Self-employed (handicraft making, tailoring)	Home	12
9	M	34	6	Self-employed	Self-employed (grocery shop, raising chicken)	VR center	14
10	F	31	6	University student	Self-employed (computer rental)	Home	14
11	F	29	6	Employee	Self-employed (selling food)	VR center	13
12	M	30	6	Employee	Employee and self-employed (graphic design)	VR center	14

VR vocational rehabilitation.

Physical limitations

The physical limitation(s) resulting from the injury were major barriers both for work and social participation. None of the eight participants that worked before the injury could return to their previous jobs, in most cases due to high physical intensity jobs pre-injury. Health problems such as fatigue, pain, and pressure ulcers were also reported as barriers to work.

“I want to work, I feel happy when I can work. But now I can do nothing. I feel like, hot, like when I move like this it feels hot. I also feel muscle ache, on the place where it is broken.” (P7).

Physical limitations considerably restricted the ability of participants to be involved in social activities with the same frequency or intensity as before the injury, especially in community events that required strenuous physical activities such as communal work in the village. Vulnerability to physical health problems hampered participation in social activities, especially as most of these events are conducted in the evening and requiring going outside.

“Physically I’m not that fit, when I am exposed to outside conditions, I will get a fever. I also feel tired easily. I don’t really want to go because meetings are mostly conducted in the evening, so I rarely go.” (P6).

Due to the SCI and associated hospitalization, participants frequently experienced long periods of absence from the community. When they returned, options to join appropriate social groups were limited.

“The ARISAN (community-level women’s rotating savings and credit associations [12]) group in which I participated before the injury had been replaced with younger generations. Most of my generation are already married and having family.” (P10).

Environmental barriers

Various physical barriers in the environment significantly curtailed the ability to work. Returning to previous employment was not possible, because of the inaccessibility of the workplace.

“I worked at an electronic service store. I can no longer work there because my employer’s place is not accessible.” (P5)

Workplace accommodations such as tools or equipment that can facilitate their work were not provided. This created dependency to other people to perform their work.

“You know, sometimes I couldn’t even pick up tools that fall to the floor. Somebody has to pick them up for me.” (P12).

Absence of transportation modalities (i.e., adapted motorcycles or cars) and distance to the workplace also prevented participants to work. Some participants used to work in various informal employments simultaneously and were highly mobile before the SCI, which was not possible anymore. It was also difficult for participants to follow education or training that required daily presence.

For self-employed participants especially, transportation was a major problem because their work often required them to go out, for example to purchase materials or fix some equipment. Marketing products were limited because their home-businesses were typically located in a village, so customers were only neighbors, other villagers or passers-by.

Physical barriers, such as lack of physical accessibility of community places (e.g. mosques, community centers) and the inaccessibility of the village roads, also substantially restricted participants to perform social activities.

“If I cannot enter the place, like when there is a funeral or neighborhood meeting, I usually stay outside with my wheelchair, at the terrace.” (P8).

Limited institutional support and services

Participants emphasized a lack of priority from the government for people with disabilities. None of them received a regular disability pension from the government. There was also a lack of support to obtain work or to establish and sustain self-employment. Services from the government were often not physically accessible.

“To request financial support from the government for my business, I had to hand in proposals to be processed through their administration. I had to go from one office to another office, and one office often required more than one visit. Most governmental buildings in the area were not adapted to people with disabilities.” (P4).

During the VR training, participants were often assigned to training programs not matching their interests. After discharge, support for starting up and promoting a business was lacking. No follow-up activities were done to assess the outcomes of the training. Those who looked for a job mentioned that it was difficult to find a suitable job because of skills or interests that did not match with the available jobs.

A lack of organized community or religious activities in the villages limited social participation. Within few years

after the earthquake, many social activities for people with disabilities and transportation were temporarily organized by non-governmental organizations (NGOs). These NGOs also provided homecare services and transportation to health facilities. However, such aid ended after earthquake response was terminated and not continued by the government.

Stigma and discrimination

Self-stigma, or internalized stigma, significantly prevented participation in social activities, especially during the first years after the injury. Participants were reluctant to engage in social activities because of fear that the community would not accept their condition and of being a burden to other people when assistance are needed for participating in social events.

“For 1 year after the injury, I never came out the house because of feeling ashamed and fear of bullying ... even until now...” (P1).

Perceived stigma or negative, stigmatizing attitude such as avoidance by community members in daily life were also reported.

Most participants found it difficult to find work, which indicated discrimination in work opportunities. However, self-stigma and stigmatizing attitude from others were less explicitly reported as barrier in work participation. Only one participant reported that individuals with disabilities experience difficulties to find work because they are perceived as not capable of doing anything.

Limited financial resources

Limited financial resources were a specific barrier faced by those starting or maintaining self-employment. Income generated from the business was often only enough to meet daily needs but not to expand the business, even tools and equipment were often sold to meet the family needs. Broken equipment was not repaired because of a lack of money.

Facilitators for work and social participation

Perceived importance of participation, adaptations to the disability and social support were identified as facilitators for both work and social participation.

Perceived importance of work and social participation

Almost all participants agreed that work is valuable because it provides monetary and nonmonetary benefits, and this has

driven participants to keep attempting to work despite the barriers.

Work also gave satisfaction through earning one's own income and reducing financial dependency on the family. The non-monetary benefits of work encouraged participants to keep trying to work or maintain work. When working, participants felt more responsible and useful to others and had something to do every day.

I supply ice cubes to the food vendors, it's not bad, sometimes I could get IDR 3000 to 4000 (around 20–30 Euro cent). It's not much but it is for my daily activities, so that I have something to do. I become more responsible. Well I can also buy some phone credits, I don't have to ask money from my parents, I can be independent.” (P11).

One individual described that the feeling of being useful and contributing to something valuable made him more satisfied with his working life than when he was able bodied.

“I feel that I am being more useful now, rather than when I was able-bodied. I learn new things. When people need my help to produce some drawing and I can help, I feel satisfied. When people need my service then I can help them.” (P12).

Social participation was highly valued as a very important domain of life that they need to engage in. Therefore, participants tried to remain active in social activities to the extent it was possible.

“For me social participation is important because it involves other people, we cannot live on ourselves, we always need other people.... We have to connect to other people, so having interactions with people is very important.” (P11).

Participants felt the responsibility to actively participate in the community particularly in rural areas where the social ties are strong. Social pressure to participate in community events and expected reciprocal relationship between individuals and their surroundings were perceived as strong driver to pursue social participation.

“We live within a community, because we live in the village, not in the city. It means that you help each other, for example when my neighbor needs help, then I or my wife will help, and when I need help my neighbor will help, so we help each other.” (P9).

Adaptation to the disability

The participants adapted themselves to their physical condition by finding or negotiating new roles that they could still perform. For example, because opportunities to obtain a regular income from formal work were dim, self-employment was particularly chosen as the most viable option.

“Working like this allows me to work without leaving home. I also feel satisfied as I am not dependent on employers.” (P12).

With self-employment, it was more convenient for participants to manage their wheelchairs. Some participants modified their workspace at home to be a workshop or kiosk located in the front part of the house and was large enough to enable maneuvering with the wheelchair during work.

“I want to have a business that I can perform, that I can do with a wheelchair. I want to have a grocery kiosk, but if not I can also sell phone credits.” (P9)

Similarly, to be able to maintain participation in social activities, adaptations of activities and negotiations with the community were also often made. For example, participants chose to engage in less strenuous activities that suited their capacity, such as administrative or coordination work.

“I contributed by painting decorations, designing invitations and so on.” (P12).

Other participants took part in *gotong royong* as supervisor or observer that required less strenuous activity. Some participants restricted their engagement to events in nearby places.

“Usually for big family gatherings, I would come. For example, during Eid (end of Ramadan month). But I will not come if it is too far, if it is nearby I will come.” (P8)

Social support

Almost all participants agreed that family, friends or peers and surrounding communities provided an important source for support, especially moral and instrumental support.

“My family always lifted me up, that is the most important. If I keep spirited, I will be motivated to live,

to work, and to earn income, so I will not be slumped.” (P8)

Families, friends, and neighbors provided instrumental support for work, for example by providing capital, purchasing and delivering materials for production and helping with transportation.

“My neighbor will come here to drop the materials, when (the orders are) ready she will pick them up. The fabrics and also sewing thread are also from them, we just provide the service.” (P11).

Practical support for social participation such as transportation for attending social events was also provided by the surrounding community. Spontaneous, practical support from the community members during the events was often received.

“When going to community events, usually others will push my wheelchair or even lift it.” (P8).

Some participants frequently received visits from friends and neighbors which was perceived as a gesture of care and acceptance. Relations with peers became an important addition to the social relations after the injury.

“I want to visit my friends (peers), so we can share stories, problems, because they are the same, they can understand what I feel.” (P6).

Recognition of their capabilities by the community members was identified as important to improve participation.

“I wish the community do not underestimate our capability and instead give us opportunities.” (P10).

Discussion

This study found that a combination between physical limitations, environmental and institutional factors resulted in a substantial restriction of work and social participation for individuals with SCI. While these barriers were mainly external factors, participation restriction were partly overcome by several facilitating factors that came mainly from personal or social networks. This study also stressed the importance of exploring the context within which the limited participation occurs, because the extent to which participation is restricted or eased is subject to the socioeconomic, cultural, health, and social welfare systems.

Self-employment was the main type of employment after the injury, driven by the inability to return to the same work and the lack of formal job opportunities which is also evident in other developing countries [13, 14]. Self-employment may partly overcome the mobility and transportation barriers and allow for more independence, flexibility, freedom and satisfaction [15, 16] and fewer stigma [17]. However, self-employment had specific barriers such as costs for workplace accommodations [18], and lack of capital and marketing skills [15, 19] which were often not adequately addressed during the VR processes [15, 20]. Moreover, although most of our participants were engaged in paid work, this engagement in paid work often seemed to be inadequate to support their needs.

The ‘mediating’ role of social support between injury and the limited participation described in this study confirms previous findings in other developing countries [21, 22]. Our data suggest that moral and instrumental support from the surrounding social networks enabled participants to perform work and social activities. Because the health infrastructure and social security for individuals with disability is poor, reliance to social support is often the main way of getting income and basic needs [23]. In contrast, in a developed country such as United States, social support had no direct influence on employment opportunities [24], perhaps because the labor market is dominated by formal employment and is less penetrable by social networks [25]. In terms of social participation, the strong social ties within the community did not only drive individuals to pursue participation but also facilitate participation by producing instrumental support.

The perceived importance of work was a strong facilitator. Literature on employment in SCI show that in addition to monetary incentives, work has been associated with life satisfaction through independence, social contacts, sense of purpose, and personal growth [26]. Work is also perceived central to a satisfactory QOL as it is inevitable for survival and creating a feeling of being useful [8]. Perceived importance of social participation was also a strong facilitating factor, partly due to concerns that those who do not participate in the community might be negatively labeled. Most social activities described by the participants involved interaction with the community aiming at shared objectives, for example attending community and religious events. In contrast, studies into social participation in Western countries focused on social contacts with friends and relatives, voluntary activities and self-initiated activities, such as leisure and sport activities [27]. This illustrates the differences in the types and nature of social participation between collectivist and individualist culture. Our study indicates that participation by individuals with SCI is influenced by societal expectations, that they are also

acting in accordance with external expectations or social norms, rather than following their internal desires or objectives [28, 29].

Adaptations to the disability condition and also re-negotiation of roles facilitated our participants in work and social participation, as has been described in previous study [30]. A study among stroke survivors in rural Indonesia also showed that participants with stroke remained a significant contributor in their family, although they performed a less physically demanding role [31]. Participation is viewed as a dynamic process that involves negotiation and balance between individual needs and societal values to maintain a meaningful role in society [11].

Different forms of stigma were found as a barrier for both types of participation. Difficulties in finding jobs was in fact a form of stigma and discrimination in work participation, while self- and perceived stigma were prominent as a barrier in social participation. While stigma towards individuals with disability in Indonesia in general is high, no study specifically examined the level of stigma towards individuals with SCI and its relationship with participation. A previous study in people with leprosy-related disability showed that stigma is a major determinant of social participation [32].

This study is the first in-depth exploration into barriers and facilitators for work and social participation among individuals with SCI in Indonesia. The first author was only involved in the first three interviews, which might limit the understanding of the meaning and probing of the participants' narratives. The study focused on Javanese people, whose values are influenced by the Islamic religion and locally rooted traditions, especially in rural areas. Family ties and community values in other ethnicities in Indonesia might be different. All recruited participants were VR clients, which might have caused bias due to self-selection, because they might give higher importance to work than individuals who did not participate in a VR program and face different types of barriers and facilitators.

Our study implied that skills to expand and maintain self-employment such as marketing skills should be introduced in VR curricula. VR should be better reoriented to ensure the viability of self-employment, for example by linking self-employed clients with the market in collaboration with the private sector and industries. Follow-up assessment of the VR outcomes should be performed at regular interval to identify barriers of sustaining self-employment. Support from the government and relevant institutions through policies and programs is needed to ensure the sustainability of self-employment, for example by micro-financing schemes for self-employment businesses. As self-employment is often not sufficient for livelihood, the government should also provide financial assistance for individuals with SCI. Those who pursue formal employment should be assisted with job placement, for example by

channeling to small industries or companies. The capacity of family and community to provide support especially moral support should be enhanced in the rehabilitation process, for example by engaging the family during rehabilitation and educating the family on how to provide support to resume participation. The perceived value of participation is a strong facilitator that could be used to provide motivation for both individuals and family during the VR process. Lastly, the role of new social networks such as peer groups and disability person organization should be strengthened to enhance participation by providing a forum for empowerment, raising awareness and advocacy on the disability rights in economic and social activities.

Finally, our study found that individuals with SCI in Indonesia experienced substantial barriers to fully engage in work and social participation. Limited participation is a result of a combination of physical limitation, physical barriers, institutional barriers, and personal factors. While we identified several facilitators that helped to overcome these barriers, these mainly came from personal or social networks and might not be sufficient to sustain survival let alone participation. Immediate policy and programmatic action is needed to enable these individuals to enhance sustainable work and social participation.

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Compliance with ethical standards

Conflict of interest The authors declare no competing interests

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