Chapter 7

General discussion
This Thesis portrays the path to resuming and maintaining work that individuals with spinal cord injury (SCI) undergo. This path starts with perceiving the values of work, associating work and quality of life (QOL), overcoming barriers of work by adapting to the condition or obtaining social support, and making efforts to return or initiate work by participating in vocational rehabilitation.

The overall objective of this thesis was to generate knowledge regarding the interrelation of QOL, work and social participation in individuals with SCI in various settings. The specific objectives of this thesis were threefold. The first objective was to generate knowledge regarding QOL, work and social participation in individuals with SCI in Indonesia. The second objective was to identify the predictors of return to work (RTW) and trajectories of employment in individuals with SCI in the Netherlands. The third objective was to identify factors associated with QOL in individuals undergoing vocational rehabilitation in Switzerland and Germany.

The chapters of this thesis are divided into three parts, according to these objectives: 1) insight into the quality of life and participation in individuals living with SCI in Indonesia, 2) return to work and trajectories of employment 5 years after discharge in individuals with SCI in the Netherlands, and 3) quality of life in individuals undergoing vocational rehabilitation in Switzerland and Germany.

In this chapter, the main findings of the thesis are summarized and discussed based on the research questions of each objective. Interpretations and discussions on the main findings are presented with theoretical and methodological considerations. Finally, the future implications for research, policy and practices are provided.

**Main findings**

**Part 1. Insight into the quality of life and participation in individuals living with spinal cord injury in Indonesia**

Research Objective 1 (Chapter 2): What is the meaning of quality of life in individuals with spinal cord injury in Indonesia and which components do they consider important to achieve a good quality of life?

Quality of Life (QOL) was not a commonly used concept in the daily life of individuals with spinal cord injury (SCI) living in Indonesia. QOL was mostly described as life...
satisfaction or happiness and associated with a person’s feeling when achieving goals or dreams and related to fulfilment of needs. It was also perceived as subjective, unreachable, and associated with God’s will. Sociocultural and religious aspects strongly affected the perceived meaning and components of QOL.

Thirteen components of QOL were identified and categorized into 5 domains transcending the health domain i.e. 1) participation, which consists of work, being useful to others, community participation, and having knowledge and skills, 2) social support and social relationships, 3) relationship with God i.e. accepting that SCI is God’s will and praying, 4) independence refers to being independent, mobility and accessibility, and a sufficient health condition and 5) psychological well-being domain, i.e. accepting the condition and maintaining goals and motivation.

Research Question 2 (Chapter 3): What are the barriers and facilitators to employment and social participation experienced by individuals with spinal cord injury in Indonesia?

Significant changes in work participation after SCI were observed in the study; none of the participants returned to his/her previous occupation. Most participants were self-employed after the injury. Substantial changes in the frequency and nature of participation in social activities after the injury were also reported.

Barriers to work and social participation were as follows 1) health conditions such as physical limitation, fatigue and frequent hospitalizations, 2) environmental barriers such as inaccessibility of roads, workplaces and lack of transportation, 3) stigma, and 4) limited institutional support and services. Identified facilitators for work and social participation were 1) perceived importance of work and social participation, 2) adaptations, and 3) social support, moral as well as instrumental support.

Part 2. Return to work and trajectories of employment 5 years after discharge in/among individuals with spinal cord injury in the Netherlands

Research Question 3 (Chapter 4): What is the return to work rate and what are the trajectories of employment in individuals with spinal cord injury in the Netherlands?

Using the definitions of return to work (RTW) as returned to paid work for ≥ 1 h and ≥ 12 h/week, we found that the RTW rates 5 years after discharge from inpatient medical
rehabilitation for ≥ 1 and ≥ 12 h/week were 50.9% and 42.6%, respectively. It took a median time of 13 months to return to work. The employment situation after injury was typically characterized by fewer working hours and lower physical intensity compared to before onset of SCI.

We found that only one fifth of individuals with SCI were able to gain and maintain steady employment during a span of 5 years after discharge from inpatient medical rehabilitation. Three distinct employment trajectories were identified. First, the ‘no employment’ group (22.2%) constituted of those individuals without employment before injury and during the 5-year follow-up. Second, the ‘low employment’ group (56.3%), that is, individuals with pre-SCI employment and a low, slightly increasing probability of employment during the 5-year follow-up. The third group was the ‘steady employment’ group (21.6%), that is, individuals with continuous employment from before SCI and within 5-year follow-up.

Research Question 4 (Chapter 5): What are the predictors of return to work and stable employment in individuals with spinal cord injury in the Netherlands?

RTW was strongly associated with the characteristics of the pre-injury occupation. Five years after discharge from acute medical rehabilitation, those individuals who had a middle/high pre-injury occupational level (for example, professional and managerial occupation) based on the Dutch classification of occupations were twice more likely to return to work than those with a low pre-injury occupational level (for example, manual laborer, agricultural worker). Those who had a pre-injury occupation with low physical intensity were also more likely to return to work than those who worked with high physical intensity prior to injury. When the cut-off of 12 h/week was used, only those who had a pre-injury occupation with low physical intensity had a higher likelihood to return to work.

We also found that having a secondary education predicted the likelihood of steady employment after SCI. Individuals with secondary education were four times more likely than those without secondary education to engage in steady employment. Meanwhile, individuals with a better physical capacity measured by a higher Functional Independence Measure (FIM) motor-score at discharge were more likely to have steady employment compared to those with a lower FIM motor-score.
Part 3. Quality of life among individuals undergoing vocational rehabilitation in Switzerland and Germany

Research Question 5 (Chapter 6): What are the levels and determinants of quality of life in individuals undergoing vocational rehabilitation in Switzerland and Germany?

We found that the health-related quality of life (HRQOL) in all SF-36 dimensions was significantly lower among vocational rehabilitation (VR) clients than in the general population. Several types of VR that are closer to competitive employment, such as returning to the former workplace and being oriented to a new job, were associated with better HRQOL scores. This was mainly observed on the HRQOL dimensions physical limitations due to physical problems, pain, vitality and mental health problems. Almost one fourth of the VR clients reported depressive symptoms. Depressive symptoms were negatively associated with all HRQOL dimensions.

Discussion of the main findings

This Thesis found that returning to work is important for QOL but remains challenging for individuals with SCI, both in developing and developed countries. Environmental barriers and stigma are major barriers to return to work. To overcome these barriers, individuals with SCI coped by attempting self-employment, adapting to the condition, and obtaining social support. When returning to work, however, there are significant changes in the work situation. Few individuals with SCI were able to sustain employment. Education is an important determinant both for returning to work and sustaining employment. We also found that in the process of vocational rehabilitation, individuals with SCI may experience certain distress that leads to low HRQOL and a high depression level.

Participation

Being useful or being able to contribute to society was described as vital component of QOL among individuals with SCI in Indonesia. This in fact reflects the World Health Organization's description of “social participation” i.e. involving, or working directly with communities, or can also be referred to as “participation” as these two constructs are not distinct concepts. Social participation is increasingly used as rehabilitation outcome, however, the International Classification of Functioning, Disability and Health (ICF) does
not provide a specific definition of social participation. In the literature, it is often defined as engagement in activities in the community\textsuperscript{2,5}, for example cultural, leisure or recreational and political activities\textsuperscript{6,7}.

Our study confirmed findings of previous studies that social participation is a central component of QOL among individuals with SCI\textsuperscript{8–10}. Various social activities have been associated with QOL including contact with friends and peers\textsuperscript{11}, leisure\textsuperscript{12,13}, sports, as well as volunteering\textsuperscript{14}. In our study, however, participants described social participation more as engagement in social events such as attending weddings, community and religious gatherings, ceremonies etc. This might relate to the cultural differences in defining social participation between Western and non-Western countries. Western countries are mostly characterized by an individualist culture, in which individual desires are highly regarded and individuals have a personal autonomy to participate or not in social activities\textsuperscript{15,16}. Meanwhile, in non-Western countries, individuals are expected to behave according to local norms, roles and obligations including maintaining social harmony through social participation\textsuperscript{17}.

Despite the potentials of social participation in leveraging QOL, its broad definition causes difficulties in determining what type, dimension or level of social participation would correlate strongly with QOL. The degree to which social participation is considered “low or high” also remains a matter of discussion\textsuperscript{7}, because the normative standards for social participation differ between cultures and contexts\textsuperscript{2}. It could be that it is not the amount or type of social participation that matter to QOL, but how meaningful the contribution to the society is as perceived by the individual\textsuperscript{14}. The latter is of course difficult to measure and is very subjective. It is also suggested that social participation should not refer to a single activity but to a set of social performance\textsuperscript{2}. In our study, social participation was defined broadly as taking part in any activity that involved interaction with others, such as social events. The level of QOL associated with social participation probably relates to the level at which an individual can meet societal or individual expectations about participation, thus is very much contextualized.

**Relationship with God**

The relationship with God was emphasized as an important component of QOL among individuals with SCI in Indonesia. All of our participants were practicing Muslim, and most reported that they used prayers as a way to feel closer to God. Despite physical limitations and environmental barriers, they attempted to perform religious practices
and attend religious events. Indonesian people perceive religion as fundamental part of life. Religion is often associated with physical and mental health outcomes and religious activities have been a part of informal healthcare processes for the terminally ill\textsuperscript{18}. For example, families often invite religious clerks to their home to pray together for the patient.

The relationship between religion and disability has been frequently discussed in previous studies\textsuperscript{19}. In difficult circumstances and after negative life events, people tend to become more religious, which explains why religion is important in chronic illness\textsuperscript{20} and disabilities, including in SCI\textsuperscript{21–23}. Several studies have also found associations between religiosity and QOL among individuals with SCI\textsuperscript{21,22,24,25}. However, the specific mechanism by which religiosity is associated with QOL is still unknown. Religiosity may act as buffer because it provides emotional support, purpose and meaning in life\textsuperscript{23,26} which facilitates coping mechanisms to the disability condition, that may affect QOL\textsuperscript{27}. Belief to adhere to God’s will may also create hope and optimism about life that influences the assessment of QOL\textsuperscript{25}. Individuals with SCI often believe that their injury happened for a reason i.e. serving a higher purpose and finding the true meaning of life\textsuperscript{23}. They also may express the sense of gratitude of being still alive\textsuperscript{28}, thus influencing QOL perception. Moreover, religiosity may also facilitate social participation and provide social support, as religious ceremonies or events are often performed in groups that individuals may take part. However, negative effects of religiosity are also possible, for example feelings of guilt and sin\textsuperscript{29}.

Despite being important to many people around the world, religiosity is still an understudied area in rehabilitation research\textsuperscript{7,27}. Religiosity is also conceptualized differently across studies and is often used interchangeably with “spirituality”. It is also measured using different parameters and scales\textsuperscript{27}. Most often, it is measured through self-rated religiousness and frequency or intensity of religious activities such as prayers and attendance to religious services\textsuperscript{19}.

Available studies concerning associations between religion and QOL in SCI were mostly conducted in Western countries, which are predominantly of the Christian religion\textsuperscript{19,22}. Studies rarely examined the relationship between the Islamic religion and QOL among individuals with SCI. In Islam religion, it is strongly believed that diseases and calamities are a test of faith from God\textsuperscript{22,30}. Muslims affected by illnesses and their families seek help from God through prayers because during hard times they are encouraged by the Quran.
script to practice patience, resilience, fortitude and also maintain a gratitude to God. Whatever the result is (cure, non-cure or death), there is a strong belief that it is God's will. It is not known whether such a belief may affect QOL positively or negatively. The influence of the Islamic religion on QOL in individuals with SCI thus represents a new area to be explored, especially as Islam is the third largest religion in the world and many individuals with SCI are Moslem.

**Work**

Being able to work was identified by individuals with SCI in our qualitative study as crucial to QOL, which emphasized the importance of work in defining QOL among individuals with SCI. Studies in both developing and developed countries consistently found beneficial outcomes of work among individuals with SCI from individual and societal perspectives. For the injured individuals, gainful employment may lead to tangible outcomes such as financial security and health benefits. Several psychological benefits have been related to work after injury, including feelings of independence, personal fulfilment and self-esteem, and reduced symptoms of depression. Moreover, employment has also been associated with long-term well-being outcomes, such as better QOL and social integration, increased life satisfaction and even decreased risks of mortality.

The importance of work in our study was especially related to being financially self-sufficient, as all participants had no stable income and governmental social security support is almost non-existent in Indonesia. These individuals are often the breadwinner of the family and when they cannot work the financial stability of the whole family is affected. The importance of financial independence as QOL component is less pronounced in studies in developed countries, perhaps because the basic needs of individuals with disabilities are relatively met from employment or social protection. In the Netherlands for example, individuals with SCI are quite satisfied with their financial situation, while in other European countries, personal satisfaction ranked first as the most important reason for work followed by monetary reasons. Economic self-sufficiency through gainful employment seems to be more urgent for those living in developing countries.

The process of returning to work, for example undergoing vocational rehabilitation, poses another challenge to individuals with disability including SCI. In our study among clients with disabilities in VR centers in Switzerland and Germany, we showed that the
level of HRQOL was low. We also found that levels of depression were high, probably due to their chronic conditions and disabilities, inability to work or still being in an adjustment process with the disabling condition. We found that those undergoing VR types close to competitive employment reported higher HRQOL levels, suggesting that expectations to return to gainful employment may lead to better QOL.

**Return to work and changes in the work situation**

We assessed the return to work outcomes five years after the individuals with SCI were discharged from the medical rehabilitation in the Netherlands. Half of our participants were able to return to work (i.e. paid work for >1 hour/week) 5-years after discharge. About 40% of our participants worked for 12 hours/week and more. This was in the range of the average rate of employment among individuals with SCI i.e. 21-67%. However, we used a rather low threshold of working hours, i.e. 1 hour and 12 hours/week. When full-time working hours were used, the employment rate would have been much lower. Earlier studies consistently showed that the employment rates and RTW among individuals with SCI are much lower than in the general population.

Among those individuals who returned to work, considerable changes in the work situation were experienced after the injury, including fewer working hours and less physical intensity, which have also been reported in previous studies. Because of their sustained injury and resulting physical limitations, individuals with SCI were no longer able to perform physically demanding jobs. Administrative and managerial types of work were most commonly performed after the injury, yet these types of occupations are often associated with a middle/high occupational level and required higher qualifications such as college and university level and further education and training. This also explains why individuals in our study in the Netherlands who had pre-injury occupations with a middle/high occupational level and low physical intensity were more likely to return to work.

Significant changes in the working situation were also experienced by individuals with SCI in our study in Indonesia. None of the participants was able to return to their previous employment. This is in line with a study in Turkey, where less than 10% of individuals with SCI were able to perform their pre-injury job. Self-employment was the main type of employment among individuals with SCI in Indonesia, which is commonly found among individuals with SCI and other disabilities in developing countries. The choice of self-employment seemed to be driven by the awareness of barriers to
enter formal employment such as lack of education, skills and confidence\textsuperscript{70} and the available VR model. In India for example, a 6-month residential VR program is provided with a focus on self-employment to overcome the lack of employment opportunities in the country\textsuperscript{68,71}. Meanwhile, employed individuals with SCI in the Netherlands and other developed countries were likely to work in administrative and managerial positions\textsuperscript{72,73}. Opportunities to work in administrative and managerial positions in Indonesia especially for people with disability are scarce. Moreover, our Indonesian participants had a low level of education and had to compete with non-disabled job-seekers. Self-employment might be a viable option in the light of absence of employment opportunities as it can lower the mobility and transportation barriers but also allows for more independence, flexibility, freedom, satisfaction and fewer stigma\textsuperscript{74,75}. Nevertheless, establishing and sustaining self-employment required a lot of financial and instrumental assistance that many individuals with SCI might be ill-equipped with. Some individuals with SCI who were not able to enter the formal employment market and not possessing enough modalities to start and maintain self-employment may fall into poverty.

**Steady employment in spinal cord injury**

Different from the majority of past studies which measured employment at a single time point, we treated employment as a trajectory over 5 years. In our study, only one-fifth of the participants was able to achieve steady employment or to be continuously employed during the period of 5 years after discharge. For almost half of the individuals the likelihood of being employed was low throughout the 5-year period after discharge. Sustainable employment in individuals with SCI is important because with increased longevity of individuals with SCI, prolonged participation in employment is necessary\textsuperscript{37}. To date, only a few studies attempted to identify different courses of employment in SCI over longer time periods. In his study in the United States, Krause et al identified four subgroups of employment status within a 11-year span i.e. stable employment, positive or negative employment transition, and no employment\textsuperscript{62}. Among those who worked before the injury, Krause et al identified two general tracks of RTW, that is, a slow track and a fast track, yet their analysis estimated only the time interval between injury onset and first post-injury employment\textsuperscript{76}. Trezzini et al\textsuperscript{38} assigned RTW pathways to individuals with SCI in a cross-sectional study in Switzerland and found that half of the individuals were able to return to their previous employer. Those who returned to
their previous employer needed shorter time to return to work than those who returned to work with a new employer.

Our study showed that despite successfully returning to or obtaining employment, maintaining steady employment is still a challenge for individuals with SCI. Individuals with chronic diseases and disability, including SCI, are likely to leave employment or experience recurrent work absences because of their medical condition and considerable challenges in accessing workplaces and performing essential work tasks. Individuals with SCI are also likely to experience secondary health conditions which may influence their work ability and require frequent re-hospitalizations.

In our study, steady employment was associated with a higher education and better physical capacity. With a higher education, individuals are able to obtain middle/high level occupations which usually do not require intense physical work. Therefore, after the injuries, individuals with higher education will be more likely to obtain employment, especially administrative and managerial type of work. Previous studies also found that individuals who returned to the former employer returned to work faster and worked for longer working hours, suggesting a more steady employment pathway.

**Environment as barrier and facilitator for work participation in individuals with spinal cord injury**

Our study showed that individuals with SCI in Indonesia encounter significant environmental barriers to participate in work, both for those who resume and start work. Not only environmental barriers at the personal level were described by the participants, but also environmental barriers at the community level. Physical barriers such as inaccessible roads and buildings as well as lack of transportation hinder individuals with SCI to work and participate in meaningful activities.

For individuals living with SCI in developed countries, finding the way back to employment is also significantly complicated by environmental barriers. Nevertheless, these barriers may be more substantial in developing countries because of the absence of transportation and accessible facilities for people with disabilities. In Indonesia, environmental constraints are also related to a lack of financial capacity at the individual and societal level to provide mobility aid and adapted facilities.
Our findings reflected what Sen has described in the capability approach. This approach asserts that disability results not merely from medical impairment, but rather from a combination of personal factors, available resources and the environment\textsuperscript{92}. Individuals with SCI living in developing countries such as Indonesia may have a similar level of impairment as their counterparts living in developed countries. However, the lack of available resources and an unsupportive environment worsen the level and consequences of their disability, rendered them poorer QOL and participation than those who live in better-off, resourced environments\textsuperscript{56}.

We found that the social environment in Indonesia substantially facilitated participation by providing moral and instrumental support which resulted in tangible benefits such as engagement in work and social activities. In many Eastern countries, since there is an inadequate formal health care and welfare system, family and kinship are often the mainstay of support to provide care and to meet the needs of individuals with disabilities\textsuperscript{93}. Social support during vocational rehabilitation should also be strengthened to overcome psychological distress leading to depression.

**Methodological considerations**

In this section, we discuss the methodological issues concerning the design, sample, and quality of the data. We also discuss the cross-cultural aspects of our study.

**Design**

To address the different objectives of this thesis, we used different study designs. We employed a qualitative design with in-depth interviews (Chapters 2 and 3), prospective cohort studies (Chapters 4 and 5) and a cross-sectional study (Chapter 7). The qualitative design was used because the aims of the study were to explore the meaning of QOL and the experiences in resuming work and social participation from the perspectives of individuals with SCI in Indonesia. The qualitative approach enabled us to explore the topics from different perspectives\textsuperscript{94}.

The prospective cohort studies were a part of a Dutch multicenter study ‘Restoration of mobility in SCI rehabilitation’, which aims and methods have been described elsewhere\textsuperscript{95}. This study followed wheelchair-dependent individuals with SCI aged 18-65 years 5 years after discharge from acute medical rehabilitation. Employment outcomes were
measured 1, 2 and 5 years after discharge. We used this prospective design to unravel associations between factors at baseline (discharge) and employment outcomes, including the sustainability of employment, during follow-up. A cross-sectional design was chosen to examine HRQOL among individuals undergoing vocational rehabilitation in Switzerland and Germany. The study provided initial information on the level of HRQOL and associated factors among individuals with disabilities in vocational rehabilitation centers, which is still under-researched. The cross-sectional nature of the study, however, does not allow any causal inference.

**Sociocultural issues**

Our study was conducted in different settings and populations using different languages that pose challenges in interpreting the findings. In the qualitative study, our aim was to explore the meaning of QOL for individuals with SCI in Indonesia. While the term of QOL has been translated into Indonesian terminology, it remained an unfamiliar term for the participants, suggesting that it was not merely a language issue but also a conceptual issue. In exploring barriers and facilitators of work and social participation, the two constructs were defined broadly during the interview. Work was defined as income generating activities, while social participation was defined as activities involving interaction with other people. Individuals with SCI in Indonesia might ascribe different definitions to work and social participation from their counterparts in other countries.

In the data collection process and analysis of the qualitative study, three languages were used i.e. Indonesian, Javanese and English. Interviews were conducted using mixed Indonesian and Javanese. Analysis was partly with the original transcripts (in Indonesian, Javanese or mixed) and partly with English translations. In qualitative research, it is suggested to stay in the original language as long and as much as possible during the analysis to avoid the loss of meaning during translations. There is no consistent translation method in qualitative studies because it depends on the data collection methods, the available resources and the language of the researchers. In our study, translation was performed to the codes, themes and quotations. Such an approach has been recommended because it ensures the authenticity of the findings. In the quantitative studies, all instruments had been translated and validated into the local language i.e. Dutch and German. However, different perceptions in the meaning of the concepts being measured, i.e. QOL, may still exist because of sociocultural differences.
Study samples

In our qualitative studies, participants were recruited from a VR center, which may have introduced selection bias. The participants may represent views from individuals with less severe SCI and those who are intending to return to or engage in work. Individuals with SCI who had a more severe injury and were not willing to work might have different views on what constitutes QOL and may value work less important. In addition, participants were all Javanese people living in rural areas, therefore their insights on QOL and participation may be different from those living in urban areas and of different ethnicities, culture and socioeconomic status. However, Javanese people comprise 60% of the Indonesian population.

The Dutch multicenter prospective cohort study ‘Restoration of mobility in SCI rehabilitation’ was used as sampling frame for the longitudinal studies on return to work and employment trajectories\textsuperscript{95}. The study specifically included wheelchair dependent individuals with SCI aged 18–65 years. Therefore, the results of the study may not be generalized to elderly people and patients with a less severe lesion, yet the sample is representative for the age group 18–65 years, and those who are wheelchair-dependent.

Participants for the cross-sectional study were recruited from five VR centers in Europe. Therefore, the results might only be representative to those with less severe SCI and intending to return to or engage in work. The use of a non-probability sampling method i.e. convenient sampling, may limit generalizability to other settings.

Lastly, samples for all quantitative studies were from developed countries with well-established clinical and vocational rehabilitation services as well as social security systems\textsuperscript{100}. In addition, most employment types in these countries are formal. Thus, our findings may not be applicable to countries with limited provision of rehabilitation services and a predominantly informal economy, such as low- and middle- income countries.

Outcome measurement

For the RTW and employment trajectories, employment was defined using cut-off points of $\geq$1 hour and 12 hours of paid work per week. The one-hour cut-off point has been used by international organizations such as the International Labour Organization and the World Bank\textsuperscript{101}. Although the one-hour cut-off point is rather low and has not been
widely used in competitive employment, it is suitable for individuals with SCI as they often work for shorter hours.

Until now, there has been no universal definition of steady employment. In defining steady employment, we used an arbitrary definition derived from our findings, i.e. working at all measurement points, i.e. 1, 2 and 5 years) after discharge from rehabilitation. Thus, if short unemployment breaks in between measurements occurred, these were not identified. This can be overcome by a more frequent and detailed employment monitoring during follow-up.

**Implications**

The Thesis presents findings that may have several implications for policy and practice related to disability and rehabilitation as well as for future research. This section will discuss implications for policy, practice and research.

**Implications for policy**

In developing countries, there is an urgent need for policies targeted at the welfare of individuals with severe disability such as SCI. In Indonesia, a number of laws and policies concerning people with disability exist. Indonesia has ratified the Discrimination (Employment and Occupation) Convention 1958 (No. 111) in 1999 and the UN Convention on the Rights of People with Disabilities (UNCRPD) in 2011. The current national legislation includes the Law on People with Disability (Law no 8/2016) which regulates the social welfare provisions and requires that all individuals with disability are given an equal opportunity to work. It also stipulates that a quota system is implemented, whereby employers must accept a number of people with disabilities at their workplace. Individuals with severe disabilities are also entitled to some amount of disability benefit and free healthcare. However, these legislations are not effectively enforced into implementation. They should be translated into more operational guidelines for line ministries and local governments for effective implementation.

Policy should also be enacted to support the environmental elements that are conducive to minimizing disability and optimizing participation in work and social activities such as accessible roads, buildings, and disability-friendly transportation. Non-governmental organizations such as disabled people organizations and civic society organizations
including individuals with disabilities should be involved in advocating, monitoring and evaluating the policy implementation.

Similarly, policies on employment for individuals with disabilities in developed countries must be better endorsed to employers. There should also be a better link between the VR system and employers. Together with VR professionals, employers should assess and identify the sets of capabilities that individuals with SCI possess, so that their work situation can be adapted to achieve the optimal work functioning\textsuperscript{102}. For example, employers should provide work support and accommodations for those with physical limitations to enable them to resume work earlier at the same workplace albeit in different functions.

In Indonesia, there are also health system challenges in improving QOL and participation of individuals with SCI. Even since the onset of injury, individuals with SCI in developed countries such as the Netherlands have a better chance of survival\textsuperscript{103} as the rehabilitation system is well-established and encompassing a comprehensive continuum from acute medical rehabilitation to long-term, long-life medical rehabilitation\textsuperscript{104}. SCI units with specialized SCI care are also available, ensuring proper treatment for SCI patients\textsuperscript{105}. Meanwhile, in Indonesia, both SCI specialized units for acute medical rehabilitation and comprehensive long-term rehabilitation are not available\textsuperscript{70}. The health insurance only covers specific aspects of rehabilitation needs. In some areas, community-based rehabilitation is provided to overcome the shortage of rehabilitation personnel, however, this system targets individuals with disabilities in general while individuals with SCI have specific rehabilitation needs. There is an urgent need for strengthening the medical and social rehabilitation system in Indonesia especially by improving the capacity of human resources and allocating more resources for long-term SCI rehabilitation.

**Implications for practice**

In both developed and developing countries, living with SCI including resuming employment and participation remains challenging for individuals with SCI. In both situations, however, VR is not generally provided during inpatient rehabilitation. VR is usually provided at some time after discharge from acute rehabilitation by VR service providers which can be part of the health or social welfare systems\textsuperscript{39}. Both entities, however, are not well connected to employers or labor markets.
To improve employment outcomes among individuals with SCI, multifaceted strategies should be applied in different stages of the rehabilitation process. First, during the medical rehabilitation process in the hospital, the focus should not only be on restoring physical functions but also on starting the process of community reintegration. Assessment of work values, readiness and functioning should start as early as possible\textsuperscript{106}. During the rehabilitation process, the psychological well-being of the clients as well as work values should also be addressed.

Second, enrolment in VR services and opportunities to retraining and re-education should be enhanced to improve the likelihood of getting back to gainful and perhaps higher-level employment. VR professionals should also be able to identify different pathways of returning to work and provide targeted strategies to support individuals in the return to work process. As there will be more aging individuals with SCI active in the labor market especially in developed countries, there should be more evidence-based interventions targeting at sustained employment in individuals with SCI.

In developing countries, with mainly informal employment, VR services should focus on enabling individuals with SCI to perform self-employment upon the completion of clinical rehabilitation. For example, individuals should not only be equipped with technical skills to perform the job, but also skills that enable them to initiate and maintain self-employment businesses.

As social support is very important for enhancing QOL and participation, individuals with SCI should also be equipped with social skills to seek social support and resources. Counseling by psychologists at rehabilitation should be provided to prevent feelings of helplessness that can lead to depression\textsuperscript{107}. Peer-support or peer-counseling using an individual or group approach for individuals with disabilities is now increasingly used to increase self-esteem and social skills which in turn may reduce stigma\textsuperscript{108}. Families should be engaged during the medical and vocational rehabilitation process, so that they will understand the particular needs of individuals with SCI in the process of reintegration in the society. This is important because families as the mainstay of support should be able to continue providing support after discharge from the rehabilitation. Social support during vocational rehabilitation should also be strengthened to help reducing psychological distress.
Implications for research

Research on Quality of Life in spinal cord injury
Many studies exist on QOL in developed countries. As the majority of these studies report low rates of QOL among individuals with SCI compared to the general population, researchers need to focus on determinants that are amenable to change and therefore to be addressed in interventions. More studies should be conducted to examine the effectiveness of interventions that address factors that can increase QOL. For example, studies should examine the influence of different types of work and social participation on QOL among individuals with SCI.

Studies on QOL in developing countries and international comparative studies are still scarce. Existing studies use available QOL instruments originated in Western countries which may not capture the components of QOL meaningful to individuals with SCI living in non-Western countries. Future studies would benefit from a contextually-adapted generic QOL instrument with SCI-specific QOL instruments, for example the WHOQOL instrument.

As participation in vocational, social and religious activities was almost universally regarded important towards QOL, more intervention studies incorporating these aspects should be conducted to improve participation. For example, studies could educate family members and religious scholars in the community to provide social support to individuals with SCI. However, to be able to measure outcomes of such interventions, it is necessary to better conceptualize social and religious participation within a certain context and culture. Then, direct and explicit links of these variables with QOL can be better established. Finally, interventions that aim to improve social skills in individuals with SCI could be another venue to strengthen social support and in turn, QOL and participation.

Research on employment in spinal cord injury
Employment research in SCI has often been focusing on employment and return to work rates using a cross-sectional survey design. Such a method fails to capture the (in)stability of employment among individuals with SCI. More importantly, the work performance and functioning of individuals with SCI should also be assessed. Research on trajectories of employment and work functioning is increasingly important and
has been done among individuals with chronic conditions such as musculoskeletal disorders, traumatic limb injuries, multiple sclerosis, cancer and common mental disorders\(^ {79,80,102,109-111}\).

Ideally, employment research on SCI should be done over time and in phases aligned with the rehabilitation process. First, studies are needed that identify factors that facilitate or impede employment participation. As socio-demographic and injury-related factors have been thoroughly studied, research should focus on other modifiable aspects. Time to return to work and factors that can shorten and lengthen that time should be analyzed. Second, research should explore the work situation such as job type, income, career structure, absenteeism and other factors that indicate the quality of employment. Third, the collection of more comprehensive indicators of employment outcomes, including employment intensity, job retention, income, job satisfaction, and work functioning will provide more meaningful data about employment outcomes following SCI\(^ {61}\). Lastly, longitudinal employment data may inform us on the sustainability of employment over the life course in SCI\(^ {112}\).

In addition, research on employment following SCI should start to focus on developing countries as most SCI cases globally occur in this part of the world. In these countries, most employment is informal, such as self-employment, and this will pose a challenge when measuring traditional employment indicators. For example, it might be difficult to define employment and employment sustainability using work status or working hours because of missing employee registries. Thus, research on employment after SCI in developing countries has to use primary data collection methods. Methods and indicators should be adjusted to accurately capture work outcomes in informal employment settings. Research could also be done by looking at the earning capacity at household level and at the contribution of individuals with SCI towards the household earnings.

**Research on social participation**

Because of the broad definition of social participation, there is a lack of consistency in defining and measuring this construct in the literature\(^ {3,5,113}\). Until now, there has been no consensus on which dimensions constitute social participation and how to quantify them, which results in a myriad of social participation measures. Enquiring about participation requires an in-depth understanding of the local social context incorporating perspectives of individuals with SCI\(^ {14,113}\). Moreover, as social participation
is highly contextualized, comparative studies on QOL and social participation between different cultures or countries should consider different conceptualization and measures.

Until now, a few instruments have been developed to measure participation in the Indonesian context, especially in individuals with SCI. In SCI research, the most frequently used participation instrument is the Craig Handicap Assessment Reporting Technique (CHART). There have been several instruments to measure participation in individuals with disabilities that are available in Indonesian, yet these instruments have not been validated for SCI. Furthermore, research should focus more on identifying and intervening amenable factors important for social participation.

**Conclusions**

Work participation is an important aspect in life after spinal cord injury. Despite the importance of work participation on QOL, significant barriers to resume and maintain steady employment remain an issue for individuals with SCI in developing and developed countries. Environmental barriers pose significant challenges to return to work, while social support greatly facilitates individuals with SCI to return to work. Those who returned to work, had to deal with significant changes in the work situation. Those with a higher education and a pre-injury occupation with low physical intensity and a middle/high occupational level were more likely to return to work 5 years after discharge from medical rehabilitation. Education and functional independence play an important role in maintaining employment over a 5-year period.

Considering the differences in the state of healthcare and social welfare systems for individuals with disabilities between developing and developed countries, different approaches should be taken to close the gaps in employment. For individuals with SCI living in developing countries, the capacity of informal structures such as the social network and the religious community to provide support should be strengthened. Meanwhile, to improve work participation and steady employment among individuals with SCI living in developed countries, education and retraining is necessary.

Addressing employment gaps in SCI in both developing and developed countries requires long-term, multifaceted and comprehensive approaches. Rehabilitation professionals should work hand-in-hand with potential employers, government and
families to facilitate return to work. Individuals with SCI must be provided with proper instrumental, social, psychological and economical support to integrate them in society and to enhance their QOL.
References


# List of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ASIA</td>
<td>American Spinal Injury Association</td>
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<tr>
<td>BIC</td>
<td>Bayesian Information Criterion</td>
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<td>BLRT</td>
<td>Bootstrap Likelihood Ratio Tests</td>
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<tr>
<td>FIM</td>
<td>Functional Independence Measure</td>
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<tr>
<td>HRQOL</td>
<td>Health-Related Quality of Life</td>
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<tr>
<td>ICF</td>
<td>The International Classification of Functioning, Disability and Health</td>
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<tr>
<td>LCGMM</td>
<td>Latent Class Growth Mixture Modeling</td>
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<td>QOL</td>
<td>Quality of Life</td>
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<tr>
<td>RTW</td>
<td>Return to work</td>
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<tr>
<td>SCI</td>
<td>Spinal Cord Injury</td>
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<td>VR</td>
<td>Vocational Rehabilitation</td>
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