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Challenges Faced by Spinal Cord Injury (SCI) Patients: A Study of SCI Patients at A Public Hospital in Penang

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Abstract

In Malaysia, there is a lack of published articles regarding spinal cord injury (SCI) and the roles played by social workers. Such information is important as SCI can affect the quality of life of the individual who experiences it. Indeed, SCI can be one of the most devastating injuries that a person can endure. The purpose of the study is to explore the challenges faced by SCI patients and to find out more about the relationship between SCI and social workers to enhance the quality of life of SCI patients. The study used purposive sampling in which 10 SCI patients were selected from a Public Hospital in Penang, Malaysia. For the in-depth interviews, the study employed a semi-structured method. The findings of the study were analysed using thematic analysis. The findings identified four main challenges, faced by people suffering SCI, namely emotional challenges, physical difficulties, stigma, and a lack of facilities for disabled people. The data findings are based on the needs and demands of SCI patients.

Keywords: Spinal cord injuries, Social Worker, Challenges, Facilities, Interventions

Introduction

According to World Health Organization (WHO) (2013), the global estimate for SCI cases annually is 40 to 80 cases per million population with a total of 250,000 to 500,000 people estimated to suffer from SCI worldwide every year (WHO, 2013). The World Health Organization also reports that men are at greater risk of suffering SCI in the young age range of 20 to 29, as well as at the older age of 70 and above. On the other hand, women are at greater risk of suffering from SCI while they are adolescents, aged 15 to 19 (WHO, 2013).

A spinal cord injury (SCI) is an injury to the human spinal canal that occurs as a result of a traumatic event such as a road accident, fall, or infection in the spinal cord. The spinal cord can also be harmed as a result of chronic diseases such as cancer or a tumor (Kassim, 2016). To be specific, the nervous system is disrupted when the spinal cord is injured. Such injuries can cause permanent or temporary changes to an individual who suffers from SCI (WHO, 2013). Basically, SCI occurs when there is damage to the spinal cord that prevents the nerves from sending messages to the brain, enabling normal function (Shepherd Center, 2019). The human brain is not able to process the information carried by the nerves in the spinal cord normally if a person suffers from SCI (Bau, 2014). An individual who suffers from SCI can lose, either temporarily or permanently, the ability to move (Klebine, 2015). Hence, those who suffer from SCI have trouble in doing their daily activities.

In Malaysia, SCI is classified as a physical disability under the Disability Act 2008 (Akta Orang Kurang Upaya, 2008). SCI can cause a person to develop a condition known as tetraplegia and paraplegia, which is a type of paralysis. This can prevent the person afflicted from carrying out basic activities such as self-care, movement, or changing body positions (Social Welfare Department, 2016).

However, SCI not only affects people physically but also has a huge impact on the emotional and mental health of the individual suffering from this injury. Previous studies have found that an individual who suffers from SCI tends to develop feelings of anger, anxiety and depression that may affect them emotionally as well as mentally (North, 1999). Depression is often associated with SCI as it can cause paralysis or muscle weakness that limits a person's movement in daily life. A person who becomes paralyzed because of SCI has difficulty in moving and is likely to suffer from other health issues as well, such as a loss of control of the gut and bladder (McDonald & Sadowsky, 2002). Such health issues have the potential to disturb the emotional and mental well-being of individuals with spinal cord injury.

In addition, researchers have found that studies regarding spinal cord injuries in Malaysia are very limited. Engkasan, Hasnan, Mohd Yusuf & Abdul Latif, (2017) found that very few studies on spinal cord injuries in Malaysia have been published and reviewed. Essentially, there are many studies that discuss the general problems faced by disabled people but don't specifically discuss the issue of SCI. In fact, all disabled people are different from one another and each individual has his or her own way of accepting and coping with the condition that affects their quality of life. Therefore, this study was conducted to specifically find out the difficulties faced by SCI patients and their relationship with social workers for them to lead to a better quality of life.

Method

The study was completed as part of requirements for Master of Social Work for the first author to explore the challenges faced by SCI patients and their relationship with social workers for them to have a better quality of life. The study employed a qualitative design and the phenomenology approach which is aimed at learning about the experiences of SCI patients and identifying the challenges faced by this group of people.

The population of this study were SCI patients in the Public Hospital in Penang who suffer from spinal cord injuries. The participants were chosen using purposive sampling. A total of ten patients with SCI were recruited as part of the sample size. Male respondents aged 20 to 40 and female respondents aged 16 to 25 were chosen for the study. Muslim (Malay) and Buddhist (Chinese) were among the respondents. The respondents had to be suffering from a spinal cord injury, including patients who were actively undergoing rehabilitation. Thematic analysis was used to code and analyse the data obtained, with a focus on the information shared by the respondents.

Result

10 SCI patients participated in the study, comprised of both male and female participants within the age range of 16-40. Based on the data obtained, the four main challenges mentioned by the respondents are emotional challenges, physical difficulties, stigma, and a lack of facilities. These themes were the results obtained through qualitative interviews and were coded using thematic analysis. Each respondent who participated in the study will be known as R plus a number. As such, the 10 respondents will be referred to as R1 until R10.

Theme 1: Emotional challenges

SCI not only affects people physically but also has a huge impact on the patient's emotions. Through a series of in-depth interviews, all 10 respondents admitted to having unstable emotions. The respondents spoke about feeling sad for long period, getting angry easily over simple matters, getting easily stressed,

and becoming more sensitive to their surroundings. Every respondent admitted that controlling their emotions represented the hardest challenge in their recovery journey as an SCI patient. Below are the dialogues quoted from a series of in-depth interviews with the respondents:

R1: *"The first feeling that I feel was sadness, I couldn't work, couldn't take care of my wife, my parents have to take care of me... I have no income... I don't know when can I walk... It's sad... I'm feeling sad for more than a month."*

"I am feeling down... I have no appetite...I'm sad... how can I eat... I have no appetite... I couldn't walk...this is not something that can be cured."

"Hmm...blame myself... I get angry easily. Little things can make me feel mad.... temper...but after that, I'll feel okay..."

R2: *"It's okay in the beginning...it feels fine since maybe Allah gave it because He wants me to become strong... but the longer it is, I feel like...why me? Why it has to be me? It's quite stressful. I feel like dying because it is too painful. After that, my dad said, how are you going to die if Allah still doesn't want to take your life yet. After that, I am feeling so stressed. After some time, I received the treatment, I can see some changes. So, I feel like I couldn't be like this. Sometimes I feel okay, but when I look at my parents, I feel sad. Because they are willing to do anything. A lot of money has been spent. I feel quite stressed... and then it feels hard since I'm going to start my rehab back. It feels hard because I was okay before, but now I'm not okay that it feels like 180-degree difference."*

"Feeling... I always want to scold other people. I couldn't do this...my temper is quite bad. After that I'll be feeling stressed again."

R3: *"I do feel disappointed. It'll be a lie if I'm not disappointed. Because I'm used to doing two to three jobs in a day before. After that, suddenly I'll be feeling down...couldn't do anything...feeling disappointed...I'm just crying... After that when I think back, it's already happened. What can I do...? So, I just move on. Just keep going. Whatever happened, happened."*

R4: *"Of course sad...hmm I can walk before right... After this happened, I couldn't walk... my mom has to take care of me...(sobbing)..."*

"Hmm I rely on other people, hundred percent. When I want to bathe at home, my older brother has to pick me up... There's one day when I wanted to bathe, he said, 'Ish you only want to take a bath when I want to go out...(sobbing)..."

R5: *"But to be honest I feel like I'm sad... It's only for a while...It's more shocking actually...It's too sudden..."*

R6: *"Ohh I do feel sad...because I used to be able to walk, but then now I can't...I get angry easily...I always get angry...ooo it's really bad during that time..."*

"During that time...my emotion...it's like what I've been saying, I always get angry...it's so bad during that time...you can ask my wife..."

R7: *"I am a happening type of person. After that accident, I could feel that I couldn't feel my leg...I feel weak... I feel like it's fine. Just accept it...because my friend and family always give me their support. In the beginning, I am really sensitive...when I watch television, if there are sad pictures, my tears could flow...it's like that. I'm not*

like that before, but after the accident, I'm being like this. Maybe because of the nerves...emotions are also related with brain..."

R8: *"When I woke up at the ICU...I can't really feel anything...my mental is okay...emotionally, sometimes I'm quick to get angry...being quite depressed... That's the time to find myself..."*

R9: *"Okay...during that time when it happened...I feel like, hmm...it's already happened. I feel quite sad. It will be a lie if I'm not feeling down. I thought of my wife and children. My parents whom relied on me...people's prayers for me...my friend also came. When the accident just happened, I don't really feel down, but what makes me feel down is when my friend said, "Allah...I couldn't accept you are like this." Haa, that's the challenge for me."*

R10: *"We will feel down...we will start to compare...because among my friends, family members...It happened to me?" ... Why am I selected... My emotion is really disturbed..."*

Theme 2: Physical difficulties

SCI patients face various physical difficulties, as often they can only make limited and small movements. To overcome this, every SCI patient must undergo a complete training process to learn about basic exercises or movements which can be used in their daily life. This training process is guided by a professional team consisting of doctors, nurses, physiotherapists and occupational therapists. This training includes learning techniques to wear their own clothes, techniques to transfer themselves from a wheelchair to bed, as well as other basic techniques. The aim of this training is to encourage SCI patients to become more independent or otherwise they tend to rely heavily on other people's help in their daily life. In the interviews, the respondents admitted having to deal with physical challenges every day. According to R1, R2, R3, R4, R6, R8, and R10, they depend heavily on their family member's assistance in doing daily activities. The respondents confided that their physical limitations have made their daily routines harder, posing a great challenge to them. Below are the dialogues quoted from a series of in-depth interviews with the respondents:

R1: *"It's hard for me to be independent, from bed to wheelchair, couldn't bath on my own...people need to help for almost everything... It's hard for me to urinate and defecate by myself...it's hard because my leg is now like this."*

R2: *"It feels hard since I'm going to start my rehab back. It feels hard because I was okay before, but now I'm not okay that it feels like a 180-degree difference."*

"I need to learn back, I need to learn how to walk again, I need to learn how to write again. When I start practicing writing, I was fed up. I feel like going home when what I've done is only holding the pen. The pain makes me want to get mad at others."

R3: *"In the beginning, it's hard to do it all on my own...because my leg has limited... I couldn't do just anything, I couldn't go anywhere by myself...it's hard when this kind of thing happened."*

R4: *"It is more physical to me. There are lots of things that I still couldn't do...so I want to be independent..."*

R6: *"What's hard is when I need to start to wear pampers... It's hard for me to practice because I am heavy...it's also hard to lift my leg... This is the physical cause."*

R8: *"I am physically limited, it's difficult to take items from high places. It's not the same as before."*

R10: *"I couldn't move...need to always depend on people. My older brother used to help me... pick me up for me to go to bath, I need someone's help when I want to bath. He will send me to hospital, he'll pick me up from hospital, when I admitted to ward, he'll push my wheelchair during follow up...people need to help me for everything."*

Theme 3: Stigma

SCI patients may look different physically, but they are human beings with the same desire to socialize and mix with others in their local community. However, the fact that they look different to others can make the public react to them negatively, making socializing more difficult for them. SCI patients often feel ashamed of or embarrassed by their physical condition. Based on the interviews, it was found that R3, R5 and R9 feel embarrassed by their condition, especially because they have to use a wheelchair in public places. Below are the dialogues quoted from a series of in-depth interviews with the respondents:

R3: *"How people look at me... until now. They look at me as if they are disgusted. After that I thought, it's up to them how they want to look at me. One day if they become like me, only then they'll know. I know it because I live in a flat. Their eyes...their faces...they looked at me with disgusting look... They look at me more because I had my urine bag with me during that time."*

R5: *"Hmm..of course from the people around me. In the beginning, I thought people will be able to accept me, but it doesn't really happen that way. I am the only one who felt that way.... because when I sit in a wheelchair...when I am outside, people will look at me. So, I'm feeling uncomfortable because of the people that keep watching me."*

R9: *"Ish, at the beginning I feel shy...people look. Yes...right. In terms of that, our mentality will become sad because people keep looking at me...I feel ashamed...shy...that's what causes me feel depressed..."*

While R1, R2, R4, R6, R7, R8 and R10 have also had similar experiences, they don't see this as a big challenge, interpreting other people's looks and intentions as more about sympathy and curiosity. Below are the dialogues quoted from a series of in-depth interviews with the respondents:

R1: *"At the beginning, I felt a little bit shy... I feel shy about using wheelchair. But I've already accepted it now... It's okay now. Wheelchair- wheelchair, so be it. It's okay. I'll be cured one day. Of course, there are people who are sick. There are people who are sick at every house. If there are people looking at me, I'll just smile. My only thought is that the people do not understand my condition...so, I'll just smile widely...hahaha..."*

R2: *"For me...if there are people staring at me... I'll just ignore them... Just let them be. Because I think they wanted to help, but they don't know how to. I did feel ashamed to go out before...but I thought that I've already sick, there's nothing to be ashamed of, right..."*

R4: *"I don't really care...I think people have already understood about the things related to OKU...so, it is not a problem for me if they look at me."*

R6: *"It is just...image is also important. If you didn't tidy up your hair, your cloth is messy... people will think that we are sick. Haa we ourselves need to make sure that people will see us nicely. If you are not tidy or clean, people will know that you*

are sick only by looking at you, right? When people are looking at me, I think they are not going to know whether I am sick or not...that's why our image is important"

R7: *"I'm okay with it...it's normal for people to look at me...because I've read...there are 250,000 people with SCI...so, it's normal...I don't feel anything about it."*

R8: *"I think when people look at me... I am just normal...I don't feel anything about it. Sometimes, I suspect these people are pity on me...but like what I've said... I think of me as a normal person...It's okay with me..."*

R10: *"It's okay... Just let them be if they want to look at me...because I think I am just the same. In fact, there are lots of things that I can do and normal people can't do. I'm just fine. People that are looking are usually those who want to help...like press the lift's button..."*

Theme 4: Lack of facilities

On top of the challenges discussed above, two of the respondents felt that there is a lack of facilities in public places for people like them. R5 revealed that this lack of public facilities poses a challenge for him. R5, along with R8, said that facilities in Penang are not wheelchair-friendly and this makes their daily life difficult.

R5: *"To me, the challenge is the facilities...for example when I want to start working back, doctor rehab needs to visit my office to suggest what are the facilities needed by me...so, if the doctor doesn't come, it'll be difficult for me...for example whether the door is heavy for me or not...so, they'll change the facilities to make it easy for me."*

R8: *"For me, I don't like to go out. Because there are fewer facilities for me. For example, when I went to the restaurant that frequently went, it's must be difficult for me to go with a wheelchair. The road is narrow...it's the same if I want to go to the bank...it's difficult...so, I rarely go out because of these kinds of facilities."*

"It makes me feel lazy to go out...it's difficult when there are no facilities for people who use wheelchairs, just like me."

Discussion

Emotions

Based on the interviews, it was found that emotions have a significant impact on the lives of SCI patients. Emotions refer to reactions in human beings like anger, fear, sadness, love and shock (Salleh & Haridi, 2016). Researchers noted that each respondent experienced various types of emotions, including the aforementioned, after being diagnosed with SCI, due to the physical changes they needed to deal with. The main factor behind these emotions is their limited ability to move and always having to depend on others. This makes the respondents feel guilty towards people and feel that they are burdening others, as conveyed in statements from R1, R2, R4, and R10.

An individual's emotional experience affects the brain cells and memories, thus creating patterns that influence one's behaviour (Zakaria & Yahaya, 2006). In addition, emotions can induce aggression, especially when dealing with sudden changes that occur (Chaplin, 2015). This is expressed by SCI patients who experience sadness, anger or shock over physical changes, including changes in daily

routine. These emotions can influence the way SCI patients act and think. For example, R2 admitted that he was so sad in the early phase as an SCI patient that he had suicidal thoughts.

According to the Malaysian Spinal Cord Injury Advocacy Association (2018), some SCI patients refuse to accept the fact that they are physically disabled and begin to feel sad and depressed over this issue. At the beginning of the injury phase, the respondents had no ability to be independent and needed help from others, such as family members or relatives. This made the respondents feel frustrated. Furthermore, SCI patients tend to develop a form of anger in the beginning phase of the SCI. They can get easily angry over simple things. Researchers view this as a normal part of the process to adapting to a different physical condition. R1, R2, R6, and R8 revealed that they tended to get mad easily in the early stages of being SCI patients. SCI patients also tend to feel shocked. For example, R5 emphasized that he was more shocked than saddened by a road accident that left him with a spinal cord injury and a paraplegic.

As such, it can be concluded that dealing with emotional states is one of the challenges faced by SCI patients. This is in line with a recent study by Livneh and Martz (2014), which found that individuals who undergo drastic physical changes that interrupt their daily routine can undergo changes to their psychological functioning while striving to adapt to their new life. Based on the data obtained, the researchers found that individuals who suddenly undergo physical changes, such as paralysis, will experience sadness. This is because they had previously lived a normal life and were now trapped in different physical conditions. Sadness can lead to depression, as is often associated with individuals with disabilities (Thompson, 2002). Hence, SCI patients who face many problems and obstacles are more at risk for developing depression (Thompson, 2002). According to WHO (2013), depression is a mental health disorder that occurs during the post-injury phase among SCI patients. Mental health problems such as depression are considered to be a natural consequence of patients with SCI (WHO, 2013).

However, in this study, none of the respondents reported suffering from depression during the interviews. The reason for this, the researchers found, was that all of the respondents had successfully responded and reacted in their own way after becoming injured. The respondents only admitted to being sad, angry and shocked in the early stages of the injury. Every respondent in the study felt that dealing with their emotions during the recovery process was one of the challenges they had to face. As such, the researchers concluded that it is a normal process for an individual who undergoes sudden and drastic physical changes to have emotional challenges, as is the case with SCI patients.

In addition, based on the data obtained it was found that social workers play a significant role in supporting SCI patients who are going through a difficult time in adjusting to a new life. This is because social workers listen to SCI patients who are talking about the hardships they face. This provides moral and emotional support to patients with spinal cord injury. Social workers should be involved at an early stage of the injury to prevent more serious health problems from arising, as is consistent with the guidelines issued by the International Federation of Social Work (IFSW) and the International Association of Schools of Social Work (IASSW, 2004) which state that as a profession, social work is a transformative agent in the social system that assists in the problem-solving process of human relations.

Physical challenges

Physical changes are the most significant change experienced by SCI patients. SCI is generally caused either by accident or illness. Individuals can become disabled, often tetraplegics or paraplegics. According to the Department of Social Welfare (2016), tetraplegia and paraplegia are types of paralysis that prevent a person from carrying out their daily routine. For this study, ten respondents who suffered from SCI were interviewed. Two of them got injured from severe falls and the rest were involved in road accidents. As a result, every respondent need equipment assistance such as a wheelchair. For example, R3 has a T7-T12 (thoracic) injury that has left him paralyzed from the waist down and completely dependent on a wheelchair to move about. Although his other limbs, starting from the upper thighs, were still functioning well, he still had difficulty moving in the early stages after the injury. Besides R3, R7 also needs to use a wheelchair to move around. R7, who is injured at C5, C6, C7, T1

and T2, needs complete assistance with daily activities such as eating, dressing, bathing, and getting into bed.

According to R3, R4, R5, R6, R7, R8, and R10, they have to use wheelchairs to move around. They admitted that in the early phase of injury they had difficulty in moving freely, and as such were very dependent on others. Basic activities, such as getting from a bed into a wheelchair or writing, were difficult for these respondents. This is in line with previous studies which have found that basic activities in life such as driving, diving, or walking up a ladder pose a challenge for suddenly-injured SCI patients as their nervous system fails to function normally (Akshay Joshi & Vidushi Sharma, 2014). Kwah and Abdullahi (2018), stated that when there is damage or injury to the spinal cord, its original function is impaired thereby affecting the patient's self-esteem and quality of life.

SCI patients not only face difficulties in doing day-to-day activities, but they also have a hard time doing exercise. R6 confides that he had difficulty when undergoing physiotherapy training that taught him to use adult diapers without the help of others. Physiotherapy training is one of the activities that form part of rehabilitation programs. Rehabilitation is a process aimed at helping patients with SCI to be independent in managing their life, while receiving appropriate treatment and support (Cheras Rehabilitation Hospital, 2019). In short, SCI patients are not able to carry out daily activities in the same way as before they were injured (Model System Knowledge Translation Center (MSKTC), 2015).

In this matter, it was found that social workers would act as educators in teaching SCI patients about their roles in the rehab centre and throughout the recovery process. This is consistent with the guidelines provided by the International Association of Schools of Social Work (IASSW, 2004) which emphasize that the profession of social work should focus on various aspects including educating clients by sharing relevant and appropriate information to help improve the client's social functioning. Therefore, in terms of SCI, social workers need to provide accurate information and explain the purpose of the patient's rehabilitation program. It is essential for SCI patients to receive rehabilitation services, assisted by doctors, nurses and physiotherapists who will help to improve the patient's strength and stamina by using various techniques to achieve maximum physical ability. In conclusion, alongside emotional aspects, SCI patients inevitably have to deal with physical challenges.

Public perception

Based on the interviews, the researchers found that there were two different opinions among SCI patients regarding public perceptions. As acknowledged by the respondents, one of the challenges SCI patients face is the public perception of their physical condition. The researchers found that patients with SCI are often discriminated against and stigmatized by members of the community. There are some people who just think of them as disabled and do not realize the psychological and psychosocial hardships they face (Tarsidi, 2009).

According to the respondents, due to their injuries they need to use a wheelchair to move about. However, the respondents feel ashamed when they are in public because they often receive negative looks from people. The findings of this study are consistent with the views of Rosli, Mahmud & Mahbob (2017) who stated that people with disabilities are often viewed negatively and are considered to be in poor health because of their need for prolonged treatment and constant assistance from others.

R3 admitted that one of the hardest challenges a SCI patient faces are the stares of people whenever in a public place. He feels that people often give him looks of disgust due to his physical disability. R3 and R5 similarly said that they feel uncomfortable and disturbed when people start staring at them while they are using a wheelchair. R9 also feels a sense of shame due to people's reactions whenever he is in a public place. These negative attitudes towards disabled people can have a bad impact on patients with SCI (Husain, 2014). People with disabilities easily feel neglected and cast out by society due to their disabilities (Rosli, Mahmud & Mahbob, 2017). The negative feelings developed by disabled people are significantly related to the attitude of people who often stereotype and discriminate against them (Rosli, Mahmud & Mahbob, 2017). Discrimination against disabled people may restrict their social activities. This finding is consistent with the results of a study conducted by Bishop (2005) who stated that

individuals with chronic disabilities will experience significant changes in their social lives and family relationships. According to Husain (2014), the effects of discrimination by society can make SCI patients feel like they do not have skills or any ability to succeed in the future.

Patients who develop low self-esteem and insecurities tend to avoid socializing within the community. This can lead to more serious health problems such as depression. Depression is one of the most common mental health problems associated with SCI. This finding is supported by Nas et al. (2015) who believe that depression is not a natural process experienced by patients with SCI, but it is a complication that needs to be treated. If not treated properly, SCI patients are more likely to develop suicide intentions.

However, not every SCI patient views the reaction of the public in a negative light or as a form of discrimination. Based on the interviews, some public reactions, including staring, are more about curiosity, concern, and sympathy for the disabled. R1, R2, R4, R6, R7, R8, and R10 do not consider public perception as one of their main challenges as SCI patients – perhaps due to the fact that many Malaysians are already aware of the disability.

In conclusion, SCI patient opinions about public perceptions of disability vary. While most of them do not consider public perception to be a challenge, there are some respondents who have had bad personal experiences with public perception/reactions. This should not be overlooked. According to Urie Bronfenbrenner, an individual can be influenced by external factors related to the physical and social environment. The ecological theory describes how environmental factors influence every human's life. Every human being has to depend on each other to survive. As such, the public has an even greater responsibility when it comes to disabled people. Society can be categorized as a macro-system in terms of its norms, cultures, and practices (Bronfenbrenner, 1997).

Acceptance of the disabled within society can make them feel part of the community, thereby enhancing their social confidence as part of the community (Kaur, Leong, Yusof, & Singh, 2015). A society that accepts people with disabilities with a positive attitude can serve as a source of encouragement to this group of people. In line with this, patients with spinal cord injury, who are categorized as disabled, should be respected by society. Society should not discriminate against them simply because they are physically different to able-bodied people. Based on the findings, the researchers believe that every human being has different feelings, opinions, and views when dealing with challenges.

This study found that society plays a significant role in influencing the life of SCI patients. For example, R9 says that there are people who stare with a sense of curiosity. They do this due to ignorance about spinal cord injury. As such, social workers can enhance public knowledge about spinal cord injury by disseminating relevant information to society. Educating and sharing accurate information is an important role of social workers, as backed up by the International Association of Schools of Social Work (IASSW, 2004).

Lack of Facilities

Based on the interviews conducted with the 10 respondents, some of the respondents said that one of the difficult challenges they face with a spinal cord injury is a lack of facilities in public places. R8 says that it is extremely difficult to get out because there are many areas that lack facilities, such as an absence of ramps that would allow him to travel. Individuals who use wheelchairs need disabled-friendly areas conducive to using this equipment. Through the interviews, however, the researchers found that there is a lack of such facilities for the disabled and that this is not something new in Malaysia. The researchers found that there is a lack of disabled-friendly facilities in areas such as banks or restaurants, which affects the potential activities of SCI patients. R8 explained his dilemma when in a public place, such as a bank or restaurant, which has no special facilities for wheelchair users. Given this situation, he prefers to stay at home rather than go out.

This lack of facilities is seen as a serious issue by the NGO Geng Utara Hebat, which has raised concerns about this in the states of Perlis, Kedah and Penang (Anonymous, 2018). The members of this group are people with disabilities who use wheelchairs and are often faced with the problem of accessibility in

public areas. They say that this lack of facilities in public places occurs in mosques and other places that need to be accessed like banks (Anonymous, 2018). Thevadass (2017) also reports that waiting areas for disabled people at bus stations and train stations in Penang could be improved, as pedestrian access for wheelchair users in these areas is currently unsatisfactory. In addition, the lack of facilities not only burdens the daily business of SCI patients but also makes them feel isolated by the community (Thevadass, 2017). Researchers argue that patients with SCI require facilities in public areas, especially infrequently accessed areas. This is crucial as it can improve the ability of SCI patients to socialize within the community. According to Tah (2019), every country should recognize the right of the disabled to live with adequate needs and social protection including clothing, food, housing, and amenities that can improve their quality of life, without their facing any discrimination. In fact, in a study conducted by Tah and Mokhtar (2018), they argue that every disabled person should be treated with dignity and fairness as the disabled also contribute to society.

Therefore, it is the view of the researchers that patients with spinal cord injury should not have to endure a lack of facilities, as they also have the right to live a normal life. Hafiz Ahmad, Rosli, Takril, & Ahmad Sabri, (2017) say that people with disabilities form part of society, so they should also enjoy the same rights and opportunities to live like everyone else. Through the interviews, the researchers found that when individuals with chronic illnesses or disabilities have less interaction with the community, they feel isolated. This finding is consistent with that of Rosli, Mahmud, and Mahbob, (2017) who stated that individuals with disabilities tend to feel isolated and neglected by society, the less they get to socialize within society.

In conclusion, a lack of facilities is a challenge that disabled people, including SCI patients, have to endure every day. Such individuals often use wheelchairs and struggle when having to get through narrow spaces or move around in facilities without ramps. This makes the day-to-day business of SCI patients even more complicated.

Interventions

Based on the data collected, social workers play a significant role in helping SCI patients to have a better quality of life. The International Federation of Social Workers (2004) calls social workers a transformative agent in the social system that assists in the problem-solving process and is capable of enhancing the well-being of people by empowering and advocating for the freedom of society. In light of this, Elfström, Rydén, Kreuter, Taft, dan Sullivan, (2005) stated that the interventions proposed below are beneficial and it is based on the needs of the SCI patients.

Early Interventions

Through a series of in-depth interviews, an early intervention module in helping patients with spinal cord injury has been shown to give a positive impact on the patients' lives. This module focuses more on cases of patients who have recently suffered a spinal cord injury. Several parties are needed in order to execute this module. A medical team consisting of doctors, nurses, and medical social workers is required. The first two components of the medical team will focus on medical aspects, while the medical social workers will need to focus on social assistance. In this module, the social workers are responsible for providing for the needs of SCI patients. The social workers will help in providing equipment assistance such as wheelchairs, crutches, wind mattresses and others. They will work with the Social Welfare Department in the Hospital to seek help on behalf of patients with spinal cord injury. The roles played by the social workers as part of the rehab team are aimed at smoothening the process of providing assistance to SCI patients. In addition, the social workers will also look at the financial aspects related to spinal cord injury patients. In this regard, the social workers will work closely with JKM, SOCSO and non-governmental organizations (NGOs) in assisting patients financially. The social workers will work closely with SOCSO by speeding up information about patients with spinal cord injury.

Support services

This intervention is divided into two support groups, namely for spinal cord injury patients themselves and for family members or caregivers of patients. Persistent and strong support is needed for patients with spinal cord injury. This support can come in many forms such as emotional, mental, or financial. NGOs such as Geng Utara Hebat - an NGO created by spinal cord injury patients and consisting of spinal cord injury patients who are from diverse backgrounds and experiences – should be involved. The researchers would like to propose a support group for spinal cord injury patients that consists of members who have SCI. These people could provide regular support to patients who have recently suffered spinal cord injury. This support group will maintain a permanent system of visiting rehabilitation wards to visit new spinal cord injury patients. This is seen as important as it can provide moral support to new patients.

The next form of support is to focus on family members and caregivers. Medical social workers will act to provide emotional and moral assistance to family members or caregivers of SCI patients. This holistic approach is important because patients with spinal cord injury always rely on the help of others in their daily routine. The researchers found that family members who are passionate and act in a positive manner can influence the behavior of patients with spinal cord injury. In addition, family members also need to be adequately educated about spinal cord injury, including the level of injury and the type of assistance needed, as this will help ease the caring process for spinal cord injury patients. Family members also need to accept the reality of disability in SCI patients and equip themselves with appropriate and sufficient knowledge about the injury, in order to facilitate the caring process.

Conclusion

From the information derived in this study, it can be concluded that SCI patients face four main themes in terms of challenges. All of the respondents have gone through emotional challenges which they characterized as feeling stressed, sad, angry, or shocked. With regard to these challenges, social workers could come up with a better support plan that will motivate SCI patients in the future. The second theme is physical challenges which concerns their difficulties in moving around independently and having to depend on others too much. SCI patients also face difficulties in participating in rehab training that requires them to exercise and practice routine techniques. With regard to these types of challenges, SCI patients need to understand their role as patients in the rehab ward so that they are able to fully cooperate during the training process. The third theme concerns public perception. Stereotyping, discriminating against and stigmatizing SCI patients will cause even more harm to this group of people. In light of this, social workers play a key role in educating society about disabilities. Lastly, the issue of a lack of facilities in frequently accessed public places has to be solved as soon as possible. Each and every disabled people has the same rights in living in this country, including being able to fully access and utilize facilities in public places.

References

- Akshay Joshi, Vidushi Sharma, A. K. (2014). Coping Strategies, Community Reintegration and Participation & Autonomy: A Correlation study in persons with Spinal Cord Injury in Delhi and NCR. *International Journal of Health and Rehabilitation Sciences*, 21(16), 2208–2230.
- Akta Orang Kurang Upaya 2008 (2008). Undang-undang Malaysia. <https://www.kpwkm.gov.my/kpwkm/uploads/files/Dokumen/Akta/Akta%20685%20-%20Akta%20Orang%20Kurang%20Upaya%202008.pdf>
- Anonymous. (2018, July 15). Kurang kemudahan di tempat awam, golongan OKU minta perhatian. *Astro Awani*. <http://www.astroawani.com/>
- Bau, A. M. (2014, January 27). Hidup Berkualiti Selepas Kecederaan Saraf Tunjang. www.myhealth.gov.my/hidup-berkualiti-selepas-kecederaan-saraftunjang/

- Bishop, M. (2005). Quality of life and psychosocial adaptation to chronic illness and disability: Preliminary analysis of a conceptual and theoretical synthesis. *Rehabilitation Counseling Bulletin*, 48(4), 219–231
- Bronfenbrenner, U. (1997). Toward and Experimental Ecology of Human Development. *Journal of American Psychologist*. 513-529.
- Chaplin, T., M. (2015). Gender and Emotion Expression: A Developmental Contextual Perspective. *Journal of Emotion Review*. Vol. 7, No. 1, 14-21.
- Cheras Rehabilitation Hospital, (2019). Spinal Cord Injury Rehabilitation. <http://www.hrc.moh.gov.my/utama/index.php/our-services/neurological-rehabilitation/inpatient-services>
- Elfström, M. L., Rydén, A., Kreuter, M., Taft, C., & Sullivan, M. (2005). Relations between coping strategies and health-related quality of life in patients with spinal cord lesion. *Journal of Rehabilitation Medicine*, 37(1), 9–16.
- Engkasan, J. P., Hasnan, N., Mohd Yusuf, Y., & Abdul Latif, L. (2017). People with Spinal Cord Injury in Malaysia. *American Journal of Physical Medicine and Rehabilitation*, 96(2), S90–S92.
- Hafiz Ahmad, M. N., Rosli, H. F., Takril, N. F., & Ahmad Sabri, S. (2017). Penyediaan Fasilitas Orang Kurang Upaya (Oku) Di Institusi Pengajian Tinggi Di Lembah Klang: Satu Kajian Kes. *Proceeding-2nd Putrajaya Conference on Children, Women, Elderly and Disabled People (PICCWED)*, (May), 20–21.
- Hazlin Falina Rosli, Wan Amizah Wan Mahmud, & Mahbob, M. H. (2017). Realiti Penerimaan Masyarakat Terhadap Orang Kelainan Upaya.
- Husain, Z. B. (2014). Keberkesanan Modul Kaunseling Pemulihan Terhadap Masalah Psikosoial Orang Kurang Upaya (OKU) Fizikal Akibat Kemalangan (Universiti Sains Malaysia) <https://www.bps.go.id/dynamictable/2018/05/18/1337/persentase-panjang-jalan-tol-yang-beroperasi-menurut-operatornya-2014.html>
- Kassim, N. (2016). Sokongan Sosial Kepada Pesakit Saraf Tunjang. <http://www.myhealth.gov.my/sokongan-sosial-kepada-pesakit-dan-ahli-keluarga-yang-mengalami-kecederaan-saraf-tunjang/>
- Kaur, G., Leong, T. P., Yusof, J. M., & Singh, D. (2015). Perception of People with Disability in Creating Sustainable Public Policy. *Procedia - Social and Behavioral Sciences*, 168, 145–155.
- Klebine, P. (2015). Understanding Spinal Cord Injury: Part 1 – The Body before and After Injury. <https://mskctc.org/sci/factsheets>
- Kwah, S. B., & Abdullahi, A. (2018). Research Paper: Coping Strategies in People With Spinal Cord Injury: A Qualitative Interviewing. *Iranian Rehabilitation Journal*, 16(2), 195–202.
- Livneh, H., & Martz, E. (2014). Coping strategies and resources as predictors of psychosocial adaptation among people with spinal cord injury. *Rehabilitation Psychology*, 59(3), 329–339.
- Malaysian Spinal Cord Injury Advocacy Association (2018, September 19). Kisah SCI. https://www.youtube.com/watch?v=MEjoortnHGU&feature=emb_logo
- Mcdonald, J. W., & Sadowsky, C. (2002). Spinal-cord injury. 359, 417–425
- Model Systems Knowledge Translation Center (MSKTC). (2015). Understanding Spinal Cord Injury: Part 2 — Recovery and Rehabilitation. *SPINAL CORD INJURIES: Management and Rehabilitation*, 4(January), 1–17.
- Nas, K., Yazmalar, L., Şah, V., Aydin, A., & Öneş, K. (2015). Rehabilitation of spinal cord injuries. *World Journal of Orthopaedics*, 6(1), 8–16.
- North, N. T. (1999). The psychological effects of spinal cord injury: A review. *Spinal Cord*, 37(10), 671–679
- Salleh, N., M. & Haridi., M. (2016). Konsep Kecerdasan Emosi Dalam Islam.
- Shepherd Center. (2019). Understanding Spinal Cord Injury. spinalinjury101.org/files/understanding-spinal-cord-injury.pdf
- Social Welfare Department. (2016). Perkhidmatan Orang Kurang Upaya. jkm.gov.my/jkm/

- Tah, I. H. M. (2019). Orang Kurang Upaya (OKU) dan Hak untuk Hidup : Satu Analisis Perundangan di Orang Kurang Upaya (OKU) dan Hak untuk Hidup : Satu Analisis Perundangan di Malaysia. (September 2014).
- Tah, I. H. M., & Mokhtar, K. A. (2018). Konsep hak asasi manusia bagi orang kurang upaya di Malaysia: suatu analisis. *Kanun: Jurnal Undang- Undang Malaysia*, 1(30), 109–36. <http://irep.iium.edu.my/61144/>
- Tarsidi, D. (2009). Model Konseling Rehabilitasi bagi Individu Tunanetra Dewasa. *Jassi Anakku*. Volume 8. 1-10.
- The International Association of Schools of Social Work (IASSW) (2004). Global Definition of Social Work. <https://www.iasw-aiets.org/global-definition-of-social-workreview-of-the-global-definition/>
- Thevadass, L. (2017, May 12). Poor facilities for the disabled. *The Star Online*. <http://thestar.com.my/metro/community/2017/05/12/poor-facilities-for-the-disabled-study-infrastructure-at-terminals-pose-danger-and-confusion>
- Thompson, K. (2002). Depression and disability: A practical guide. 1–36. www.fpg.unc.edu/~ncodh
- World Health Organization (WHO). (2013). International Perspectives on Spinal Cord Injury. https://www.who.int/disabilities/policies/spinal_cord_injury/en/
- Zakaria, S. A. S., & Yahaya, A. S. (2006). Tinjauan Tentang Reaksi Emosi di Tempat Kerja: Satu Aspek Pengurusan Sumber Manusia Dalam Organisasi. *Jurnal Teknologi*. 44(E), 1-1