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Research Article

ASSESSMENT OF THE ROLE OF SUPPORT GROUPS WITH SPINAL CORD INJURY (SCI) PATIENTS IN RIYADH, SAUDI ARABIA

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ABSTRACT

Introduction: Saudi Arabia has the highest car accidents rates, which is known to result in traumas including Spinal Cord Injury (SCI). SCI is a damage to any part of the spinal cord that results in weakness or paralysis below the level of injury. Studies show that SCI has various negative impacts on the patients' lives, including psychological, social, and financial hardships. Support groups have proven their efficacy in improving aspects of the patients' lives who suffer from lifelong conditions. However, no previous research was done to assess the support groups in Saudi Arabia and how it impacts the lives of people with SCIs.

Objectives: The overall objective of this study was to examine the role of support groups with SCI patients regarding the psychological, social, and financial aspects of their lives. This study also aimed to assess the support provided for those who are not involved in a support group and the general perceptions about support groups.

Methods and materials: A qualitative cross-sectional study design where data were collected at one point in time. A sum of 285 SCI patients were interviewed at three different hospitals at King Fahd National Guard Hospital (NGHA), Sultan Bin Abdulaziz Humanitarian City, King Fahad Medical City (KFMC) and one association The Adults Motor Disabilities Association [Harakia] in Riyadh. Participants from the three hospitals were interviewed at the hospitals' settings and participants from the association were interviewed by telephone call. The data was collected using a suitably structured schedule that was developed based on reviewed existing literature, and piloted with 10 patients.

Results: 163 of participants in this study were engaged in a support group (122 paraplegic, 41 quadriplegic). The form of support provided by support groups was categorized into psychological (60.7%), financial (52.1%), and social (70.6%). Ninety-two out of the 163 participants said the support groups were motivational, and 25 participants did not find the support groups to be motivational. 52% reported that the support obtained from the support group was non-continuous. 93.3% of the participants agreed that there is a need for support groups for SCI patients.

Conclusion: The results of this studies showed the need for psychosocial, social, and financial supports. It was revealed that support groups exist in Saudi Arabia, Riyadh among the SCI community. However, throughout the responses, it was found that these groups need to be improved and distributed on a wider range in the country so the patients to benefit from them. The people with SCI reported high rates of willingness to participate in such groups, and high tendencies to be support providers for newly injured patients which can facilitate establishing future support groups for people with SCI.

INTRODUCTION

Spinal Cord Injury (SCI) is known to be a damage to any of the spinal cord's 31 segments due to trauma or degenerating disease, according to the World Health Organization[1], which causes a disruption of signals between the patient's brain and body resulting in loss of motor and sensory functions below the level of the injury. As more than 250, 000 people suffer SCIs annually world-wide, according to WHO, Saudi Arabia has estimated the highest prevalence rates of SCIs around the globe, stated the Ministry of Health[2], with gender being a significant factor in the level of injury; one study reported males injuries as 43.9% at cervical level, 40.4% at the thoracic, and 3.5% at the lumbar level, while another study showed that 80% of females injuries were at the level of thoracic[3,4]. Regardless of their level of injury, SCI patients confront challenges that affect their quality of life (QoL) including

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medical, psychological, social, and economic consequences in the long term (el Masri & Short, 1997). Thus, effective and long lasting support is needed. One form of support that has proved its positive efficacy on QoL of patients with prolonged conditions like diabetes[5] and cancer[6] is support groups. However, little research is found to evaluate the support provided for SCI patients. Therefore, this research aims to investigate about support groups and their role in the lives of SCI patients and assesses their needs regarding the provided form of support.

LITERATURE REVIEW

Effect of SCI on Psychological Aspect

There is a variety of consequences after having an SCI, these patients are proved to be greatly vulnerable to many psychological problems such as depression, anxiety disorder, and post -traumatic stress disorder[7] Studies show that SCI patients have a high prevalence of psychological problems[8]. Nineteen studies confirm that the mean of depression's prevalence after spinal cord injury is 22% [9]. Another cohort study shows that 28.9% out of 201 patients with SCIs suffer depression throughout a period of six years from the incidence date[10]. Trieschmann, however, concluded after a review of numerous studies that depression was not a definite consequence of SCI[11]. As approved by Orenczuk *et al.*, which conducted a study on eighty-four SCI patients of different diagnoses, only eight of which developed depressive illness after the injury[12]. Another study that interviewed 22 SCI patients for depression, revealed that five of them developed minor depressive illness which was less than anticipated, Howell *et al.* suggest that the assumption of the relation of depression with SCI patients might be due to an observer bias that resulted in an overestimation of the prevalence of depression[13].

Effect of SCI on Social Aspect

Moreover, SCIs also have an effect on the social part of the patients' lives[14]. Geyh *et al.*, concurred a study including SCI patients and a comparison group without SCI; these researchers compared many variables, including participation, which was shown to be significantly lower in SCI patients[15]. Poor coping and adjustment skills can occur when patients experience feelings like denial, anger, and frustration that are associated with SCIs (16). In Saudi Arabia particularly, old estimates used to show low rates of disability, because being disabled is thought to be a stigma that might cause the patient to be hidden in their homes and isolated from the society, according to M. Al-Jadid [17].

Effect of SCI on Financial Aspect

With regard to the financial aspect, studies found that SCI patients are least satisfied with their financial status, and according to a study done in Saudi Arabia, Al-Kharj; it is stated that patients after SCIs suffer from a shortage in the financial status, which has a negative relation to the patients' QOL, although the result of the study indicated that 45% of the equipment and supplies that SCI patients need (other than wheelchairs) were provided by Al-Kharj Hospital Program (RKH), 19.3% were provided by the Ministry of Health (MOH), 22.8% were of unknown resources, possibly by Ministry of Labour (MOL) and Social Affair or charitable organization, and only 12.3% were by self-purchase. Furthermore, concerning the wheelchairs, 40.4% of patients obtained them from RKH, 26.3% by MOL, 10.5% by charity, and 19.3% was from their own resources. It was concluded that the diminished financial status hinders their ability to practice their daily activities smoothly[18]

SCI and Quality of Life

The main model in treating SCI patients is biomedical, which overlooks these aspects of the patients[19]. Yet, the WHO International Classification of Functioning, Disability and Health (ICF) biopsychosocial model suggests that impaired body functions and structures with existing diseases or disorders affect the participative aspect of individuals, and studies emphasize that participation in community life and engagement in out-of-home activities have a dramatic impact on the patients' QoL[20]. Kinney & Coyle also concluded in a study on SCI patients that in the last three decades, some factors "good health, emotional stability, control, positive perception of disability, economic security, productive activity, peer and social interaction, and unconstrained living environment" are associated with patients' satisfaction in life[21].

Because a good QoL is a significant reflection of success of the rehabilitation goals, it is very important for the rehabilitation team to consider ways to enhance QoL in SCI patients[22]. One way to do that is by involving SCI patients in support groups.

Support Groups

Psychology dictionary defines a support group as a set of individuals who have similar conditions and meet periodically to support each other by giving advice and sharing experiences[23]. The National Spinal Cord Injury Association has stated that, "support groups provide a valuable service not only for counselling and support, but also for socializing and information sharing" [24]. A survey of prostate cancer patients acknowledged how exchanging experiences in a support group helped alleviate anxiety and contributed to a positive outlook regarding their treatment[25]. Geyh *et al* recommends in the study the need for strengthening social support resources in the community-based rehabilitation[15]. Other studies emphasize that support groups have an important role in improving the psychological aspects, and psychosocial aspects of patients' lives[26, 27]. Another study also shows that support groups can offer a nice blend of information, emotional support, and social interaction, not to mention their importance to those who are newly injured [28].

From the literature above, we can conclude that in order to maximize the QoL in SCI patients, it is essential to engage this population in a support group that considers the psychological, social, and financial dimensions of these patients' condition; which have been proven to be negatively affected in SCI patients. However, there is a limited available research about the relation of these aspects in individuals with SCI and support groups in Saudi Arabia and worldwide.

MATERIALS AND METHODS

This is a qualitative cross-sectional study design that all the data are collected at one point of time.

The study was conducted at three different hospitals at King Fahd National Guard Hospital (NGHA), Sultan Bin Abdulaziz Humanitarian City, King Fahad Medical City (KFMC) and one association The Adults Motor Disabilities Association [Harakia] in Riyadh,. A sum of 285 SCI patients were interviewed, the sample size was determined by using Rao soft online software. The sample size calculated with margin of error of 5% at 95% confidence level.

Stratified sampling technique was used to select the participants. The three hospitals and one association formed the strata (See Figure 1), the sample size for each stratum was calculated using the following formula:

[Sample size of the study / population size of the study] x size of each stratum
Samples from each stratum were selected randomly.

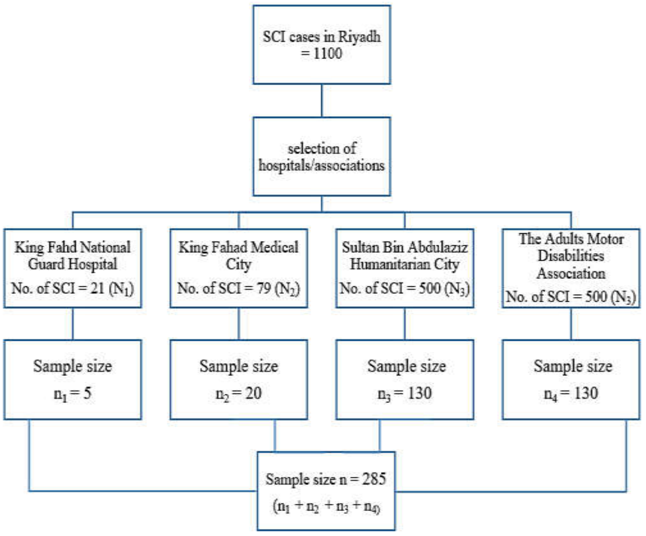

Figure 1 Outline of sampling technique

Participants were eligible if their age was between 17 – 70 years with a confirmed diagnosis of SCI, willing to participate, able to communicate and understand, and willing to give informed consent. Exclusion criteria included: those who have SCI with head injury or bedridden patients.

The data was collected using a suitably structured schedule, it was developed based on reviewed existing literature, and piloted with 10 patients. Participants from the three hospitals were interviewed at the hospitals settings and participants from the association were interviewed by telephone calls. The structured schedule contains both open ended and closed ended questions. Moreover, it included questions about their life after spinal cord injury, the impact on psychological, social, and financial aspects, and investigates the need of support groups. Data was analyzed using SPSS (version 22). Frequencies and percentages are used for categorical variables. Continuous variables are represented as mean and standard deviation.

The study was approved by Institutional Review Board Approval IRB and informed consent was obtained from all participants.

Demographics detailes

Table 1 Demographic characteristics of the respondents

Demographic characteristics	**Details of respondents (n= 285)**
	No. (%)
Gender	
Male	236 (82.8)
Female	49 (17.2%)
Marital status	
Married	145 (50.9%)
Single	122 (42.8)
Divorced	16 (5.6%)
Widowed	2 (0.7%)
Living status after the injury	19 (6.7%)
On my own	262 (91.9%)
With family	2 (0.7%)
Rehabilitation center	2 (0.7%)
Else	
Time of injury	
Less than two months	5 (1.8%)
Several months before	37 (13.0%)
A year before	20 (7%)
Several years before	223 (8.2%)

In this study, 215 out of 285 participants were paraplegic, and 70 were at quadriplegic level of SCI (See Figure 1). The sample of this study included 236 males and 49 females, with 50% of these were currently married at the time of the interview. After the injury, 262 out of 258 patients reported to live with their families, while the remaining 23 lived on their own or rehabilitation centers. Most of the participants' injuries (78.2%) occurred more than several years at the time of the interview, while 21.8% had the injury since a year or less. As shown in Table 1.

Participants perception about their injury

Table 2 Participants perceptions about SCI injury

Particulars		**SCI level**		**Total (n=285)**
		Quadriplegia (n1= 70)	**Hemiplegia (n2= 215)**	
		No. (%)	**No. (%)**	**No. (%)**
Received detailed information about the condition after an injury.	Yes Partially No/Not yet Total	37 (52.9) 12 (17.1) 21 (30) 70 (100)	107 (49.8) 40 (18.6) 68 (31.6) 215 (100)	144 (50.5) 52 (18.2) 89 (31.3) 285 (100)
Accepted the new situation easily after the injury.	Yes Partially No/Not yet Total	24 (34.3%) 19 (27.1%) 27(38.6%) 70 (100%)	79 (36.7%) 33 (15.3%) 103 (47.9%) 215 (100%)	103 (36.1%) 52 (18.2%) 130 (45.6%) 285 (100.0%)
Difficulties in life after the injury.	Yes Partially No/Not yet Total	59 (84.3%) 3 (4.3%) 8 (11.4) 70 (100%)	169 (78.6%) 23 (10.7%) 23 (10.7%) 215 (100%)	228 (80.0%) 26 (9.1%) 31 (10.9%) 285 (100.0%)
Needed psychological help or encouragement.	Yes Partially No/Not yet Total	55 (78.6%) 6 (8.6%) 9 (12.9%) 70 (100%)	176 (81.9%) 13 (6%) 26 (12.1) 215 (100%)	231 (81.1%) 19 (6.7%) 35 (12.3%) 285 (100.0%)
Accepted the new health condition by family & friends after the	Yes Partially No/Not yet Total	45 (64.3%) 13 (18.6%) 12 (17.1%) 70 (100%)	131(60.9%) 48 (22.3%) 36 (16.7%) 215 (100%)	176 (61.8%) 61 (21.4%) 48 (16.8%) 285

injury.				(100.0%)
Family & friends are collaborating to overcome the disability.	Yes	62 (88.6)	183 (85.1%)	245 (86.0%)
	Partially	5 (7.1%)	18 (8.4%)	23 (8.1%)
	No/Not yet	3 (4.3%)	14 (6.5%)	17 (6.0%)
	Total	70 (100%)	215 (100%)	285 (100.0%)
Society takes into account the disability rights or violate the rights.	Yes	20 (28.6%)	49 (22.8%)	69 (24.2%)
	Partially	25 (35.7%)	73 (34%)	98 (34.4%)
	No/Not yet	25 (37.7%)	93 (43.3%)	118 (41.4%)
	Total	70 (100%)	215 (100%)	285 (100.0%)

Results show that 50.5 % received sufficient detailed information about the injury, 18.2% received information but not as sufficient, and 31.3% reported they did not receive enough detailed information about their condition. Regarding their acceptance of the injury, a number of 24 out of 70 quadriplegic participants accepted their new situation after the injury, while the rest reported partial or no acceptance. The majority of paraplegic participants (136 out of 215) also partially or did not accept their new situation after the injury.

Figure 2 Pie diagram showing participants level of spinal cord injury

80% of all the participants said to have difficulties in their lives after the injury, and 81.1% needed psychological support at some point of their lives after the injury. Although a percent of 61.8 of the participants' families & friends accepted their new situation, 86% of participants agreed that their family and friends were collaborative with them to overcome the disability. However, one hundred and eighteen participants reported that society did not respect their rights as disabled persons in the community, and ninety eight said that the society partially violates their rights.

Financially, 60% of SCI participants declared that the assistive equipment they need after the injury are expensive as shown in Figures 3.

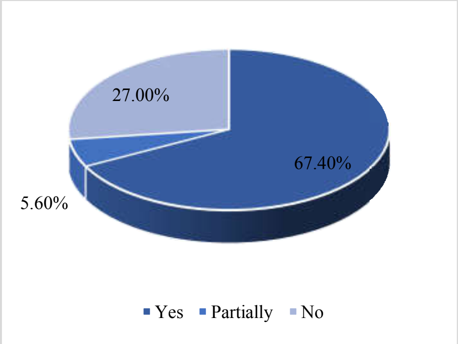

Figure 3 Whether participants suffer from high equipment prices

*Respondents have chosen more than one option

Majority of the SCI participants (90%) obtain equipment from the hospital, whereas 57% buy some or all from personal budget, and 4.3% are given by a donor (see Figure 4).

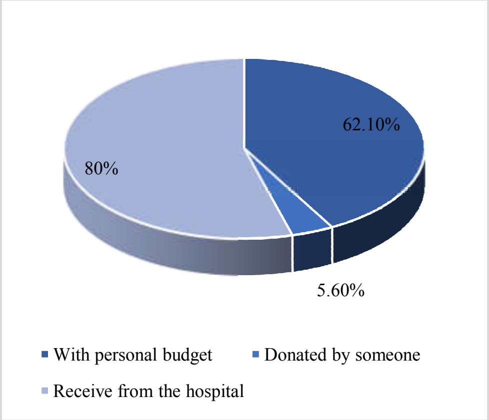

Figure 4 Participants' method of attaining assistive equipment

Respondents have chosen more than one option

The results showed no relation between the duration of the injury with either the acceptance of the injury (see Figure. 5) or the need of psychological support (see Figure. 6).

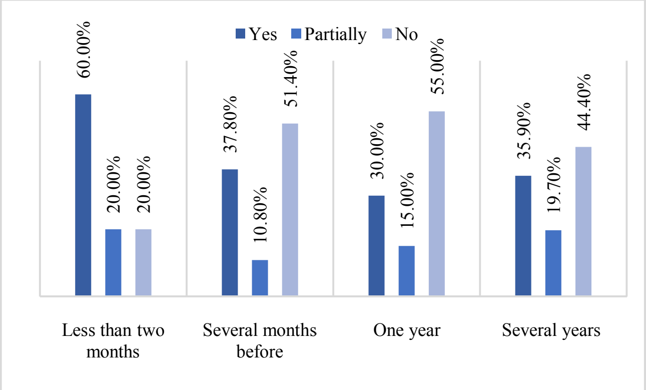

Figure 5 Participants' acceptance of condition in regards to duration of injury

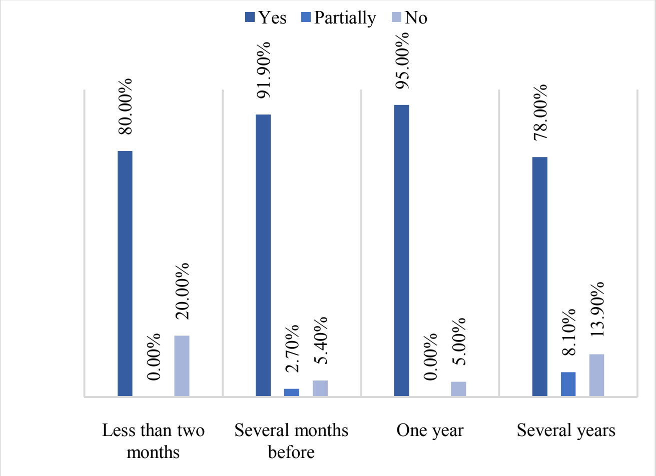

Figure 6 Participants' need of psychological support in regards with duration of injury

Participants involved in SCI support group

Table 3 Participants answers regarding the support groups

Particulars	**Details of respondents (n= 163)**
	No. (%)

The type of support received is*	Psychological	90	(60.7%)
	Financial	85	(52.1%)
	Social	115	(70.6%)
Overview of the support is	Motivational	92	(56.4%)
	Partially motivational	46	(28.2%)
	Not motivational	25	(15.3%)
The motivation, support & encouragement needed is	Continuous	50	(30.7%)
	Sometimes	85	(52.1%)
	When asked	28	(17.2%)
The support obtained is	Better than expected	38	(23.3%)
	As expected	61	(37.4%)
	Less than expected	64	(39.3%)
Satisfaction of the support provided	Very satisfied	57	(35.0%)
	Average satisfaction	67	(41.1%)
	Not satisfied	39	(23.9%)

*Respondents have chosen more than one option

A sum of 163 participants in this study were engaged in a support group (122 paraplegic, 41 quadriplegic). Table 3 shows this portion of the sample's answers regarding the support groups, the form of support provided by support groups was categorized into psychological (*60.7%*), financial (*52.1%*), and social (*70.6%*). 92 out of the 163 participants said the support groups were motivational, 46 found it partially motivational, and 25 participants did not find the support group to be motivational. A percentage of fifty-two reported that the support obtained from the support group was non-continuous and 17.2% said that the support is only given when asked. Sixty-four of the support group participants thought that the support was less than expected, and sixty-one said that it was as expected, and a lesser portion (38 participants) found it better than expected. The satisfaction rates ranged greatly between very satisfied (35%) and average satisfaction (41.1%). A considerable portion (42.3%) of participants said that they face difficulties when one/any type of support, psychological, financial, and social, is needed, and 17.8% cannot find it, while 39.9% are able to find support easily (see Figure 7).

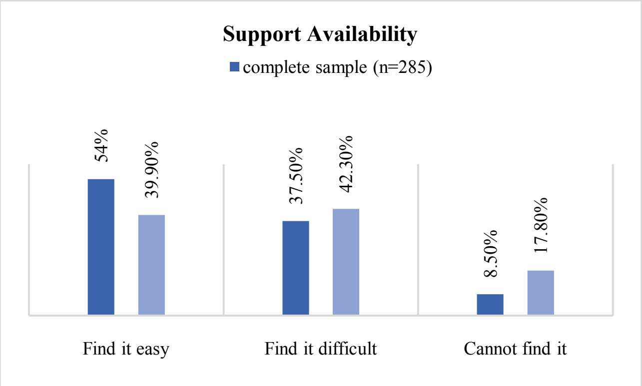

Figure 7 Depicts participants answers about how do they find help regarding the three types of support

All participants' perception about support groups

Table 4 Responses of SCI participants regarding the received support.

Particulars		SCI level		Total
		Quadriplegia (n1= 70)	Hemiplegia (n2= 215)	
		No. (%)	No. (%)	No. (%)
Received the names of institutions or persons who can provide help & support (Q23)	Yes No Total	41 (58.6%) 29 (41.4%) 70 (100)	111 (51.6%) 104 (48.4%) 215 (100)	152 (53.3%) 133 (46.7%) 285 (100)
Do you think the support can be improved? (Q24)	Yes No Total	58 (82.9%) 12 (17.1%) 70 (100%)	169 (68.6%) 46 (21.4%) 215 (100%)	227 (79.6%) 58 (20.4%) 258 (100%)
Did your life change by hearing the stories of success of disabled people?	Yes No Total	41 (58.6%) 29 (41.4%) 70 (100%)	134 (62.3%) 81 (37.7%) 215 (100%)	175 (61.4%) 110 (38.6%) 258 (100%)
Did you think about helping others who need support?	Yes No/Not yet Total	61 (87.1%) 9 (12.9%) 70 (100%)	188 (87.4%) 27 (12.6%) 215 (100%)	249 (87.4%) 36 (12.6%) 258 (100%)

Figure 8 shows responses of SCI participants regarding the received support.

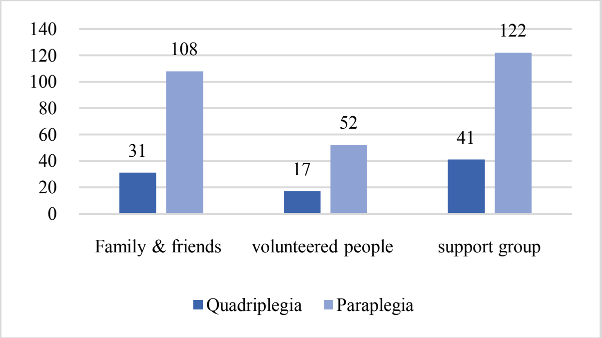

Figure 8 Source of support for patients with SCI

**Respondents have chosen more than one option*

53.3% of participants received the names of institutions or persons who can provide help & support, and the majority of responses were from their friends & relatives, hospitals and rehabilitation centers, and then social media and events.

A great portion of participants (79.6%) reported that the support groups can be improved, by provide suitable education and awareness for SCI patients, boost the psychological support, and modify the structure of the support groups. 87.4% of the participants were willing to provide help for other people with SCI if needed, preferring to provide psychological supports and visiting the patients after the injury to provide the support as shown in the table below. The study shows that 61.4% of the participants said that hearing the stories of success of disabled people had a positive effect on their lives after the injury, giving them hope and raising their ambitions to live their lives, while a percent of 38.6 reported that such stories did not change their life or they have not heard any (see Table 4).

Figure 9 conveys that regardless of whether the participant received support from a support group or not, a total of 78.6% of the participants were excited and willing to communicate with support groups to get support to gain multiple benefits mainly aiming to make friendship, share experience, and obtain support.

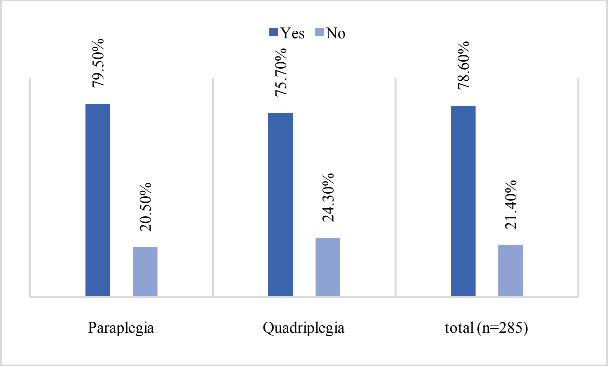

Figure 9 Willingness of SCI participants to communicate with and benefit from support groups

When asked about the need of establishing support groups for SCI patients in Saudi Arabia, 93.3% of the participants agreed that there is a need for support groups for SCI patients. (see Figure 10)

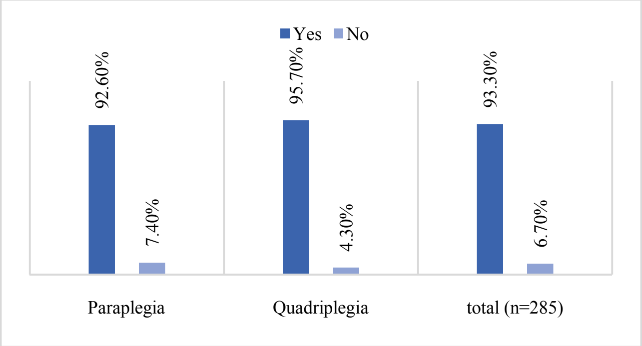

Figure 10 Perception of SCI participants regarding the need of support groups

DISCUSSION

This is the first study that concerns of examining the need of support group for people with SCI in Saudi Arabia. The ratio of females and males participants in the study is 5:14. This can be explained by the fact that Saudi Arabia has the highest rates of car accidents [2, 29, 30], and females are not allowed to drive in this country. Support groups have been found to help in meeting psychological, and social needs with other chronic conditions [14, 25-28], which have been proven to be affected in people with SCI [8, 14, 15, 16, 18]. Additionally, it was found in Saudi Arabia that social stigma hinders people with disability from involving in the society and getting outside of their homes, except during a medical crisis or hospital visits [17], results of this study show that 75.8% of the participants do not think that society takes their rights as people with disability into account, other than having a social effect, these factors relatively influence them psychologically. Plus it prevents them from finding suitable jobs easily which results in financial misfortunes.

In agreement with the previous literature, it was found throughout the responses that 80% of the participants with SCI face general difficulties in their lives that include psychological, social, and financial hardships after the injury. Also, 46% percentage of the people with SCI reported that they either cannot find or face difficulties in seeking psychological, social, and financial support when needed. One study conducted in SCI patients assessing their acceptance of the disability find that duration has no significant relation with the acceptance [31], which is in consistence with the finding of our data. Also found that there is no relationship between duration and psychological support.

More than half of the previously determined sample were found to be involved in a support group. However, when in need of support (psychological, social, and/or financial), a sum of 60.1% still find it difficult or cannot find it at all. Although 76.7% of those involved in support groups thought the support obtained was as expected or less, the satisfaction rates ranged greatly between very satisfied (35%) and average satisfaction (41.1%). which may be due to the Islamic culture and how it is believed that everything that happens to humans is part of *Qadar* (Arabic: قدر, transliterated qadar, meaning "fate", "divine fore-ordainment", "predestination").

One reason for non-involvement of nearly half of the participants could be because they did not encounter or hear about any support group (46.7% said they did not receive any names of institutions or persons who can provide help & support), and because 78.6% were excited and willing to communicate with support groups. Plus, nearly all participants agreed on the need and importance of establishing support groups for SCI patients in the community.

These findings imply how essential it is to establish support groups in Saudi Arabia, Riyadh for people with SCI in a more effective and considerable manner to help them fulfil their needs and overcome SCI privations.

Recommendations for Future Support Groups

Throughout the study, participants provided suggestions to improve the structure of support groups. They included the importance of building the groups based on a strong administration which allows more organization. Therefore, be able to facilitate a good rapport between members and to advocate for their right. In addition, the SCI participants stated that the group members should be of similar ages to meet the interest of each other's.

The findings show that most of the SCI patients knew about the support groups informally from friends and family. It is recommended that support group be introduced more officially in rehabilitation centers, which will probably play a major role in introducing the support groups to the newly injured patients.

Limitations

Interviewing the previously determined sample of 120 participants from The Adults Motor Disabilities Association [Harakia] could only be done using telephone calls. This may have limited the ability to build the appropriate interviewer/interviewee rapport that allows the participant to answer comfortably and provides the interviewer a better understanding of the respondent's opinion and suggestions.

Other limitation that could have affected the results may be the convenient sampling technique that resulted in more men, and more paraplegic patients than quadriplegic, who may have different perceptions about the injury and the support needed.

CONCLUSION

This cross-sectional study aimed to assess the role of support groups available for SCI patients in Riyadh. It reveals that SCI patients need support to overcome the psychological, social and financial consequences of their injuries. It shows that a majority were involved in support groups, regardless of how effective these groups were. The largest percentage of the provided type of support from the support group to SCI patients was social support. Most participants found out about the support groups informally from their family and friends. The support group participants were satisfied generally about the support but a great percentage believe it should be improved to meet their needs and desires.

Recommendations for Research Field

It is recommended for further studies to compare patients' status before and after exposing them to support group to produce more valid results of the effect of support groups in QoL of SCI patients.

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