Exploring the Quality of Life in Spinal Cord Injury Patients and Challenges, in Tertiary Care Hospital in Saudi Arabia.

By:

Dr. Anas J. AlSaleh

Supervised by:

Prof. Khaled M. Al-Mutairi

Executive master's in health administration

December 2024

List of Content:

LIST OF APPREVIATIONS:

SCI	Spinal Cord Injury
MENA	Middle East and North-Africa
QoL	Quality of Life
WHO	World Health Organization
CRF	Case Report Form
HIS	Health Information System
FIM	Functional Independence Measure
ASIA	Activities Daily Living
ANOVA	Analysis of Variance
SPSS	Statistical Package for the Social Sciences

Chapter 1:

Introduction:

Spinal cord injuries (SCIs) are severe traumas that can lead to significant physical, psychological, and socio-economic consequences for individuals. These injuries result from damage to the spinal cord, which affects nerve communications between the brain and the body (1,2,3), leading to multiple medical manifestations and complications; paralysis, sensory loss, bowel and bladder dysfunction, pain, pressure ulcers and spasticity, which can affect the quality of life for people with spinal cord injury (4,5).

Worldwide, road traffic accidents known as the main cause of spinal cord injuries, followed by falls, sport injuries and gunshot injuries (6). The annual incidence of SCI in the Middle East and North-Africa (MENA) region was found to be 23.24/million. (7,8). Saudi Arabia considered one of highest incidents rates of spinal cord injury worldwide, with 62 people injured per 1 million, and the injuries are mostly due to traffic accidents (9).

Rehabilitation for spinal cord injury patients is crucial and typically involves a multi-disciplinary approach, including physical therapy, occupational therapy, psychological support, and social reintegration programs. The goal of rehabilitation is to enhance functional recovery, minimize secondary complications, and empower individuals to achieve the highest possible quality of life (10-12).

Chapter 2

Literature Review:

Quality of life (QoL) is a nuanced and multi-dimensional concept that includes both objective factors (like disability, pain, and fatigue) and a subjective evaluation of how significantly these factors affect one's happiness (13). Quality of life as defined by the World Health Organization (WHO) is: "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (14). Spinal cord injury due to its complexity effect in the human body and its association with multiple physical and psychological complications, it's reported to that spinal cord injury patients have lower quality of life (15).

Rohit¸ studied and quality of life within the spinal cord injury population in India using WHOQOL-BREF and concluded that SCI have low QoL scores as compared to general Indian population. Pain and dependent mobilisation were found to be most significant predictors of poor QoL (16).

A prospective cross-sectional analysis and longitudinal study examining outcomes across the lifespan for people with SCI in the Australian population found QoL for people with SCI to be lower than normal population (4).

Recently, Ren´ee has studied the factors that could contribute to quality of life in spinal cord injury, he found that Working hours and work stress contributed to quality of life in people with SCI, but the number of related health complications was the strongest contributor (17). Meanwhile, employment statues and level of education was found to be significantly related to the quality of life among spinal cord injury population in Iran 18.

Despite extensive global research on spinal cord injuries, there is a notable gap in the research specifically to Saudi Arabian patients, especially regarding their quality-of-life post-injury. Al-Jadid studied the quality of life among individuals with spina cord injury in 2004, and found different factors directly related to quality of life; financial status, employment, equipment supply and social isolation 19.

Al-Owaisi, has studied the level of anxiety and depression among spinal cord injury population in Saudi Arabia, the study concluded that women with SCI have higher level of anxiety and depression comparing to male patients. Pain and level of education found to be correlated to their anxiety and depression level (20).

Study Objective:

In Saudi Arabia, the healthcare system is tasked with addressing the needs of spinal cord injury patients amidst unique cultural, economic, and infrastructural landscapes. Advances in healthcare infrastructure and increasing governmental focus on healthcare quality and accessibility have improved the prognosis for SCI patients. However, challenges such as limited specialized facilities, social stigma, and regional disparities in healthcare services persist. Understanding and addressing these challenges is vital for improving rehabilitation outcomes and enhancing the overall quality of life for SCI patients in the region.

This lack underscores the need for targeted research to address these unique challenges for spinal cord injury patients, to evaluate and enhance the management of spinal cord injury patients in Saudi Arabia, with a focus on improving quality of life outcomes.

Chapter 3

Methodology:

Study design and setting

The study conducted in the outpatient clinic at Sultan bin Abdulaziz Humanitarian city during the duration of September and October 2024, a questionnaire distributed to all patients who presented to the spinal cord injury clinic and fitted the criteria, 50 patients included, and the response rate was 100%, consent obtained by participate electively in the study. Arabic version of World Health Organization Quality of Life-BREF (WHOQOL-BREF) used, which is reliable and validated by WHO and commonly used to measure the quality of life among disability population (14).

Case report form (CRF) used to collect the data from the health information system (HIS), CRF contains patients' demographic information, level of injury and American Spinal Injury Association (ASIA) scale, The Functional Independence Measure (FIM) score, number of admissions to inpatient rehabilitation.

Inclusion and Exclusion Criteria:

Our target population included people with spinal cord injury, traumatic in nature, who attended their follow up to the spinal cord injury rehabilitation clinic. The inclusion criteria included Saudi male and female individuals with traumatic spinal cord injury, adults with aga between 18-50 years old, received a complete intensive inpatient rehabilitation program and able to read and answer the questionnaire. Our exclusion criteria included those patients who refuse to participate in the study, patients with co-exciting brain injury or mental disorders.

Measurement

Different measurement tools have been used to study the quality of life among the spinal cord injury population, however, there is no specific measurement tool for this population (21). WHO has developed a validated cross-cultural QL measurement tool by organizing a collaborative project in 15 centers. The outcome of this project was the development of the World Health Organization Quality of Life-BREF (WHOQOL-BREF) (22,4). Which is considered acceptable and well-established instrument to assess QoL within the spinal cord injury population based on a systematic literature review that assessed the measurement properties of QOL outcome measures (23).

This instrument is a condensed version of the original, featuring 24 items across four quality-of-life domains: physical health (7 items), psychological well-being (6 items), social relationships (3 items), and environment (8 items). It utilizes a five-point Likert scale. Scores for each domain were recoded to align with specific interpretations, such as: (1 = not at all, 2 = a little, 3 = moderately, 4 = mostly/very much, 5 = completely/extremely). Other scores were classified as follows: (1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4 = satisfied, 5 = very satisfied). The average score of the items in each domain was used to calculate the overall domain score. Additionally, two items were analyzed independently: the first assesses the individual's overall perception of quality of life ("How would you rate your quality of life?") with scores as follows: (1 = very poor, 2 = poor, 3 = neither good nor poor, 4 = good, 5 = very good). The second item evaluates the individual's general perception of their health ("How satisfied are you with your health?") with scoring as (1 = very dissatisfied, 2 = dissatisfied, 3 = neither satisfied nor dissatisfied, 4 = satisfied, 5 = very satisfied). In total, the instrument includes 26 items, with items Q3, Q4, and Q26 being reverse-scored (14) .

The American Spinal Injury Association (ASIA) scale categorizes spinal cord injuries from A to E based on motor and sensory assessments. Specifically, ASIA A denotes a complete spinal cord injury with no sensory or motor function preserved. ASIA B indicates no motor function, but some sensory functions may remain below the level of injury. ASIA C describes a situation where both sensory and motor functions are partially preserved, and ASIA D is characterized by the preservation of motor function below the injury level despite being an incomplete injury (24) .

Functional evaluation is defined as the assessment of an individual's ability to carry out self-care and fulfill basic daily necessities, such as activities of daily living (ADLs). The Functional Independence Measure (FIM) was developed in the 1980s to quantify functional capacity and independence. This scale measures the level of difficulty or limitation each individual experiences. It was created by a group led by the American Academy of Physical Medicine and Rehabilitation and the American Congress of Rehabilitation Medicine. Their goal was to devise a tool that could assess the independence levels of individuals with disabilities in performing both motor and cognitive tasks. The FIM was validated in 1986 (25). The assessment consists of 13 motor items and 5 social-cognitive items, evaluating self-care, sphincter management, transfers, locomotion, communication, social interaction, and cognition. It employs a 7-level scale, ranging from total dependence (1) to complete independence (7). The intermediate levels are defined as follows: 6 for modified independence, 5 for supervision or setup, 4 for minimal contact assistance (where the individual performs at least 75% of the effort), 3 for moderate assistance (where the individual performs 50–75% of the effort), and 2 for maximal assistance (where the individual performs 25–50% of the effort). While originally designed as an 18-item scale, it has been demonstrated to consist of two distinct scales: a 13-item motor scale and a 5-item social-cognitive scale (26). We have divided the FIM into two parts; self-care and Mobility. Self-care included eating, grooming, bathing, upper

body dressing, lower body dressing, and toileting, while mobility included bed to wheelchair transfer, toilet transfer, tub-shower transfer, walking, wheelchair mobility, and stairs use.

Data Collection:

The principal investigator approached the participant who is fitting the inclusion criteria in the clinic during their visit for follow up during the duration of September and October 2024, the purpose of the study explained to the participant and consent taken. The needed medical information obtained from the health information system (HIS).

Ethical Considerations

Ethical approval was obtained from the Institutional Review Board (IRB) at Sultan Bin Abdulaziz Humanitarian City where study conducted. All participants asked to sign consent to participate in the study, the consent included a permission to access the medical record files. Form with permission to access their medical files. Participants assured that participation is completely voluntary and that they can withdraw at any time without any consequences. They were also assured that their answers will remain confidential.

Statistical analysis:

Data were collected in a master sheet using MS Excel, double-checked for accuracy, refined, coded, and prepared for analysis. The scores for the WHOQOL-BREF domains were managed in accordance with WHO guidelines. Each question was coded on a scale of 1 to 5. Questions 3, 4, and 26, being negatively framed, were reverse-coded. Domain scores were then converted to a 4–20 scale by multiplying the mean scores by 4. Subsequently, these scores were transformed to a 0–100 scale using the formula:

$$\text{Transformed Score} = (\text{score} - 4) \times (100 / 16)$$

The results were appropriately tabulated. Means and standard deviations were reported for continuous variables, while frequencies and percentages were used for categorical variables. A normality test revealed that three domains followed a normal distribution ($P > 0.05$), whereas the general questions and the social relationships domain exhibited a non-normal distribution ($P < 0.05$). Based on these findings, differences in study variables related to the three WHOQOL-BREF domains were analyzed using one-way analysis of variance (ANOVA). For the general questions and the social relationships domain, differences were tested using the Mann-Whitney U test or the Kruskal-Wallis test, as appropriate. Correlations were assessed using Spearman's correlation coefficient. All analyses were performed using SPSS version 25.0 for Windows (IBM Corp., Armonk, NY, USA), with a P-value of less than 0.05 considered statistically significant.

Chapter 4

Results:

A total of 50 patients, with a mean age of 35 ± 10.46 years, who completed the questionnaires were included in this study. The majority were male (92.0%), 68.0% were unmarried, 32.0% resided in the central region of Saudi Arabia, 44.0% were employed, and 52.0% had attained higher education. Additional details are provided in Table 1.

Table 1: Characteristics of the study sample

	Frequency	Percent
Gender		
Male	46	92.0
Female	4	8.0
Marital status		
Unmarried	34	68.0
Married	16	32.0
Place of residency		
Western	8	16.0
Southern	10	20.0
Northern	6	12.0
Eastern	10	20.0
Central	16	32.0
Source of income		
Working	22	44.0
Supported by family	9	18.0
Social Affairs	5	10.0
Retired	14	28.0
Education level		
Primary level	24	48.0
Higher level	26	52.0

Most spinal cord injuries (SCIs) (84.0%) were caused by motor vehicle accidents. Among the patients, 54.0% had a grade A injury, and 74.0% were classified at the paraplegia level. The average time since SCI was 6.3 ± 6.0 years, ranging from 1 to 35 years. The mean number of admissions was 3.2 ± 1.6, while the average time between SCI and initiation of the first rehabilitation program was 16.5 ± 13.2 weeks, ranging from 3 to 56 weeks (Table 2). The selfcare Functional Independence Measure (FIM) score (32.0 ± 9.3) was higher than the mobility FIM score (25.1 ± 8.4). Regarding the WHOQOL-BREF assessment, the overall quality of life (QoL) score was 75.5 ± 24.5, while the overall general health score was 66.5 ± 31.0. Among the WHOQOL-BREF domains, the psychological domain had the highest score (71.7 ± 17.5), while the physical health domain had the lowest (55.9 ± 18.8). More details are presented in Table 2.

Table 2: Descriptive statistics of the study variables related to SCI, FIM score, and WHOQOL-BREF domains		
	Frequency	**Percent**
Cause of SCI		
Accident	42	84.0
Fall	8	16.0
Grade of SCI		
Grade A	27	54.0
Grade B	8	16.0
Grade C	7	14.0
Grade D	8	16.0
Level of SCI		
Paraplegia	37	74.0
Quadriplegia	13	26.0
	Mean±SD	
Time since injury (years)	6.3±6.0	
Number of admissions	3.2±1.6	
Time between injury and 1st rehab. program (weeks)	16.5±13.2	
Selfcare FIM	32.0±9.3	
Mobility FIM	25.1±8.4	
Overall quality of life (QoL)	75.5±24.5	
Overall general health (GH)	66.5±31.0	
Physical health (D1)	55.9±18.8	
Psychological (D2)	71.7±17.5	
Social relationships (D3)	66.2±22.6	
Environment (D4)	62.9±17.0	

The subjective complications of SCI, as documented in the HIS system, are summarized in Table 3. The most common complications were neurogenic bladder and neurogenic bowel (n = 48 each), followed by spasticity (n = 31) and neuropathic pain (n = 26). Other complications were reported less frequently.

Table 3: Complications of the SCI as reported by patients (multiple choice)		
	Present	**Not present**
Spasticity	31 (62.0)	19 (38.0)
Neurogenic bladder	48 (96.0)	2 (4.0)
Heterotopic ossification	6 (12.0)	44 (88.0)
Depression	10 (20.0)	40 (80.0)
Neurogenic bowel	48 (96.0)	2 (4.0)
Osteoporosis	18 (36.0)	32 (64.0)
Pressure ulcer	16 (32.0)	34 (68.0)
Anxiety	7 (14.0)	43 (86.0)
Neuropathic pain	26 (52.0)	24 (48.0)
Respiratory complication	1 (2.0)	49 (98.0)
Autonomic dysreflexia	12 (24.0)	38 (76.0)

As shown in Table 4, male patients reported higher scores in overall quality of life, psychological health, and environmental health domains compared to female patients, while female patients scored higher in the remaining domains. However, these gender differences were not statistically significant (P > 0.05). Unmarried patients recorded higher scores in nearly all domains, except overall general health, compared to married patients, but these differences were also not statistically significant (P > 0.05). Patients with primary education scored higher only in overall quality of life, whereas those with higher education achieved higher scores across all other domains, though the differences were not significant (P > 0.05). Similarly, no significant associations were observed between source of income and WHOQOL-BREF scores (P > 0.05), despite working patients generally reporting higher scores in most domains.

Patients with SCI caused by falls recorded higher scores in overall quality of life and general health, while those with motor vehicle accident-related SCIs scored higher in the physical, psychological, social, and environmental domains. However, none of these differences were statistically significant (P > 0.05). Similarly, no significant associations were found between the level of SCI and WHOQOL-BREF scores (P > 0.05), although patients with paraplegia tended to score higher across most domains. Additionally, there were no significant associations between the grade of SCI and WHOQOL-BREF scores (P > 0.05). Further details are presented in Table 4.

Table 4: Associations between WHOQOL-BREF with the demographic characteristics and cause, level, and grade of the SCI injury

		Overall quality of life		Overall general health		Physical health		Psychological health		Social relationships		Environment health	
		Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P
Gender	Male	76.1±24.7	0.500*	66.3±31.7	0.959*	55.7±18.2	0.888	72.5±16.8	0.334	65.4±23.2	0.457*	63.2±17.2	0.672
	Female	68.8±23.9		68.8±23.9		57.1±28.7		63.5±26.0		75.0±11.8		59.4±15.1	
Marital status	Unmarried	75.7±22.6	0.860[a]	66.2±28.8	0.682[a]	58.6±18.0	0.132	71.9±19.4	0.914	68.1±17.6	0.584[a]	63.0±17.1	0.960
	Married	75.0±28.9		67.2±36.2		50.0±19.7		71.4±13.3		62.0±31.0		62.7±17.2	
Education level	Primary level	79.2±24.1	0.251[a]	61.5±33.0	0.299[a]	51.2±16.1	0.188	71.7±16.8	0.985	63.5±21.1	0.436[a]	62.4±16.1	0.842
	Higher level	72.1±24.8		71.2±28.9		60.2±20.4		71.8±18.5		68.6±24.1		63.3±18.1	
Source of income	Working	78.4±19.4	0.707[a]	68.2±31.0	0.381[a]	60.6±19.3	0.377	74.1±18.9	0.127	71.6±20.7	0.111[a]	65.8±20.4	0.385
	Supported by family	75.0±21.7		80.6±16.7		56.3±16.1		72.2±15.0		70.4±17.7		61.1±15.6	
	Social Affairs	60.0±37.9		50.0±35.4		48.6±16.5		54.2±21.2		55.0±26.1		51.3±12.4	
	Retired	76.8±28.5		60.7±35.0		50.8±20.1		74.1±13.1		58.9±25.8		63.6±12.1	
Cause of SCI	Accident	75.0±25.3	0.887*	66.1±31.1	.825*	57.1±19.7	0.306	72.6±17.8	0.428	66.9±22.1	0.524*	62.9±17.3	0.947
	Fall	78.1±20.9		68.8±32.0		49.6±12.1		67.2±16.3		62.5±26.4		62.5±16.1	
Level of SCI	Paraplegia	75.0±24.3	0.761*	67.6±30.5	0.705*	58.6±18.7	0.083	73.8±16.9	0.174	68.5±21.3	0.231*	65.4±17.9	0.079
	Quadriplegia	76.9±25.9		63.5±33.3		48.1±17.4		66.0±18.7		59.6±25.6		55.8±11.8	
Grade of SCI	Grade A	75.9±27.3	0.255[a]	63.0±31.3	0.595[a]	55.4±19.2	0.469	70.1±20.4	0.150	63.3±22.1	0.051[a]	61.6±19.0	0.128
	Grade B	78.1±16.0		75.0±40.1		60.7±22.0		81.2±12.4		82.3±10.4		74.2±10.3	
	Grade C	85.7±19.7		71.4±22.5		61.2±18.4		77.4±7.2		71.4±20.9		64.3±14.1	
	Grade D	62.5±23.1		65.6±29.7		47.8±13.9		63.0±13.3		55.2±28.1		54.7±12.9	

** Mann Whitney U test was used; a Kruskal Wallis test was used; P-value was considered significant at P< 0.05.*

The associations between WHOQOL-BREF scores and SCI complications are summarized in Table 5. A significant association was observed between environmental health and spasticity (P = 0.042), with patients without spasticity scoring higher than those with spasticity (69.1 ± 17.5 vs. 59.1 ± 15.8). Another significant association (P = 0.047) was found between depression and physical health, where patients without depression recorded higher scores than those with depression. Patients with anxiety scored significantly lower in overall quality of life compared to non-anxious patients (53.6 ± 30.4 vs. 79.1 ± 21.8; P = 0.022). Neuropathic pain was significantly associated with overall quality of life (P = 0.033), physical health (P = 0.022), and psychological health (P = 0.044). Although only one patient reported a respiratory

complication, its association with psychological health was significant (P = 0.013). Further details are provided in Table 5.

Table 5: Associations between the reported SCI complications and WHOQOL-BREF

		Overall Quality of Life		Overall General Health		Physical Health		Psychological Health		Social Relationships		Environment Health	
		Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P	Mean±SD	P
Spasticity	No	71.1±28.0	0.422	76.3±29.4	0.055	60.7±20.9	0.155	71.5±19.2	0.936	71.1±23.6	0.163	69.1±17.5	**0.042**
	Yes	78.2±22.1		60.5±30.8		52.9±17.0		71.9±16.8		63.2±21.8		59.1±15.8	
Neurogenic Bladder	No	75.0±0.0	0.794	75.0±0.0	0.877	55.4±12.6	0.970	68.8±8.8	0.808	66.7±11.8	0.764	65.6±0.0	0.257
	Yes	75.5±25.0		66.1±31.6		55.9±19.1		71.9±17.9		66.1±23.0		62.8±17.3	
Heterotopic Ossification	No	76.1±25.3	0.430	65.9±30.5	0.620	56.7±18.6	0.376	72.6±18.0	0.341	65.2±23.6	0.432	62.4±17.8	0.428
	Yes	70.8±18.8		70.8±36.8		49.4±20.4		65.3±13.6		73.6±12.3		66.2±8.9	
Depression	No	76.9±22.2	0.663	65.0±31.4	0.513	58.5±17.5	**0.047**	72.6±17.5	0.497	66.0±22.4	0.806	63.1±17.3	0.837
	Yes	70.0±32.9		72.5±29.9		45.4±21.0		68.3±18.3		66.7±24.5		61.9±16.3	
Neurogenic Bowel	No	75.0±0.0	0.794	75.0±0.0	0.877	55.4±12.6	0.970	68.8±8.8	0.808	66.7±11.8	0.764	65.6±0.0	0.257
	Yes	75.5±25.0		66.1±31.6		55.9±19.1		71.9±17.9		66.1±23.0		62.8±17.3	
Osteoporosis	No	75.0±24.6	0.798	67.2±31.4	0.826	55.2±19.3	0.763	72.4±16.3	0.733	69.3±23.8	0.094	65.6±16.6	0.128
	Yes	76.4±25.0		65.3±31.1		56.9±18.4		70.6±20.0		60.6±19.8		58.0±17.0	
Pressure Ulcer	No	74.3±25.0	0.606	68.4±29.7	0.619	56.0±18.2	0.944	73.0±16.8	0.455	64.7±25.4	0.705	64.8±17.8	0.247
	Yes	78.1±23.9		62.5±34.2		55.6±20.6		69.0±19.4		69.3±15.4		58.8±14.8	
Anxiety	No	79.1±21.8	**0.022**	68.0±29.5	0.495	57.5±17.9	0.133	72.4±18.2	0.532	66.9±19.7	0.724	63.2±17.0	0.776
	Yes	53.6±30.4		57.1±40.1		45.9±22.6		67.9±12.9		61.9±37.8		61.2±17.9	
Neuropathic Pain	No	83.3±20.4	**0.033**	74.0±25.0	0.161	62.1±14.3	**0.022**	76.9±16.2	**0.044**	70.8±21.1	0.118	67.6±16.1	0.059
	Yes	68.3±26.0		59.6±34.7		50.1±20.8		67.0±17.7		61.9±23.5		58.5±16.9	
Respiratory Complication	No	76.0±24.5	0.227	66.8±31.2	0.450	56.6±18.3	0.064	72.6±16.6	**0.013**	66.0±22.8	0.779	63.4±16.7	0.132
	Yes	50.0±		50.0±		21.4±		29.2±		75.0±		37.5±	
Autonomic Dysreflexia	No	73.0±25.6	0.230	67.8±29.0	0.823	56.3±18.7	0.772	72.1±17.4	0.778	66.2±23.2	0.945	63.9±17.9	0.454
	Yes	83.3±19.5		62.5±37.7		54.5±19.9		70.5±18.8		66.0±21.7		59.6±13.8	

ᵝ Mann Whitney U test was used; P-value was considered significant at P< 0.05.

Table 6 presents significant positive correlations between the time since injury and selfcare FIM scores with physical health (P = 0.039 and P = 0.031, respectively). No significant correlations were observed with the other domains (P > 0.05). Similarly, no significant correlations were found between age, number of admissions, time between injury and the first rehabilitation program, or mobility FIM scores with the WHOQOL-BREF domains (P > 0.05).

Table 6: Correlations between age, time of injury, number of admissions, FIM scores with the WHOQOL-BREF

		Overall quality of life	Overall general health	Physical health	Psychological health	Social relationships	Environment health
Age (years)	*Correlation*	0.176	0.040	-0.195	0.065	-0.235	-0.179
	P-value	0.222	0.783	0.176	0.655	0.100	0.213
Time since injury	*Correlation*	0.076	0.131	.292*	0.203	0.117	0.021
	P-value	0.602	0.364	**0.039**	0.158	0.417	0.885
Number of admissions	*Correlation*	0.114	0.242	0.230	0.064	-0.013	-0.015
	P-value	0.430	0.090	0.109	0.660	0.929	0.918
Time between injury and 1st rehab. program	*Correlation*	-0.123	0.011	0.035	0.130	-0.238	-0.020
	P-value	0.396	0.938	0.810	0.369	0.096	0.889
Selfcare FIM	*Correlation*	-0.120	0.188	.306*	0.142	0.270	0.214
	P-value	0.406	0.191	**0.031**	0.326	0.058	0.135
Mobility FIM	*Correlation*	-0.203	0.063	0.146	-0.015	0.125	0.108
	P-value	0.157	0.663	0.312	0.920	0.387	0.454

*Spearman Correlation Coefficient test was used; * P-value was considered significant at P< 0.05.*

Chapter 5

Discussion:

The findings of this study contribute to a deeper understanding of the complex interplay between various factors influencing the quality of life (QoL) among spinal cord injury (SCI) patients in Saudi Arabia. Despite significant medical advances and rehabilitation techniques, SCI patients continue to face substantial challenges that affect their overall QoL. This research underscores the multifaceted nature of these challenges and highlights the critical role of comprehensive rehabilitation programs.

The results indicate that SCI significantly impacts patients' physical, psychological, social, and environmental domains. The lower scores in the physical health domain reflect the profound physical limitations imposed by SCI, aligning with previous studies that document the direct impact of physical disability on QoL. However, it is noteworthy that the psychological domain scored relatively higher, suggesting that mental resilience and coping strategies might evolve as patients adapt over time.

Anxiety and neuropathic pain found to have significant negative impact on the overall quality of life among people with spinal cord injury, putting in consideration; neuropathic pain is a common complaint after spinal cord injury, the neuropathic pain showed significant impact all domains of WHOQoL-BREF, while in our study pain found to affect all domains but it's statistically significant on physical and psychological health, which is well reported in the literature (27).

Interestingly, in despite to the increased health condition associated with aging in spinal cord injury (28,29), our study showed that the longer duration since injury the high physical quality of life, this can be explained by the learned adaptation strategies for the people with spina cord injury, these results were similar to other study (29). Other statical significant results in the study were the negative relationship between spasticity and environmental health, where the literature review showed contradict evidence of spasticity been positive factor versus negative factor on people with spinal cord injury population (30). The correlations between QoL and SCI complications such as neuropathic pain and spasticity are particularly telling. These complications directly diminish physical health and overall QoL, emphasizing the need for targeted medical and rehabilitation strategies to manage these issues effectively.

Social relationships and environmental factors also play crucial roles. Although not statistically significant, the trends suggest that individuals with better social support and more accessible environments tend to report higher QoL. This finding is consistent with literature suggesting that social integration and support systems are pivotal in enhancing the QoL for individuals with chronic disabilities (30).

Employment status emerged as an interesting aspect, with employed patients generally reporting better QoL. This could be attributed to the financial independence and social interactions that employment offers, echoing the findings of studies like those conducted by Renée et al., which highlighted the positive impact of work on QoL (17).

The lack of significant differences across most demographic variables, such as gender, marital status, and educational level, may point to the overarching influence of the SCI itself over these socio-demographic factors. However, these results should be interpreted with caution given the small sample size and the high variability in individual experiences of disability.

Conclusion:

This study highlights the pressing need for a holistic approach in the rehabilitation of SCI patients, considering not only the physical but also the psychological, social, and environmental dimensions of recovery. Tailored interventions that address the specific needs and complications of SCI patients can significantly enhance their rehabilitation outcomes and overall quality of life. This underscores the broader implications for healthcare policy and rehabilitation practices, suggesting that a shift towards more integrated and patient-centred care is essential for improving the lives of those affected by SCI in Saudi Arabia.

Limitations:

This study has several limitations that should be considered when interpreting the findings. First, the relatively small sample size (50 participants) limits the generalizability of the results to the broader population of SCI patients in Saudi Arabia. Second, the study was conducted in a single tertiary care centre, which may not reflect the experiences of SCI patients receiving care in other facilities or regions. Third, the cross-sectional design captures QoL at a single point in time, making it difficult to assess changes over time or the impact of rehabilitation interventions longitudinally. Additionally, the study relied on self-reported data, which may be influenced by recall bias or social desirability. Finally, while the WHOQOL-BREF is a validated tool, it may not capture all culturally specific or nuanced factors affecting QoL in the Saudi context.

Recommendations:

1- Expand the Study Population: Future research should include a larger, more diverse sample across multiple healthcare centres in Saudi Arabia to improve generalizability and provide a comprehensive view of SCI patients' QoL
2- Longitudinal Studies: Conduct longitudinal studies to track changes in QoL over time and assess the long-term impact of rehabilitation interventions.
3- Develop Culturally Specific Tools: Consider developing or adapting QoL measurement tools to better capture culturally specific factors affecting SCI patients in Saudi Arabia.
4- Integrate Multidisciplinary Care: Encourage the adoption of holistic, multidisciplinary, patient centred rehabilitation approaches that address physical, psychological, and social dimensions of recovery.

References:

1. Dumont, R. J., Okonkwo, D. O., Verma, S., et al. (2001). Acute spinal cord injury,: Pathophysiologic mechanisms. *Clinical Neuropharmacology, 24*(5), 254-264.
2. Stahel, P. F., VanderHeiden, T., & Finn, M. A. (2012). Management strategies for acute spinal cord injury: Current options and future perspectives. *Current Opinion in Critical Care, 18*(6), 651-660.
3. Al Taweel, W., & Alkhayal, A. (2011). Neurogenic bladder evaluation and management after spinal cord injury: Current practice among urologists working in Saudi Arabia. *Urology Annals, 3*(1), 24-28.
4. Barker, R. N., Kendall, M. D., Amsters, D. I., Pershouse, K. J., Haines, T. P., & Kuipers, P. (2009). The relationship between quality of life and disability across the lifespan for people with spinal cord injury. *Spinal Cord, 47*(2), 149-155. https://doi.org/10.1038/sc.2008.82
5. Boakye, M., Leigh, B. C., & Skelly, A. C. (n.d.). Quality of life in persons with spinal cord injury: Comparisons with other populations.
6. Elshahidi, M. H., Monir, N. Y., Elzhery, M. A., Sharaqi, A. A., Haedaya, H., Awad, B., & Zaghloul, K. (n.d.). Epidemiological characteristics of traumatic spinal cord injury (TSCI) in the Middle-East and North-Africa (MENA) region: A systematic review and meta-analysis.
7. Ansari, S., Akhdar, F., Mandoorah, M., et al. (2000). Causes and effects of road traffic accidents in Saudi Arabia. *Public Health, 114*(1), 37-39.
8. Alshahri, S. S., Cripps, R. A., Lee, B. B., et al. (2012). Traumatic spinal cord injury in Saudi Arabia: An epidemiological estimate from Riyadh. *Spinal Cord, 50*(12), 882-884.
9. Bakhsh, A., Aljuzair, A. H., & Eldawoody, H. (n.d.). An epidemiological overview of spinal trauma in the Kingdom of Saudi Arabia.
10. Bickenbach, J. (Ed.). (2013). *International perspectives on spinal cord injury*. World Health Organization.
11. Scivoletto, G., Morganti, B., & Molinari, M. (2005). Early versus delayed inpatient spinal cord injury rehabilitation: An Italian study. *Archives of Physical Medicine and Rehabilitation, 86*, 512-516.
12. Yang, J. F., & Musselman, K. E. (2012). Training to achieve over ground walking after spinal cord injury: A review of who, what, when, and how. *Journal of Spinal Cord Medicine, 35*, 293-304.
13. Brazier, J. E., & Roberts, J. (2004). The estimation of a preference-based measure of health from the SF-12. *Medical Care, 42*(9), 851-859.
14. World Health Organization. (n.d.). WHOQOL: Measuring quality of life.
15. Lude, P., Kennedy, P., Elfström, M. L., & Ballert, C. S. (2014). Quality of life in and after spinal cord injury rehabilitation: A longitudinal multicenter study. *Topics in Spinal Cord Injury Rehabilitation, 20*(3), 197-207.
16. Jindal, R., Bansal, P., Gupta, S., & Garg, S. K. (n.d.). Quality of life after traumatic thoracolumbar spinal cord injury: A North Indian perspective.
17. van Dinter, R., Reneman, M. F., & Post, M. W. M. (n.d.). Relation between work hours, work control, work stress, and quality of life in persons with spinal cord injury.
18. Moghimian, M., Kashani, F., Cheraghi, M. A., & Mohammadnejad, E. (n.d.). Quality of life and related factors among people with spinal cord injuries in Tehran, Iran.
19. Al-Jadid, M. S., Al-Asmari, A. K., & Al-Moutaery, K. R. (n.d.). Quality of life in males with spinal cord injury in Saudi Arabia.

20. Al-Owesie, R. M., Moussa, N. M., & Robert, A. A. (n.d.). Anxiety and depression among traumatic spinal cord injured patients.
21. Aquarone, R. L., & Mancussi e Faro, A. C. (n.d.). Scales on quality of life in patients with spinal cord injury: Integrative review.
22. The WHOQOL Group. (1997). WHOQOL: Measuring quality of life. Geneva: WHO.
23. Hill, M. R., Noonan, V. K., Sakakibara, B. M., & Miller, W. C. (2010). Quality of life instruments and definitions in individuals with spinal cord injury: A systematic review. *Spinal Cord, 48*(6), 438-450.
24. American Spinal Injury Association. (n.d.). International standards for neurological classification of spinal cord injury. Retrieved [insert access date] from [URL].
25. Barbetta, D. C., & Assis, M. R. (2008). Reproducibilidade, validade e responsividade da escala de medida de independência funcional (MIF) na lesão medular: Revisão da literatura. *Acta Fisiatr, 15*(3), 176-181.
26. Linacre, J. M., Heinemann, A. W., Wright, B. D., Granger, C. V., & Hamilton, B. B. (1994). The structure and stability of the functional independence measure. *Archives of Physical Medicine and Rehabilitation, 75*, 127-132.
27. Andresen, S. R., Biering-Sørensen, F., Hagen, E. M., et al. (2016). Pain, spasticity and quality of life in individuals with traumatic spinal cord injury in Denmark. *Spinal Cord, 54*, 973-979.
28. Rivers, C. S., Fallah, N., et al. (n.d.). Health conditions: Impact on function, health-related quality of life, and life satisfaction following traumatic spinal cord injury. A prospective observational registry cohort study.
29. Westerkam, D., Saunders, L. L., & Krause, J. S. (n.d.). Association of spasticity and life satisfaction after spinal cord injury.
30. Hess, D., Meade, M., Forchheimer, M., & Tate, D. (2004). Psychological well-being and intensity of employment in individuals with a spinal cord injury. *Spinal Cord Injury Rehabilitation, 9*, 1-10.

Appendix (1)

مدينة سلطان بن عبد العزيز للخدمات الإنسانية
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY

Date: **05 September 2024**
IRB No.: **123-2024-IRB**

To: **Dr. Anas J. Al Saleh**
MSc: "Exploring the Quality of Life in Spinal Cord Injury Patients and Challenges, in Tertiary Care Hospital in Saudi Arabia"
Sultan bin Abdulaziz Humanitarian City
E-mail: aalsaleh@sbahc.org.sa

Subject:	Approval for Research No. 119/SBAHC/MA/2024
Study Title:	"Exploring the Quality of Life in Spinal Cord Injury Patients and Challenges, in Tertiary Care Hospital in Saudi Arabia"
Study Code:	119/SBAHC/MA/2024
Date of Approval:	05/September/2024
Date of Expiry:	30/January/2025
Board approval:	All members except the absentees

Dear **Dr. Anas J. Al Saleh**,

Your Project has been approved and you have the permission to conduct this study following your submitted documents as follow:

1. Curriculum Vitae for the PI researcher
2. Letter from researcher's affiliating Organization/College
3. Letter from the researcher requesting SBAHC participation in the clinical study
4. Letter from the researcher's supervisor requesting supervision in the clinical study
5. Research proposal according to SBAHC IRB Guidelines
6. SBAHC Informed Consent Template
7. Research Obligatory Agreement. Available upon the completion of the other requirements

You are required to obey by the rules and regulations of the Government of Saudi Arabia, the SBAHC IRB Policies and procedures and the ICH-GCP guidelines. You have to note that this approval mandate responding to IRB's periodic request and surveillance result. Drawing your attention to the following:

- Amendment of the project with the required modification to providing Periodical report for this project specially when study extension is required or expiry before study completion

مدينة سلطان بن عبد العزيز للخدمات الإنسانية
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY
لجنة أخلاقيات البحوث الطبية
Institutional Review Board (IRB)

- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the IRB as soon as possible
- Personal identifying data should only be collected when necessary for research.
- Secondary disclosure of personal identifiable data is not allowed.
- Monitoring: projects may be subject to an audit by the IRB at any time.
- The PI is responsible for the storage and retention of original data pertaining to the project for a minimum period of five (5) years.
- Data should be stored securely so that a few authorized users are permitted access to the database.

The IRB registered with the IRB KACST Registration No. H-01-R-090. It is authorized to conduct the ethical review of clinic studies and operates in accordance with ICH-GCP Guidelines and all applicable national/local and institutional regulations and guidelines which govern Good Clinical Practices.

For Future Correspondence, please quote the project number and project title above and you are requested to keep IRB informed about your study progress and submit project progress report every six (6) months. A final report should be provided upon completion of the study.

Wish you a success in your research project.

Yours sincerely,

Prof. Khalid Al-Rubeaan
Chairman-Institutional Review Board
Sultan Bin Abdulaziz Humanitarian City

مدينة سلطان بن عبد العزيز للخدمات الإنسانية
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY
لجنة أخلاقيات البحوث الطبية
Institutional Review Board (IRB)

Appendix (2)

مدينة سلطان بن عبد العزيز للخدمات الإنسانية
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY
لجنة أخلاقيات البحوث الطبية
Institutional Review Board (IRB)

Appendix E: WHOQOL-BREF

يرجى قراءة كل سؤال و تقيم ما تشعر به ووضع دائرة حول الرقم الذي يعطي أفضل إجابة بالنسبة لك

		سيئة للغاية	سيئة	لا بأس	جيدة	جيدة جدا
(G1)1	كيف تقيم نوعية حياتك	1	2	3	4	5

		غير راض على الاطلاق	غير راض	لا راض ولا غير راض	راض	راض تماما
(G4)2	ما مدى رضاك عن صحتك	1	2	3	4	5

الأسئلة التالية تستفسر عن مدى تعرضك لأشياء معينة خلال الأسبوعين الماضيين

		لا يوجد	قليلا	بدرجة متوسطة	كثير جدا	بدرجة بالغة
(F1.4) 3	إلى أي حد تشعر بأن الألم الجسدي يمنعك من القيام بالأعمال التي تريدها ؟	1	2	3	4	5
(F11.3)4	الى أي مدى أنت بحاجة للعلاج الطبي لتتمكن من القيام بأعمالك اليومية ؟	1	2	3	4	5
(F4.1)5	إلي أي مدى تستمتع بالحياة ؟	1	2	3	4	5
(F24.2)6	إلي أي مدى تشعر بأن حياتك ذات معنى ؟	1	2	3	4	5
(F5.3)7	الى أي مدى أنت قادر على التركيز ؟	1	2	3	4	5
(F16.1)8	الى أي مدى تشعر بالأمان في حياتك اليومية ؟	1	2	3	4	5
(F22.1)9	إلى أي حد تعتبر أن البيئة المحيطة بك صحية ؟	1	2	3	4	5

الأسئلة التالية تستفسر عن مدى قدرتك على إتمام أمور معينة خلال الأسبوعين الماضيين

		لا يوجد	قليلا	بدرجة متوسطة	كثير جدا	بدرجة بالغة
(F2.1)10	هل لديك طاقة كافيه لمزاولة الحياة اليومية؟	1	2	3	4	5
(F7.1)11	هل أنت قادر على قبول مظهرك الخارجي؟	1	2	3	4	5
(F18.1)12	هل لديك من المال ما يكفي لتلبية احتياجاتك؟	1	2	3	4	5
(F20.1)13	ما مدى توفر المعلومات التي تحتاجها في حياتك اليومية ؟	1	2	3	4	5
(F21.1)14	إلي أي مدى لديك الفرصة لممارسة الأنشطة الترفيهية؟	1	2	3	4	5

		سيئة للغاية	سيئة	لا بأس	جيدة	جيدة جدا
(F9.1)15	الى أي مدى أنت قادر على التنقل بسهولة؟	1	2	3	4	5

الأسئلة التالية تطلب منك أن تعبر عن مدى رضاك نحو جوانب مختلفة من حياتك خلال الأسبوعين الماضيين

		غير راض على الاطلاق	غير راض	لا راض ولا غير راض	راض	راض تماما
(F3.3)16	كم أنت راض عن نومك ؟	1	2	3	4	5
(F10.3)17	إلي أي مدى أنت راض عن قدرتك على القيام بنشاطاتك اليومية ؟	1	2	3	4	5
(F12.4)18	كم أنت راض عن قدراتك على العمل ؟	1	2	3	4	5
(F6.3)19	كم أنت راض عن نفسك ؟	1	2	3	4	5
(F13.3)20	كم أنت راض عن علاقاتك الشخصية ؟	1	2	3	4	5
(F15.3)21	كم أنت راض عن حياتك الجنسية ؟	1	2	3	4	5
(F14.4)22	كم أنت راض عن الدعم أو المساعدة من الأصدقاء ؟	1	2	3	4	5
(F17.3)23	كم أنت راض عن الأوضاع في مكان سكنك؟	1	2	3	4	5
(F19.3)24	كم أنت راض عن الخدمات الصحية المتوفرة لك ؟	1	2	3	4	5
(F23.3)25	كم أنت راض عن وسائل المواصلات التي تستخدمها ؟	1	2	3	4	5

الأسئلة التالية تشير إلى كم من المرات شعرت أو تعرضت فيها لأشياء معينة خلال الأسبوعين الماضيين

		أبدا	نادرا	غالبا	غالبا جدا	دائما
(F8.1)26	كم من المرات كانت لديك مشاعر سلبية مثل المزاج السئ، اليأس، القلق، الاكتئاب؟	1	2	3	4	5

هل قام أحدهم بمساعدتك لتعبئة هذه الاستمارة؟ (رجاءً قم بوضع دائرة: نعم أو لا)	نعم	لا

كم استغرق من الوقت لتعبئة هذه الاستمارة؟ .....

شكرا لك

Appendix (3)

Exploring the Quality of Life in Spinal Cord Injury Patients and Challenges, in Tertiary Care Hospital in Saudi Arabia

Case Report Form

Date: SN: IRB number:
Duration since injury:
Age:

Sociodemographic Data

Patient Name: Hospital Number

Gender: Male ☐ Female ☐ Number of Admissions:

Duration between injury and 1st rehab program:

Marital Status:	Region:	Source of income:	Education
☐ Single	☐ Central	☐ Working	☐ Illiterate
☐ Married	☐ Eastern	☐ Retired	☐ Student
☐ Divorced	☐ Western	☐ Supported by family.	☐ Primary Level
☐ Widow	☐ Northern	☐ Social Affairs	☐ Postgraduate
	☐ Southern		

Causes of Spinal cord injury

☐ **Traumatic SCI**

- ☐ Motor vehicle accidents
- ☐ Falls
- ☐ Sports-related accidents
- ☐ Violence
- ☐ Other remaining causes of injury

Grade of SCI according to the American Spinal Injury Association (ASIA) grading scale

☐ Grade A	Complete spinal cord injury with no sensory or motor function preserved
☐ Grade B	A sensory incomplete injury with complete motor function loss
☐ Grade C	A motor incomplete injury, where there is some movement, but less than half the muscle group are anti-gravity (can lift up against the force of gravity with a full range of motion)
☐ Grade D	A motor incomplete injury with more than half of the muscle groups are anti-gravity
☐ Grade E	Normal

Level of Spinal cord injury

☐ Quadriplegia ☐ Paraplegia

Post SCI complications

☐ Spasticity	☐ Neurogenic Bowel	☐ Cardiovascular complication
☐ Neurogenic Bladder	☐ Osteoporosis	☐ Respiratory complication
☐ Heterotopic ossification	☐ Pressure ulcer	☐ Autonomic dysreflexia
☐ Depression	☐ Anxiety	

Exploring the Quality of Life in Spinal Cord Injury Patients and Challenges, in Tertiary Care Hospital in Saudi Arabia

Functional Independence Measure (FIM)

Description	
Self-care Eating	7/
Self-care Grooming	7/
Self-care Bathing	7/
Self-care Dressing upper	7/
Self-care Dressing lower	7/
Self-care Toileting	7/
Bladder sphincter control	7/
Bowel sphincter control	7/
Transfer bed-wheelchair	7/
Transfer Toilet	7/
Transfer tub showed	7/
Locomotion -Walk	7/
Locomotion Wheelchair	7/
Locomotion Stairs	7/
Total:	

Form Filed by:			
Name:		Signature:	Date:

مدينة سلطان بن عبد العزيز للخدمات الإنسانية
SULTAN BIN ABDULAZIZ HUMANITARIAN CITY
لجنة أخلاقيات البحوث الطبية
Institutional Review Board (IRB)