Quality of life in males with spinal cord injury in Saudi Arabia

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ABSTRACT

Objective: To assess the interests and post-hospitalization of quality of life (QOL) and career of patients with spinal cord injury (SCI).

Methods: This study took a period that extended for 20 years (1982-2003). Fifty-seven male patients in the Riyadh, Armed Forces Hospital and Al-Kharj Hospital Program (RKH), Kingdom of Saudi Arabia (KSA) with SCI responded to a questionnaire, which was distributed manually to 120 contributors. The questionnaire items include health status, occupation and educational level.

Results: The majority of the SCI patients belonged to the age group of 21-30 years (40.4%) and 31-40 years (33.3%). The injury levels were cervical (43.9%), thoracic (40.35%) and lumbar (23.5%). The urinary incontinence was managed by intermittent catheter (28%), indwelling catheter (17.5%), suprapubic cystostomy (15.8%), condom (12.3%) and continent (14.1%). Pressure sores were common and complication led urinary tract infections in 80.7% of patients. Spinal cord injury was a major cause and has a significant influence on patients' employment and career. Rehabilitation equipments and supplies support were provided by the RKH (45.6%), Ministry of Health (19.3%), self-purchasing (12.3%) and other source (22.8%). The important factors affecting the patient's QOL were financial status, employment, equipment supply and social isolation.

Conclusion: Spinal cord injury is practically affecting the young adult population of KSA. The patient's QOL is significantly affected and hampered by factors such as accessibility, financial status and employment. Effective measures for the management and social awareness may improve the patient's style and QOL.

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The problems faced by spinal cord injury (SCI) persons are numerous and usually difficult to manage, especially those concerning coping with the changes in their mode of life due to the injury. Lots of information and special education awaits them to resume a better quality of life (QOL).[1] Access to information at research and technology of SCI fields and sites offers these patients a positive attitude of enthusiasm, empowerment, self-reliance and independence in coping with their new situation.[1-5] Motor and sensory neuropathy, bladder and bowel dysfunction, following the accident are handicaps that render normal daily living uncertain.[1,6] Rendering QOL of SCI patients to adjustment and measurement had always been a difficult matter for researchers.[7] Some workers[7,8] referred to QOL as physical, social, psychological, and existential aspects of well-being that might be affected by disease, disability, and treatment. Many studies predicting the neurological recovery and functional outcome after rehabilitation were conducted for information and treatment.[6,9-14] As a result, increased survival rates of these patients were a direct consequence of such assessments of QOL

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and health management.[15-17] Factors that affect survival rates were summarized in the works of McColl et al[18] and others.[19,20]

Emphasis on major effects and consequences of collective factors such as clinical, psychological, social and relational, occupational, and environmental issues, lead to realization and foundation of rational parameters in assessing and dealing with SCI patients.[21] Some reports discussed the necessity of other parameters as being associated with injury duration, such as gender,[21,22] partner relationship,[23,24] parenthood,[25,26] mobility freedom,[21,22,27-29] employment,[21,22,30-33] level of social interaction and integration,[21,22] reintegration,[34-36] psychological implications,[37] sports,[38] and other hobbies.[39] Some workers made suggestions for the repair of SCI.[40] In fact, the outcomes of SCI have improved substantially over the past few decades,[41] due to augmented treatment and better methods and management of neurological complications.[15,41,42] Patient recovery was affected by severity of injury, and potentially this was rated as evidence of longer survival, reduced morbidity, and better use of functional ability.[43,44]

In this study, the questionnaire dealt with most of the previously mentioned fields, surveying a group of patients, some of them had a long period that elapsed after injury. Among the major points of interest that received great attention in the past works were the health status, occupational and educational level, national support, home support and autonomy, and general life practice difficulties.

Methods. This retrospective study was designed to accommodate many parameters that define the status of the SCI patients. The mortality rate was omitted from the duration of the survey that extended for 20 years (1982-2003). Only those who completed the questionnaire (57 patients) were included in this study. All patients were rehabilitated, or seen several times at the Riyadh, Armed Forces Hospital and Al-Kharj Hospital Program (RKH), Kingdom of Saudi Arabia (KSA)

The questionnaire was made up of 20 main questions that were categorized into 5 parts, with subdivisions (***Appendix 1**). An Excel program and GraphPad Instat were used in the evaluation of the data.

Results. The SCI population was made up of 57 male participants with an age range of 6-60 years. They were divided into 6 groups, with 10 years intervals. The lowest frequencies were seen in group 1 (0-10 years, 2 patients, 3.5%), group 2 (11-20 years, 2 patients, 3.5%), group 5 (41-50 years, 4 patients, 7%), group 6 (> 50 years, 4 patients, 7%), in addition to a group with unknown age (3 patients, 5.3%). The highest frequencies were seen in group 3 (21-30 years, 26 patients, 40.4%) and group 4 (31-40, 19 patients, 33.3%).

The level of injury was shown in **Table 1**, where 43.9% had cervical injury and the majority of these were represented by group 3 and group 4. Thoracic injury was represented by 40.4%, majoring in the same previously mentioned group ranges. The least frequency of injury level was the lumbar vertebrae region (3.5%), also seen in the same group range. Seven (12.3%) patients were with unidentified.

Patients were rehabilitated nationally and abroad (**Table 1**). In local rehabilitation, RKH assisted 64.9% of the patients and 19.3% were rehabilitated by other centers or non-RKH and 12.3% were sent abroad initially for rehabilitation. International rehabilitation was experienced in 23 persons as they seek second rehabilitation opinion at 5 countries; 8 were sent to United Kingdom, one was sent to the USA, 6 were sent to the Czech Republic, 7 were sent to Germany and one was sent to Egypt.

Concerning the health status, management of the urinary bladder neuropathy (**Table 1**) showed that 28.1% were using intermittent catheterization (IC), either carried out by themselves or by attendants. The next group 19.3% was having indwelling urethral catheter (IUC). Successive groups were employing suprapubic cystostomy (14%), continent 3.5% and condom 35.1%. In case of managing bowel incontinence, 75.4% were using suppositories, 12.3% could do manual evacuation, 8.8% were assisted by enema and 3.5% were continent.

Complications of the genitourinary system were shown in **Table 1**. More than three quarters of the patients (80.7%) have developed recurrent urinary tract infections, and almost all patients (94.7%) were on regular genitourinary checkup, whether carried out at RKH or at another health institute.

Approximately half of the patients (50.9%) had developed pressure sores during their life course and 21.1% were already contracting chronic diseases such as diabetes or hypertension or others (**Table 1**).

The level of education reflected the situation that none of the patients had any postgraduate degrees, 2 (3.5%) were uneducated before the injury, but one of them started his studies after it. Three were university graduates before the injury and were joined by 3 after. The diploma graduates were 2 before the injury, after that they were 4. Only one after the injury joined the high school graduates. The intermediate school graduates count dropped from 20 to 12 after the injury. Fifteen were elementary school graduates before the injury, but the count dropped to 11 after that (**Table 2**).

The occupation status was also assessed before and after injury. It was observed that before the

*The full text including Appendix 1 is available in PDF format on Saudi Medical Journal website (www.smj.org.sa)

Table 1 - The level of injury, rehabilitation location, bowel and urinogenital complications and development of chronic diseases.

Patient's medical status	**Age range (years)**								
	Group 1 0-10	**Group 2 11-20**	**Group 3 21-30**	**Group 4 31-40**	**Group 5 41-50**	**Group 6 > 50**	**Not available**	**Total n**	**(%)**
The level of injury									
Number	2	2	26	19	4	4	3	**57**	**(100)**
Vertebrae									
Cervical	1	2	16	4	3	1	2	**25**	**(43.9)**
Thoracic	0	0	13	6	1	2	1	**23**	**(40.4)**
Lumbar	0	0	0	2	0	0	-	**2**	**(3.5)**
Not available	1	0	3	2	0	1	-	**7**	**(12.2)**
Rehabilitation location (Initially in Saudi Arabia)									
Number	2	2	26	19	4	4	-	**57**	**(100)**
National									
Riyadh Al-Kharj Hospital	2	2	19	13	0	1	-	**37**	**(64.9)**
Non Riyadh Al-Kharj Hospital	0	0	4	5	0	2	-	**11**	**(19.3)**
Abroad	0	0	1	1	4	1	-	**7**	**(12.3)**
Not available	0	0	2	0	0	0	-	**2**	**(3.5)**
Rehabilitation location (Initially outside Saudi Arabia)									
Number	1	0	5	8	6	3	-	**23**	**(100)**
Country									
United Kingdom	0	0	0	1	4	3	-	**8**	**(34.8)**
United States of America	0	0	0	0	1	0	-	**1**	**(4.4)**
Czech	1	0	3	2	0	0	-	**6**	**(26)**
Germany	0	0	2	5	0	0	-	**7**	**(30.4)**
Egypt	0	0	0	0	1	0	-	**1**	**(4.4)**
Management of urinary bladder and bowel neuropathy									
Number	2	2	26	19	4	4	-	**57**	**(100)**
Urinary bladder									
Continent	-	-	1	1	-	-	-	**2**	**(3.5)**
Indwelling urethral catheter	-	1	8	2	-	-	-	**11**	**(19.3)**
Intermittent catheterization	1	-	6	6	1	2	-	**16**	**(28.1)**
Suprapubic-cystostomy	1	-	4	3	-	-	-	**8**	**(14)**
Condom	-	1	7	7	3	2	-	**20**	**(35.1)**
Bowel									
Suppository	2	2	17	13	3	3	3	**43**	**(75.4)**
Manual evacuation	-	-	2	4	-	1	-	**7**	**(12.3)**
Enema	-	-	3	1	1	-	-	**5**	**(8.8)**
Continent	-	-	1	1	-	-	-	**2**	**(3.5)**
Urinogenital complications and checkup									
Number	2	2	23	19	4	4	3	**57**	**(100)**
Urinary tract infection									
Yes	2	-	19	17	3	3	2	**46**	**(80.7)**
No	-	2	4	2	1	1	1	**11**	**(19.3)**
Not available	-	-	-	-	-	-	-		**(0.0)**
Checkup									
Riyadh Al-Kharj Hospital	-	-	3	8	1	1	-	**13**	**(22.8)**
Ministry of Health	2	2	18	11	3	2	3	**41**	**(71.9)**
Not available	-	-	2	-	-	1	-	**3**	**(5.3)**
Development of pressure sores and chronic diseases									
Number	2	2	23	19	4	4	3	**57**	**(100)**
Sores									
Sacrum	1	1	6	2	2	1	1	**14**	**(24.6)**
Trochanter	1	1	1	1	2	-	-	**6**	**(10.5)**
Ischium	-	-	5	1	-	-	1	**7**	**(12.3)**
Leg	-	-	-	1	-	-	1	**2**	**(3.5)**
Not available	-	-	11	14	-	3	-	**28**	**(49.1)**
Chronic diseases									
Yes	-	-	8	2	1	1	-	**12**	**(21.1)**
No	-	1	12	15	1	2	2	**35**	**(61.4)**
Not available	-	1	3	2	2	1	1	**10**	**(17.5)**

Table 2 - The educational level, type of occupation, marital and children, before and after injury.

Patient's demography	Before injury n	(%)	After injury n	(%)
Educational level				
Uneducated	2	(3.5)	1	(1.7)
Elementary	15	(26.3)	11	(19.3)
Intermediate	20	(35.1)	12	(21.1)
High School	11	(19.3)	12	(21.1)
University	3	(5.3)	6	(10.5)
Diploma	2	(3.5)	4	(7)
Not Available	4	(7)	11	(19.3)
Type of occupation				
Military	27	(47.4)	0	(0)
Civilian	7	(12.3)	16	(28)
Student	15	(26.3)	3	(5.3)
Unemployed	8	(14)	33	(57.9)
Not Available	0	-	5	(8.8)
Marital status and children				
Single/Remained single	37	(64.9)	26	(45.6)
Married/Remained married	16	(28.1)	7	(12.3)
Got married after	-		11	(19.6)
Married with children	14	(24.6)	8	(14)
Divorced	0		9	(15.8)*
Not Available	4	(7)	4	(7)

*-% of patients divorced after injury

injury, 8 patients were unemployed. After the injury, this number rose to 33. Those who had military jobs were 27 before the injury but after it, there were none. On the other hand, the number of civilians increased from 7-16 after the injury. Only 3 out of 15 resumed studying as students (**Table 2**).

The marital status, before and after the injury was shown in **Table 2**. Singles were 37 before the injury but after the injury, this number was reduced to 26. There were 14 married patients with children out of 16. After the injury, 9 of the married patients got divorced.

The national support was summarized in **Table 3**. Equipment and supplies (other than wheelchairs) were provided to patients, where 45.6% of this service was carried out by RKH, 19.3% by Ministry of Health (MOH), 12.3% by self-purchase and 22.8% were from unknown sources, possibly including Ministry of Labor (MOL) and Social Affair or charitable organization. Wheelchairs were obtained from RKH by 40.4% of the patients, from the MOL by 26.3% of the patients, 19.3% were bought from their own resources and 10.5% were provided by charity.

Concerning home support and autonomy it appeared that 24.5% of the patients were assisted and cared for by their relatives. Eleven (19.3%) were helped both by relatives and maids, 8.8% were cared for by maids and only 3.5% could take

Table 3 - Providers of supplies, wheelchairs, caring support and accommodation.

Patient's source of support	Age range (years) 0-10	11-20	21-30	31-40	41-50	> 50	Not available	Total	(%)
Equipment, supplies providers									
Number	2	2	23	19	4	4	3	**57**	(100)
Ministry of Health	-	-	7	1	2	1	-	**11**	(19.3)
Riyadh Al-Kharj Hospital	-	-	13	13	-	-	-	**26**	(45.6)
Purchase order	-	-	3	4	-	-	-	**7**	(12.3)
Not available	2	2	-	1	2	3	3	**13**	(22.8)
Wheelchairs									
Purchase	1	-	4	4	2	-	-	**11**	(19.3)
Ministry of Labor	-	-	7	7	-	-	1	**15**	(26.3)
Riyadh Al-Kharj Hospital	-	1	10	7	1	2	2	**23**	(40.4)
Charity	1	1	2	1	-	1	-	**6**	(10.5)
Not available	-	-	-	-	1	1	-	**2**	(3.5)
Caring support									
Number	2	2	23	19	4	4	3	**57**	(100)
Maid	-	-	1	3	-	-	1	**5**	(8.8)
Relative	2	-	7	4	-	-	1	**14**	(24.5)
M+R	-	1	2	3	3	2	-	**11**	(19.3)
Self Care	-	-	-	-	1	-	1	**2**	(3.5)
Not available	-	1	13	9	-	2	-	**25**	(43.9)
Housing									
Changed house	-	1	-	8	4	4	1	**2**	(20)
Modified house	-	2	3	9	-	2	1	**17**	(29.8)
Same house	-	-	9	6	-	1	-	**16**	(28.1)
Hospital	-	-	3	-	-	-	-	**3**	(5.3)
Not available	1	-	-	-	-	-	-	**1**	(1.7)

care of themselves, whilst 43.9% did not specify their means of assistance. Twenty (35.1%) of the patients changed their living house following the injury, 29.8% modified the house, 28.1% lived in the same house and 5.3% were still in hospital (**Table 3**).

Smooth practicing of the patients' daily life is hampered by difficulties such as the financial status (43.9%) and employment (26.3%). Equipment supply were problems to 12.3%, social isolation 35.1% and access to domestic places 70.2% of the patients. Parking, facilities at religious places and dependency scored 21.1%, 8.8% and 10.5%. Problems of travel were admitted by 28.1% and understanding the nature of the injury in 8.8% of the patients (**Table 4**).

Discussion. Data analysis has emphasized that SCI patients experience an appreciable daily life problems. The group range with the highest frequency of injury was the middle-aged, which is usually endowed by high energy potential, sports and driving activity, and hence vulnerability to accidents. A correlation was found between driving, age and the level of injury.[45] Members at this age range should be productive in fields of education, training and gainful work. Sadly these groups are the most enduring and suffering from this crippling injury. However, studies that correlate occupation with factors such as age and education have postulated predictors for employment in favor of this age group.[21,30-32,46] Other younger or older age groups seem to be less affected by this problem, but this does not merit an employment advantage.

Table 4 - Difficulties facing patients in practicing their life.

Difficulties	**Patients**	
	n	**(%)**
Financial	25	(43.9)
Employment	15	(26.3)
Equipment	7	(12.3)
Social isolation	20	(35.1)
Access	40	(70.2)
Parking	12	(21.1)
Access to religious places	5	(8.8)
Dependency	6	(10.5)
Travel	16	(28.1)
Understanding of the Injury	5	(8.8)

The level of injury showed that the cervical vertebrae region was the most sensitive one, with the highest number of casualties, compared to the thoracic and lumbar regions. It is of interest to notice that the most active middle-aged group was having the highest rate of cervical injury casualties, as it is the case all over the world.

The health status was reviewed initially through urinary bladder and bowels continence. Aids for management of urinary bladder were predominantly intermittent IC, this is usually selected due to the patient's preference. Indwelling urethral catheter is being more and more acceptable in the Islamic countries, but the problem remains the possibility of urine contact to the clothes, which is a polluting burden in performing prayers. The patients are usually applying urosheaths in between. Other applications such as the supra pubic cystostomy (SPC), urosheath /condom (Cd) were of minor inconvenience, as they only require doing atrial voiding and success depends on the type of the bladder (contractile or acontractile) used. Bowel evacuation was mostly assisted by suppositories in case of more than three quarters of the patients. Manual evacuation and enemas were of lesser degree of practice. Patients who were practicing normal bowel evacuation were a minority. Complications of the genitourinary system were additional factors and parameter in health status evaluation. Almost all of the patients were on regular genitourinary checkup and more than three quarters had developed UTI. It was reported that the most frequent reasons for readmissions were the urinary tract complications.[47] Pressure sores were another inconvenient situation of half of the patients and contracting chronic diseases was observed in an appreciable group. It is to be emphasized here that urinary and skin complications are the 2 main reasons for hospital readmissions in people with chronic SCI.[47]

Spinal cord injury is a real dilemma in the third world countries and could be a crippling medical problem, this is noticed from the very few patients who could keep and practice their previous jobs. It was found from previous works that approximately one thirds of the patients could be employed after injury.[31] In another report, a drop in employment to less than half of rehabilitated patients was documented.[34] In this recent study, more than half of the patients were unemployed, and another quarter had quitted their military jobs to civilian life or were civilians before. This situation is in line with other findings.[33] The level of education reflected fragmented groups with low percentage of degree award. It is of importance to note that none of the patients had any postgraduate degrees and university graduates were the least found.

National support of equipment and supplies was mostly carried out by RKH program and MOH.

Al-Kharj Hospital Program, or MOL provided the majority of wheelchairs and commode shower chairs, while some of the patients got them either through their own resources or from charity. Al-Kharj Hospital Program represented the initial rehabilitation of more than two thirds of the patients, while a few got international assistance and left for United Kingdom, Germany and some other countries. Even following the rehabilitation abroad, most of them approached RKH for continuum of care and follow up.

Relatives took the burden of caring for a quarter of SCI patients, and this could point to the degree of social bond and familial ties. Previous works reflected data, which showed that occupation variables were not an indication for economic independence.[34] Family and pension were the main financial support for patients.[21,34] A majority of the patients did not really specify the means of assistance they got, whilst a few got maids' assistance or took care of themselves. More than a third of the patients have changed their houses and fewer groups either modified their houses to suit the new situation or were still in hospital.

The majority of patients were suffering from shortage in the financial status. This difficulty was usually enhanced by the second problem, employment. Various circumstances related to employment, relationships, autonomy and mobility were vital for patients' QOL.[21,22,48-51] Being unable to move freely without external help, inability to drive, park or reach domestic places, religious and critical work places, were a combination of difficulties that represented a challenge for all SCI patients. The time factor ensuing after injury is an appreciable remedy for the psychological status and a modulator of QOL.[21,51,52] Other problems like the social look and understanding of the surrounding environments were of vital importance for self-confidence and QOL level.

We recommend further studies on larger groups of patients especially in females with SCI from Saudi Arabia. Deeper exploration of the difficulties encountered by patients with spinal cord injury and planning for future preventive measures, acute care, rehabilitation and follow up could prove to be vital in improving their QOL.

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