

# The effect of family-centered education on the quality of life of adolescents with spinal cord injuries

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## ABSTRACT

**Background and Purpose:** Spinal injury is a destructive complication creating huge changes in the teen health and lifestyle, depending on its extent and severity. Although most of the complications of this disease are treatable, they impose huge costs on the healthcare system, the patient, and his family. The present study was conducted to investigate the effect of family-centered education on the quality of life and self-esteem of adolescents with spinal cord injuries. **Method:** The present study is a quasi-experimental study. Adolescents (108 old) with spinal cord injuries entered the present study through stratified sampling with appropriate allocation. The participants were compared in two groups of experimental and control. The data was collected using demographic information questionnaire as well as Ferrans and Powers' quality of life index in spinal cord injury. Four weeks after the intervention, the research questionnaires were completed once more by the adolescents of both groups. Data analysis was conducted by using T-square test, independent *t*-test, Fisher's exact test, and analysis of variance. **Finding:** According to results, quality of life mean score of adolescents with spinal cord injuries was  $23.05 \pm 122.65$  before the intervention. It became  $22.64 \pm 148.15$  after the intervention. With respect to importance, quality of life mean score of these adolescents changed from  $20.83 \pm 164.07$  to  $21.62 \pm 174.99$ . **Conclusion:** Given the effect of family-centered education on the quality of life in adolescents with spinal cord injuries, it seems essential to create necessary grounds for training families having adolescents with spinal cord injuries by nurses to improve their quality of life as well as conducting researches on their problems.

**Keywords:** Adolescents, family-centered education, parents, quality of life, spinal cord injuries

## Introduction

Spinal cord injury is one of the most important factors of sensory, motor, urinary tract disorders, or a combination of them. The strikes on the vertebral column are likely to injure spinal cord, spinal nerves root, or both;<sup>[1]</sup> it has been estimated that all over the world, there are around 3 million people who suffer from spinal cord injuries.<sup>[2]</sup> The average age of spinal cord injuries is 15 years, and 72% of these individuals are males.<sup>[3]</sup> In Eastern areas such as Iran, the prevalence of spinal cord injuries has reached 72.4 cases in a million.<sup>[4]</sup> According to the reports

released by Spinal Cord Injury Association of Tehran, there are 70,000 individuals with spinal cord injuries in Tehran. In 56% of these cases, the average age is 15 years old.<sup>[5]</sup>

Spinal injury is a destructive complication creating huge changes in the teen health and lifestyle, depending on its extent and severity. This complication is included as one of the most difficult physical disabilities. The sensory and motor symptoms of spinal cord injury bring about disability in doing the simplest daily activities, and the child will be dependent or face various disorders in conducting all activities of his life.<sup>[6]</sup> Functional failure of multiple systems will increase the likelihood of secondary complications associated with these failures. These complications include pressure ulcers (sores), urinary

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tract infections, pneumonia, deep vein thrombosis, intestinal problems, chronic pains, and depression disorder.<sup>[7]</sup> Involving with issues such as reduced mineral density of scoliosis bone and lung-limiting diseases have resulted in a lower life expectancy among under-16 individuals suffering from spinal cord injuries in comparison to normal individuals and individuals with spinal cord injuries that are 16 years old and higher.<sup>[8]</sup> Although most of the complications of this disease are treatable, they impose huge costs on the healthcare system, the patient, and his family.<sup>[9]</sup> With these secondary complications, the individuals suffering from spinal cord injuries are more involved with the healthcare system than the normal population. They are hospitalized more frequently as well. In a study conducted by Ryden *et al.* (2004), they found out that in comparison to control group, individuals suffering from spinal cord injuries need home care services more 30 hours a week. Moreover, they spend 3.3 days more in the hospital and they are hospitalized 2.6 times more.<sup>[10]</sup>

Numerous studies have been conducted in countries such as the United States, England, Australia, the Netherlands, and Turkey on the hospitalization of individuals after the spinal cord injuries. These studies indicate that one-third of the individuals suffering from spinal cord injuries are hospitalized every year. Thus, the importance of acquiring information on the spinal cord injuries by the healthcare team (especially nurses) is well understood.<sup>[11]</sup> In addition to their referring to healthcare-therapy centers, taking care of these patients is also conducted at homes, and the main caregivers are highly responsible for these individuals. Individuals taking care of patients have a lower quality of life with respect to physical performance, general health, and liveliness.<sup>[12]</sup> Parents are commonly involved with feelings such as depression and anxiety. Parents that have children with disabilities are more likely to suffer from depression than other parents. These parents are likely to take days off from work to take care of their children and they may face financial, physical, and emotional problems. Their sibling might also experience emotional reactions and they might feel upset for having a sibling distinct from others. The high prevalence of disabilities and their effects on both the individual and his family call for special attention. The nurses play an important role in studying and providing supportive and educational interventions, and they can reduce the complications of this disability for both the person and his family.<sup>[13]</sup> In a study conducted by Lee *et al.*, it was indicated that if the family members of the spinal cord injury patients have information on this disease, this will help them reduce the mental care burden. Since individuals suffering from spinal cord injuries are usually bedridden, the caregiver (a family member) will help the patients in doing activities such as eating, taking a shower, going to WC, and other daily activities and even therapeutic activities such as rehabilitation.<sup>[14]</sup> Empowering adolescents suffering from spinal cord injuries as well as his family through education can help them control the situation better. Most of the specialists maintain that empowering is a social, dynamic, and interactive procedure improving the quality of life in individuals suffering from different kinds of disabilities. Moreover, empowering the individuals will help them

respond better to the treatment process, reduce the care costs, and acquiring a positive attitude toward the disease. Over the recent years, the concept of “patient and family” has found a special place in medical and nursing studies and it can be included as one of the requirements of nursing.<sup>[15]</sup> Healthcare workers need to communicate with parents and adolescents in order to be aware of parents’ experiences and needs as well as the quality of life of adolescents suffering from spinal cord injuries. One of the efficient strategies is family-centered education that is known as a method to take care of adolescents and their families through providing health services so that we can make sure that caring is planned not only for the adolescent (the patient) but also for his family and all family members are recognized as recipients of care. Communicating with the family as a whole can be beneficial for both the family and healthcare staff.<sup>[16]</sup> The present study was conducted to investigate the effect of family-centered education on the quality of life in adolescents with spinal cord injuries.

## Method

In the present quasi-experimental study conducted from January 2016 to April 2016, 110 adolescents suffering from spinal cord injuries in exceptional schools (physically disabled) were studied. After acquiring the permit from the Ethics Committee of Iran University of Medical Sciences (with the registration code of IR.IUMS.REC.1395.9211196228) and obtaining informed consent from the adolescents suffering from spinal cord injuries, the stratified sampling was conducted with appropriate allocation. The inclusion criteria of the present study are being able to read and write, having a family member as the main caregiver, passing at least 6 months from the spinal cord injury, being 12–20 years old, full or partial spinal cord injury of C6 to T12, and being able to sign the letter of consent.

Having been explained the purpose and the method of project, the adolescents were invited to participate in the study, and if they agreed, they filled out the letter of consent knowingly and willfully. The research tool includes demographic questionnaire as well as Ferrans and Powers’ quality of life index. This questionnaire was written in 1984 at the University of Illinois at Chicago to measure the quality of life in individuals suffering from spinal cord injuries. This tool includes two parts: satisfaction and importance. Each part has four domains including health and functioning, psychological/spiritual, social and economic, and family.

The first part includes 34 questions measuring the individual’s satisfaction in different aspects of life. The questions of this part are scaled on a 6-point Likert Scale from 1 (very dissatisfied) to 6 (very satisfied).

The second part includes the same 34 questions. However, this time, the importance of those items is measured. The questions of this part are scaled on a 6-point Likert Scale from 1 (very unimportant) to 6 (very important).

Importance ratings are used for weight responses of satisfaction, so that scores reflect satisfaction with the aspects of life that are valued by the participant in the study. The quality of life index crops five scores: quality of life overall and in four domains (health and functioning, psychological/spiritual domain, social and economic domain, and family).

The scores of this questionnaire are measured both as the total quality of life and the quality of the four domains separately. The scores range from 0–30. The higher the score is, the better is the quality of life. Self-execution takes about 10 min and does not need any special education. The total scores from the quality of life are classified into three groups (desirable, fairly desirable, and undesirable). Scores 0–9 were considered as undesirable quality of life, 10–19 were considered as fairly undesirable quality of life, and 20–30 were considered as desirable quality of life.

This questionnaire has been written for patients suffering from different diseases (including different kinds of cancers, kidney diseases, diabetes, etc.). Various studies have confirmed its internal consistency, reliability in retest, content validity, and construct validity.<sup>[17–20]</sup> In Iran, Rafiei *et al.* have evaluated the validity and reliability of the Persian version of this questionnaire.<sup>[21]</sup>

The content of this educational program was provided to five specialists working at Spinal Cord Injury Association of Tehran. They were then asked to comment on the program.

Control group first completed the questionnaires and then they were completed by the experimental group. For the experimental group, a training course on issues related to spinal cord injury was conducted in four 2-hour sessions 4 weeks in a row (one session a week).

The training was conducted as a group discussion (5–8 people). All the sessions were held in the schools with the presence of main family caregiver. The first sessions started with being familiar with families and their problems. The following sessions started with reviewing the materials of the previous sessions. Then, new issues were discussed. It was attempted to involve the individuals. At the end, the session finished by concluding the discussion, delivering pamphlets and the list of issues discussed in that session, and requesting the adolescents to apply the issues discussed in that session. The adolescents were encouraged to execute the educational program for 4 weeks. The training sessions of the experimental group focused on the following issues: Familiarity with the problems of the circulatory system, respiratory system, digestive system, and bladder in spinal cord injuries and methods to deal with these problems; familiarity with spasms, musculoskeletal system pains, osteoporosis, skin care, diet groups, sports exercises; necessary adaptations in the living environment; trimness; and ways to increase happiness, humor, and self-confidence.

Although only one of the parents attended the session, the other parent was encouraged to participate as well. In the present study,

the adolescents and their parents were ascertained that they had the right to enter the study freely and withdraw from study at any stage they wish. They were also assured that the data collected would remain confidential. To observe the ethical issues, after data collection, the educational pamphlets were also provided to control group participants. Data analysis was conducted by using T-square test, independent *t*-test, Chi-square test, Fisher's exact test, and analysis of variance in SPSS 21.

## Findings

The findings of the present study indicated that almost half of the 110 adolescents participating in the present study were aged 15–16 years. In the experimental group, the mean age was  $1.42 \pm 15.42$ , and in the control group, it was  $1.47 \pm 15.57$ . From among all participants of both control and experimental group, 70.4% were male. With respect to the duration of suffering from the disease, 75% of the experimental group and 63.2% of the control group had suffered from the spinal cord injuries for more than 15 years. Other demographic characteristics are given in Table 1.

The mean scores of quality of life aspects and total quality of life in adolescents suffering from spinal cord injuries in two groups were compared (experimental and control), it was indicated (by using independent T-test) that there was no significant statistical difference between the two groups before the intervention ( $P > 0.05$ ) [Table 2].

Moreover, the mean scores of quality of life aspects in the experimental group were compared both before and after the intervention by using T-square test, it was indicated that there was significant improvement in domains of health and functioning, family, social–economic, psychological–spiritual, and the total quality of life ( $P > 0.05$ ) [Table 3].

## Discussion and Conclusion

In the present study, the quality of life has improved with respect to both activities and the importance in the domain of health and functioning in the experimental group after the family-centered education in adolescents suffering from spinal cord injuries. Moreover, with respect to psychological–spiritual and social–economic domain, a significant improvement is observed after family-centered education. The findings of the present study indicate significant differences before and after the intervention.

In the study of Metoo *et al.* conducted on the effect of parental education on the quality of life in children suffering from diabetes, it was indicated that parental education not only affects the child's quality of life and tension reduction, but also it will improve the care given by parents through communicating with the child, promoting effective care, and dealing more efficiently with disease-related problems. As a result, the child will have a better quality of life. Thus, the present study clarifies the necessity of parental education about the effects of chronic diseases

**Table 1: The demographic characteristics of adolescents suffering from spinal cord injuries in experimental and control group at exceptional schools (physically disabled), Tehran, 2016**

Characteristics		Experimental group		Control group	
Adolescents Gender	Female	16	29.6	16	29.6
	Male	38	70.4	38	70.4
Age	Total population	54	100	54	100
	12-14 years	9	16.7	11	20.4
	15-16 years	37	68.5	27	50
	17-18 years	8	14.8	16	29.6
Educational level	Total	54	100	54	100
	Middle school	32	59.3	19	35.2
	High school	22	40.7	35	64.8
Duration of suffering from the disease	Total	54	100	54	100
	10 years and less	10	12.5	12	18.4
	11-14 years	10	12.5	12	18.4
	15 years and more	34	75	30	63.2
Injury level	Total	54	100	54	100
	Full disability of hands	1	1.9	1	1.9

**Table 2: The comparison of quality of life aspects with respect to satisfaction in adolescents suffering from spinal cord injuries both before and after the intervention in experimental and control groups**

Subscales	Quality of life	Evaluation stage	Experimental group		Control group		P
			Mean	Standard deviation	Mean	Standard deviation	
Health and functioning		Before the intervention	51.45	11.21	51.78	12.99	0.876
		After the intervention	64.68	9.82	61.24	9.64	0.069
		P		0.001		0.001	-
Family		Before the intervention	16.01	3.64	16.07	3.72	0.938
		After the intervention	18.57	3.15	17.55	2.87	0.082
		P		0.001		0.030	-
Social-economic		Before the intervention	26.68	7.12	+27.06	7.76	0.795
		After the intervention	33.24	6.86	30.33	7.83	0.043
		P		0.001		0.021	-
Psychological-spiritual		Before the intervention	28.54	5.68	28.11	6.6	0.718
		After the intervention	31.66	5.95	29.96	5.33	0.121
		P		0.008		0.134	-
Total quality of life	Total quality of life	Before the intervention	122.65	23.05	123.02	26.2	0.937
		After the intervention	148.15	22.64	139.09	22.43	0.039
		P		0.001		0.001	-

affecting the child and his family's quality of life and helps them learn appropriate methods of dealing with the complications of such diseases.<sup>[22]</sup>

In the clinical trial conducted by Vahedian Azimi and Teymouri to study the effect of family-centered education on the quality of life in adolescents suffering from asthma, they concluded that applying family-centered education and empowering families by group discussion, scientific shows, and practical participation would promote the quality of life in adolescents suffering from asthma.<sup>[23]</sup>

Another clinical trial conducted by Clary attempted to study the empowerment of patient and his family. He concluded that providing a series of cares aiming at empowerment could improve the patients' quality of life. The findings indicated that by providing collective education for patients suffering from

chronic diseases and their families through inviting them to direct participation, the experimental group's quality of life changes were significantly more than those of the control group. In the present study, the method of conducting the education was through group discussion, shows, and practical participation. Thus, the method is quite different from that of Clary, he used only collective education in his study, and the information was merely provided collectively to the individuals suffering from chronic diseases. However, in the present study, in addition to collective education, show and practical participation were used as well. Moreover, the family's direct participation was intended in the education program. Furthermore, Clary evaluated the quality of life and self-efficacy right after the intervention. However, the studies indicate that there must be a gap between the intervention and the evaluation of its effect. In the present study, the researcher evaluated the components of the study 4 weeks after the intervention.<sup>[24]</sup>

**Table 3: The comparison of quality of life aspects with respect to importance in adolescents suffering from spinal cord injuries both before and after the intervention in experimental and control groups**

Subscales	Quality of life	Evaluation stage	Experimental group		Control group		P
			Mean	Standard deviation	Mean	Standard deviation	
Health and functioning		Before the intervention	73.58	9.92	69.61	11.21	0.054
		After the intervention	78.04	9.94	76.38	8.3	0.335
		P		0.033		0.001	-
Family		Before the intervention	18.88	3.34	17.48	3.91	0.047
		After the intervention	19.79	3.09	19.93	2.93	0.796
		P		0.190		0.001	-
Social-economic		Before the intervention	35.81	6.11	33.04	6.21	0.022
		After the intervention	38.76	6.15	36.79	6.76	0.183
		P		0.018		0.001	-
Psychological-spiritual		Before the intervention	35.77	4.99	33.32	6.33	0.028
		After the intervention	38.33	4.74	36.38	5.88	0.086
		P		0.009		0.009	-
Total quality of life	Total quality of life	Before the intervention	164.07	20.83	153.61	23.82	0.017
		After the intervention	174.99	21.62	169.52	20.81	0.197
		P		0.015		0.001	-

Aggarwal *et al.* in a study titled “family support and its relationship with following the therapeutic program in patients suffering from chronic diseases” have concluded that patients who were deprived of appropriate family participation tended to have a significant reduced adherence to the therapeutic plan. Thus, given the importance of the family participation and their support in chronic diseases, the present study was conducted with the presence of the main family member caregiver to promote the quality of life in individuals suffering from spinal cord injuries. Adolescents have different mental and psychological characteristics as well as different motivations for learning the materials. This was one of the limitations of the present study that was likely to affect the findings and it was out of the researcher’s control.<sup>[25]</sup>

According to the evaluation made by the research team, group discussion was an effective educational method through which the adolescents could become familiar with each other’s experiences and apply them. Group discussion has been approved as an effective method in the studies conducted by other researchers as well.<sup>[26]</sup> In the present, group discussion was used for adolescent education, and according to the researcher, this method not only help the participants transfer the intended material but also will provide them with an opportunity to share experiences and reduce stress.

Given what is discussed so far, it is of great importance to consider educational indices for these individuals and their families to promote the health status and quality of life in adolescents suffering from spinal cord injuries. In doing so, the health managers need to pay due attention for providing appropriate family-centered educational programs for these adolescents, so that they can enjoy a normal life like their peers.

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### Conflicts of interest

There are no conflicts of interest.

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