

What are the people's attitudes toward spinal cord injury victims (from common to elite)

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ABSTRACT

Background: One of the acutely fatal and prevalent crises in all societies is acute spinal cord injury. Individuals with a spinal cord injury are prone to numerous challenges, perturbation, and acute mental distresses. One of their concerns, often expressed generally and in the form of a complaint, is how people deal with them. The present study aims to analyze the experiences and interactions of the disabled with the society and to achieve a deep clarification of their internal attitudes and realistic approaches in various social classes (from common people to elite).

Materials and Methods: The present study is a part of a greater research with a classical grounded theory approach conducted on 12 successful and nationally and internationally popular disabled people. Sampling was firstly purposive and then continued with snowball sampling. The data were collected by open deep interviews which were recorded and transcribed verbatim. The obtained data were analyzed by Graneheim content analysis method.

Results: The findings obtained through analysis of the interviews yielded the theme of a socially suppressing attitude which contained four subthemes of compassionate attitude, disability attitude, inhuman attitude, and atonement attitude.

Conclusions: The results showed that both groups of common, and educated and elite classes of Iranian society have identically suppressing attitudes and interactions toward spinal cord injury victims. It seems that traditional attitudes yet preponderate academic and scientific knowledge in Iranian society. This gap needs notable attention of all the Iranians, especially policy makers and social personalities.

Key words: Content analysis, disabled, Iran, society

INTRODUCTION

One of the prevalent and life-threatening crises in all societies is spinal cord injuries (SCIs).^[1] Statistics report annual average of 20-50 people out of 1,000,000 suffering from SCI in the world.^[2] Annually 40-50 out of 1,000,000 are affected in Iran, which shows that there are over 30,000 SCI patients yearly in Iran (84% due to impacts and accidents and 16% due to spinal cord diseases).

In other words, every half an hour, one SCI occurs in Iran, resulting from falling off the heights, accidents, climbing, or playing various sports. Most of these injuries are caused to young healthy adults, so the injury is the most prevalent among 15-37 year old men.^[1] SCI is conventionally divided into two groups of acute (often including traumatic injuries) and chronic (leading to a progressive disease) injuries.^[3] The

main causes for traumatic injuries include accidents, falling off the heights, fights, and sports. Over 50% of traumatic injuries are accompanied with complete loss of movement down the injury site and are commonly associated with bowel and bladder degeneration and pressure bed sore. Nontraumatic injuries include the injuries resulting from spinal cord infarctions, tumors, and progressive injuries such as multiple sclerosis, etc. Both groups of acute and chronic injuries cause one of the most serious problems involving the central nervous system (CNS). Despite psychomotor and sensory problems which lead to physical limitation for the individuals, all organs get All organs are outside the control of the brain, and based on the location of injury site, the patients experience numerous and complicated syndromes.^[4,5] Marcel and Noreen believe that these individuals are predisposed to acute mental distresses due to their rapid disabling changes,^[6,7] and often experience anxiety, depression, and fear,^[8] post traumatic growth^[9] and even suicidal thoughts. They are also more prone to loneliness and social isolation, feeling different from peers, lower education and lower employment chance, and more limited social interactions, compared to healthy individuals of the society.^[10-12] Therefore, life conditions, from the physical and mental aspects, seem to be very complicated and tense not only for these patients but also for their families and friends after the event.^[5]

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In addition to the above-mentioned personal and familial problems, SCI patients seem to face numerous destructive obstacles such as poor social culture to deal with them, poor urban planning and architecture for the disabled, and many other problems at the social level. These factors, in addition to causing mental distress for them, lead to failure in their primary struggles to achieve self-care and lead an independent life.^[13-16] Negarandeh *et al.* showed that one of the main obstacles in SCI patients' adaptation with their new condition after the event is lack of social acceptance and support.^[17]

Based on symbolic interaction theory, the meaning the people give to life events is one of the most important elements in understanding the reason for their behaviors and interactions with each other. In fact, individuals either construct or reconstruct the meaning of the events through their constant interactions with others, and select their future functions.

Based on this, nurses are among the few health and treatment groups who remain by the disabled and work with them from the time of event to the end of rehabilitation program. Therefore, their deep and precise recognition of individuals' attitudes in the society toward this group of clients can highly affect care and rehabilitation programs and detection of the roots of their probable problems. In addition, nurses themselves as the members of the society, and more importantly, as the agents directing patients' attitudes will be more sensitive to and aware of these patients' daily attitudes and functions. On the other hand, it should be noted that facing non-effective and non-informed attitudes and interactions can destructively influence the disabled peoples' self-perception and lower their interest to efficiently and purposefully attend in the society, and consequently, worsen their isolation in a vicious cycle.^[15,18] In this direction, one of the concerns of the authorities in Iranian society, which is always expressed as a complaint and has been less explored scientifically and academically, is the manner of interaction with the disabled. So, the present study aimed to analyze the interactions between the disabled and the social authorities in order to deeply understand the individuals' internal attitudes and realistic approaches in different social levels (from common to elite) toward the disabled through a qualitative method. The researchers hope the obtained results may make us (in every social class) take enough care at least not to make the problems of these patients more complicated.

MATERIALS AND METHODS

The present study is a part of a greater research with classical grounded theory approach. This section of data was analyzed by Graneheim content analysis method. The final outcomes of this approach are obtained by analysis of qualitative data,

which yield concepts and descriptive categories of the studied phenomena.^[19,20] The participants comprised 12 successful and nationally and internationally popular disabled people from four provinces of Tehran, Isfahan, Kerman, and East Azerbaijan. The term "successful and popular disabled people" refers to the individuals with acute SCI who had gained brilliant position in the domains of sports, education, business, art, technology, academics, etc., and acquired national and international ranks. Purposive sampling started after obtaining the approval of ethics committee of Ahvaz University of Medical Sciences and continued through snowball method in the subsequent stages. Firstly, the goal and method were explained to the participants. It was also emphasized that they could stop their participation in the study at any step due to any reason with no limitation.

Recording the interviews, and at times, filming the sessions were all conducted after getting a written consent from the participants. Main method of data collection was through personal deep and open interviews. If needed, field notes were used through researcher's attendance in the related workshop, sessions were performed, which were specified for the SCI disabled and involved recording the interactions of the disabled. It also included recording the explanations after the interviews (complement or explanation of the issues discussed in the interview) as well as reviewing the evidences (reviewing the reports of the corresponding films related to defending the disabled rights). The location and time of interviews were fixed after obtaining the agreement of the participants.

Mean length of the interviews was 70 min, and on average, two to three interviews were conducted with each participant. Interviews started with the general question, "please explain all about that happened in your life after you knew you were paralyzed," and continued with the subsequent questions, based on the answers to the first question. Sampling continued until data saturation.

All interviews were digitally recorded and transcribed word by word and were analyzed by Graneheim content analysis method of which the main steps are as follows:

1. Transcribing the interviews verbatim and reading through several times to obtain the sense of the whole
2. Dividing the text into meaningful units that were condensed
3. Abstracting the condensed meaningful units and labeling with codes
4. Sorting the codes into subcategories and categories, based on comparisons regarding their similarities and differences
5. Formulating themes as the expression of the latent content of the text^[21]

For rigor of data, in order to maximize credibility of the findings in this study, prolonged engagement with data and members' check were used. This was done by confirmation of the pages typed from open coding and clear diagrams from the subcategories and allocated categories by the participants at each stage. In addition, external check (academic members out of research team and university) and indications of the faculties were used several times. Maximum case the variance and external check in the form of revision of obtained codes and categories, as well as including all suggestions of semi-annual report sessions approved conformability of data in the present study. Informed consents and other ethical considerations have been done under supervision of Islamic Azad University of Iran.

RESULTS

Participants were 12 nationally and internationally successful and popular disabled people (7 women and 5 men). Their mean age was 34.3 years, with a mean length of 12 years after their SCI event. The injury sites ranged from C7 to T12.

[Table 1] presents demographic characteristics of the participants in detail.

The main finding obtained by analysis of the interviews in response to the main research question was a socially suppressing attitude toward the disabled from both common and elite classes of society in the first years after the event. This contained four subthemes of compassionate attitude, disability attitude, inhuman attitude, and atonement attitude.

Suppressing attitude

The main theme of participants' interaction experiences with common and elite members of society in the first years

after the event was a suppressing attitude. Some participants believed that in such challenging conditions, the victims need social attention, acceptance, and support of the society members. Meanwhile, facing inefficient attitudes, especially from the personalities of the society such as the highly educated ones, has had a very destructive effect on the SCI patients' attitude toward life and, consequently, their physical and mental rehabilitation. Most of the participants remembered the moments which drove them to the end of their life and attempt suicide under the negative effect of such attitudes. This theme included four subthemes as follows:

1. Compassionate attitude
2. Disability attitude
3. Inhuman attitude
4. Atonement attitude

Compassionate attitude

The disabled often needed the help of their family members and friends more than before in the first years after the event. They suffered from compassionate attitude of common, elite, and even educated people in the society, and this issue worsened their hard condition after the event.

For instance, participants 1, 2, 5, 7, 10, and 11 stated: "... When I was in line at the bus station to go to university, two middle-aged women were staring at me and with a special sense of compassion said, '...what a pity ... such a young girl! ¼ Poor girl ... God forbid for everybody ... what is she going to do now?'"

Most of the participants actually emphasized on the point that the disabled need bravery, determination, and hope to return to life, but not a compassionate attitude in the first years after the event.

Table 1: Participants' demographic characteristics

Participants' numbers	Sex	Age (years)	SCI site	Occupation	Marital status
1	Female	28	T10	MS students, head of public communications office	Married
2	Female	42	C7	Manager and founder of SCI Association	Single
3	Female	28	T10	Wheelchair champion	Married
4	Male	32	T11	Wheelchair champion	Married
5	Male	43	C7	Professional painter	Single
6	Female	28	T12	Paralympic bow and arrow champion	Married
7	Male	34	C7	Writer and journalist	Married
8	Female	37	T11	PhD in history and disabled rights activist	Single
9	Male	38	T10	University teacher	Married
10	Male	30	T10	MS student web designer	Single
11	Female	44	T10	Physician	Married
12	Female	38	T11	Teacher	Married

Participants 3, 6, 7, and 11 said:

"... In the street and more often at university, the first person we meet comes to push the wheel chair ... he/she thinks he/she should necessarily help ... I did not ask for help! When I need help, like healthy people, I ask for it They should know it Helping a disabled without his/her permission is a sort of insult, or evading his/her privacy."

Some of the successful or brilliant SCI patients in the present study had an identical attitude toward this issue. They believed that reaction of compassionate in the society toward them, in fact, is somehow showing individuals' high emotion and kindness, but without wisdom and understanding. In other words, it is a sort of unmanaged sympathy, which not only has no negative effect, but if managed well, can act as a powerful stimulator for improvement and growth of the disabled.

Participants 1 and 12 said

"... I do not suffer from street people's behaviors which disturb my companions (other disabled) ... you know, our people are too kind.... It is somehow admirable that they are not indifferent and stony hearted ..., but they do not know how to manifest their emotions..."

Disability attitude

Most of the disabled have experienced severe psychological injury when faced with the social attitude toward them as a disabled. The disabled wondered, "We have just lost movement of our legs, why do people see us so disabled?"

Participants 1, 5, 6, 7, 9, and 10 said:

"... When I referred to an office or organization to get a job, they rejected me by just looking at me and not knowing about my CV, or letting me convince them."

In such conditions, the group of the disabled who had high education and experience and believed in their abilities did not pay attention to this sort of attitude and did not give up. They got the job by every effort. But there were many disabled who unfortunately were influenced with others' reaction and made their judgment as a scale for their ability.

Participants 1 and 2 said:

"... When I went to university dean's office by a wheel chair to see if it is possible to change my course, and gave him my request, he looked at me as an idiot and said, 'my dear, why do you bother us and hurt yourself so much? Go home and stay. Why do you want to study with such a condition'."

Participants expected the head of a cultural organization to look at this issue with a brighter and more scientific approach

and to negotiate the issue and be more motivating, highly valued and humanistic, and not to suppress the initial struggles of the disabled at the very beginning and in the worst way. On the other hand, participants believed that the disability attitude of society members made a background for the others to force the disabled to have amusement instead of giving them a goal.

For instance, participants 1, 3, 9, and 12 said:

"... You see, ... what makes you as a fossil (passive) is that everybody around you, your family and the disabled home authorities, try to amuse you ... to teach you to crochet or to do embroidery, ... watch TV, ... these are not a life for me ... they do not give me a sense of being alive ... it is a gradual death."

Inhuman attitude

Participants believed it is so hard for everybody to tolerate an inhuman attitude. It is worse for an SCI disabled person as he/she had no role in the event and did not deserve such an attitude.

Participant 4 stated:

"... Once I went to visit a waterfall in Hamedan (Iran); it was somehow steep. I was slowly wheeling down, I heard some apparently gentle people who were whispering, 'does he have to come to such places ... Even we cannot manage it! How about him, what does he think?'"

Based on such experiences, participants believed most of the people tease at their right to have a happy purposeful life.

Participants 1, 9, and 10 stated:

"... Six months after the event, my family took me to the office of one of the most popular specialists despite a lot of trouble. He looked at my X-rays, glanced at me, and then, privately told my parents, 'Do not waste your time ... Let it be so ... Do not take her to different physicians ... What do you think may happen, a miracle?'"

This inhuman attitude of people has led to disturbing behaviors toward the disabled in some cases.

Participant 3 stated:

"... My spouse left me alone with the kids and went abroad after my SCI ... Once in a while, he would pay me a visit ... 5 years after, we divorced due to problems.... I had to raise the kids myself"

Atonement attitude

One of the other attitudes that the participants believed to have rooted from the cultural background and improper interpretation of religious principles, in addition to the highly

negative effect of TV series of recent years which brought such a perception among people was the atonement attitude.

Participants 1, 4, 7, 8, 10, and 12 stated:

"... The attitude I have not been able to understand yet after many years, which still disturbs me so much when I face, is the atonement attitude. The others say, 'What he has done to deserve such a condition in his youth!'"

Participants believed tolerating such an attitude is more difficult than the pressure of the event itself, as the people do not help, but just worsen their condition, and it has a very miserable and destructive meaning to them.

DISCUSSION

One of the most important findings of the present study was compassionate attitude of the society toward the disabled. Based on the results of numerous studies, involving the disabled in the social activities of their interest through provision of chances to discover their unique potentialities, companionship, meaningful communications, helping them to understand the event more deeply, and giving them the meaning of life after the event can have positive valuable impact on their mental growth.^[22,23] Based on the study results, existence of such traditional compassionate attitudes toward the disabled in Iranian society diminishes their efficient and active attendance in the society and, consequently, increases the intensity of their isolation in a vicious cycle.^[1,14,15,24] From the social model view, one of the reasons for incidence of compassionate behavior is that people frequently witness struggles of the disabled and the others helping them to do their most of the simple daily activities such as transportation in the city or doing their daily shopping.^[25] Meanwhile, if a disabled is on an appropriate wheel chair in a specially designed building with ramps, standard lifts, and proper width of doorways, he/she can conveniently do the needed activities efficiently and feels no limitation or disability and, consequently, provokes the sense of public compassion to a lesser extent.^[26] So, if the sense of compassion is supposed to be less highlighted in the society, in addition to making it a public culture, the people should feel that the disabled can do their daily activities independently and do not need others' help. As discussed in the "Results" section, some participants believed that such compassionate attitudes are a sign of sort of unmanaged sympathy and kindness. As the people watch the disabled struggling to do their simplest daily affairs every day, they feel sorry and find no other ways, except presenting their feelings in a compassionate form. Meanwhile, if the general policies of the societies are founded based on supporting the life conditions after the SCI event and the disabled are provided with the equipments and strategies of an efficient

and qualified life, positive and valuable emotions of the society members can be used in a more appropriate way and in a stronger way.

The disability attitude of people (from common to elite) toward the SCI disabled was one of the other findings of the present study, especially at the time of getting a job. Such an attitude, often experienced by the disabled in the first years after the event, plays a key role in formation of a self-belief in their abilities among the disabled.^[5] This finding is consistent with the study of Deroon reporting that medical injury of spinal cord is not associated with the level of psychological well-being, but is inversely associated with the level of physical function loss.^[27] So such perception (the level of disability) is formed in daily interactions of the disabled with their family members, friends, and society members.^[28] Prevalence of a disability attitude toward the SCI disabled leads to selection of the strategy of amusing them instead of giving them a goal in their function; so, most of the family members of the disabled or even the managers in disabled homes try to amuse them instead of enabling them and giving them a goal. The point is that educated disabled understand the difference between being amused and having a goal and being in a path of success and, consequently, feel that this type of life is not what they expected from themselves.^[1]

Owesie's study showed that this group of successful and noble disabled experience more anxiety and depression in such conditions.^[29]

In addition to the above-mentioned issues, despite the governmental rule in relation with specification of 5% of total employment in governmental organization to the disabled, existence of latter attitudes and lack of a legal guarantee to apply such a rule is one of the main problems of the disabled who are expert or skillful. It leads to no financial independency after the event, which is counted as the main obstacle in their return to normal life and adaptation with their new conditions.^[17,30] In relation with the disability attitude of society members toward the disabled, it should be considered by the managers and policy makers that despite the fact that Iran has joined the international convention of disabled rights, disintegrations and ignorance in applying the related rules have led to consideration of total physical health as the first condition for employment in governmental organizations even though high-quality skills existing among the disabled.^[26]

It indirectly means that in viewpoint of common and educated individuals, a wheel chair equals total disability of a disabled, while use of this tool reflects the beginning of a movement toward development of abilities. This finding

can be compared with that of Murta *et al.* who showed that use of wheel chair by a disabled causes the individuals' mental image about the disabled as them having reduced physical attraction and, consequently, being a threat to efficient communications.^[31]

The finding of the present study showed that despite managers' disability attitude toward the disabled, educated and skillful disabled who believed in their abilities did not care and give up, and got the job they liked through every effort needed. This finding is consistent with the results of numerous studies which showed that high self-confidence, having positive attitudes, and meeting the life challenges efficiently are among the characteristics effective on improvement of life conditions after the event, social participation, and achievement of independency of action.^[32,33] On the contrary, many disabled gave up when exposed to such conditions and beliefs, and never experienced ability and efficiency in their life after the event. Inhuman attitude of people toward the disabled in daily life affairs was another finding in the present study. Participants believed that the people spoil their right of having a purposeful, efficient, and happy life after facing an SCI event due to their improper reactions to SCI and losing just a part of their physical activity. In this direction, symbolic interaction theorists believe that people balance their reactions and behaviors based on the meanings they give to the events.

These meanings are formed through the interactions of individuals with the society.^[34] Harrison believes that the interactions that frequently have a negative effect have a severely destructive impact on individuals' quality of life.^[35] It seems that inhuman attitude and ignoring the disabled in Iranian society is among those destructive interactions which have agonizing outcomes. An atonement attitude is another disturbing issue for which the participants believed cultural problems and improper understanding of religious instructions, as well as recent TV series played a major role in their spread. The fact that most of the people and even educated and elite ones accuse and blame the disabled for their past life events when they see them in the society is severely destructive and under no circumstances acceptable as it threatens the whole identity of the disabled. Incidence of such reactions should make us, especially the professionals of mass media, think of paying close attention to the indirect message a TV series sends to its addresses group. We should try to get help in this issue from related experts. The obtained results showed that SCI patients' exposure to feelings such as anger, guilt, fiasco, and especially, self-blame for their past function makes a background for their deep psychological disorders, which consequently have a destructive impact on their attitude

toward life after the event and their ability for an efficient rehabilitation.^[36,37]

Application of findings and suggestions for further studies

The goal of the present study was to analyze the experiences of SCI victims in the society in order to deeply understand individuals' realistic and internal attitudes and approaches in different social classes (common to elite) toward them through a qualitative and deep method. The obtained findings can be used in different educational fields including nursing students' education and public education, as well as conducting education in rehabilitation centers with goal of analyzing the roots of problems for both the disabled and the personnel in the form of educational workshops. They can be also considered in nursing management and education of efficient communications in relation with attitude change and prevailing efficient interactions. The researcher suggests assessing such factors in other disabilities in order to obtain a unique agreement through their outcomes to apply the findings in the domain of mental rehabilitation of different types of disabilities.

CONCLUSION

As unfortunately both common and elite classes of Iranian society have a similar and suppressing attitude toward and interactions with the SCI victims, it seems that traditional compassionate attitudes and disability and atonement attitudes still preponderate the academic and scientific peoples' attitude toward the disabled. This gap requires our more attention, as well as the researchers', policy makers', and social personalities' attention.

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