External power or internal transition: Iranian disabled people’s experiences

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Abstract

Background and Aim: Spinal cord injuries (SCI) are one of the fatal and common crises in all societies. According to symbolic interactionism, the meaning that people give to such events and crises are the most important elements in understanding their behaviors and quality of interactions. Indeed, development of social self is an outcome of self-expectations, self-assessment and the impact of community attitudes. The aim of the present study was in-depth analysis of empirical experiences of Iranian successful disabled people to understand which domains --self-expectations and assessment or impact of the community attitudes - are more essential and highlighted to achieve the success.

Methods: This study was conducted on fifteen disabled people with national and international success. Purposeful sampling method was employed initially, then sampling was continued through snowball and theoretical method. In-depth and open interviews were used for data collection. All the interviews were recorded and transcribed. Obtained data were analyzed by content analysis with Granheim approach.

Findings: The findings composed of two main themes and seven subcategories in the two different periods. In the period before individual and social growth and development, the main theme was reparative viewpoint with four sub-categories including compassionate, impotent, being ignored and atonement viewpoint. The period after individual and social growth and development, the main theme was facing respectful shame with three sub-categories including impressive admirable viewpoint, disbelief encountering, and shame of past performance.

Conclusion: Individual and social development occurs where one changed his/her situation from external reliance and hope toward accepting responsibility and internal reliance.

Key words: Disabled, Spinal Cord Injuries (SCI), Content Analysis

Introduction

Spinal cord injuries (SCI) are of one of the most fatal and common crises and conflicts in all societies. The global rate of SCI is averagely between 20 to 50 people per million per year. This rate is approximately 40-50 people in a million per year in Iran, and more than 3000 people are affected by SCI each year (84 percent by trauma and disasters and 16 percent by spinal cord diseases). There are almost 40,000 to 50,000 disabled people due to SCI in Iran. This means that SCI occurs every half-hour by various events such as fall from height, accidents, climbing or various exercises in Iran. Most of the SCIs occur in healthy youths, mostly among men aged 15-37 years. SCIs are categorized into acute and chronic injuries comprising traumatic events and progressive diseases, respectively. The main causes of traumatic injuries are accidents, falling from the height, wounds, and exercises. Over 50% of the traumatic injuries are associated with complete loss of movements below the lesion level and commonly have comorbidity with respiratory problems, intestinal and bladder degeneration and pressure ulcer. Non-traumatic injuries include damages caused by spinal cord infarction, tumors and neurodegenerative disease such as multiple sclerosis. Both groups of injuries cause the most vital nervous system issues; because not only the sensorimotor problems cause physical limitations, but also CNS loses the control over all the body organs and patients will experience...
various complex syndromes based on the injury site. The management of such catastrophic situation is hard and intolerable, with various physical and social problems and financial burden that are suddenly imposed on patient and his/her family. Songhee and Noreen (year) believed that these individuals are exposed to intense psychological distresses due to debilitating changes and various challenges. They experience anxiety, depression and fear, posttraumatic stress disorders (PTSD) and even suicidal thoughts; they are also more exposed to the loneliness and social isolation, sense of peers differentiation, poorer education, limited employment, and social conflicts. Thus, it seems that following the trauma, life would be extremely hard and complex, not only for the very victim but for the family and friends. In addition to individual and family problems, patients with SCI face numerous destructive barriers at the social level every day. These barriers and obstacles are mostly propounded as complaints and dissatisfaction, and many researchers believe that in addition to their psychological distresses, their initial efforts for self-care and self-surveillance fails to establish an independent life. The results of a study conducted by Negarandeh et al. in Iran suggested that the main barriers of adaptation SCI disabled people with new conditions after the trauma is the lack of social acceptance and social support. According to the symbolic interactionism approach, meanings that people give to such events and crises are the major elements in understanding behavior and quality of their interactions together. Individuals construct and reconstruct the definitions and meanings of realities by continuous interactions with themselves and others. In other words, self-social development is resulted from individual’s expectations, assessments of their condition, and the effect of community attitudes about them. Accordingly, the present study aimed at in-depth analysis of concrete experiences of successful Iranian disabled people in order to understand this concept which of the two domains (i.e. self-expectations and assessment or impact of the community attitudes) is more essential and highlighted in their success

Methods

There are numerous approaches to analyze qualitative data. Content analysis has been used in many studies particularly in nursing for many years. This method provide data from the content of the applicable and valid interferences, which aims to prepare knowledge, new insights, representation of facts and practical guide to action. It aimed to attain condensed and broad description of the phenomenon. The outcome of the analysis is concepts or categories describing the phenomenon. The study participants included fifteen disabled individuals who have nationally and internationally success. They were selected through purposeful sampling and have been later continued through snowball sampling. Method after obtaining the approval by the Ethics Committee of the Ahwaz University of Medical Sciences. All the subjects participated in the study with informed and written consent. Data were collected through in-depth interviews. However, due to the necessity of the prerequisites and field notes, registering the descriptions after the interviews and reviewing the documents have also been utilized. The interviews were generally held at the study participants’ house. The mean duration of interviews was 70 minutes; each participant was interviewed 2-3 times. Interview was started with a general question i.e. “Please let me know about the way you get over your life and whatever happened to you since you’ve realized you have suffered from SCI”. Further questions were developed concentrated more on the previous responses. Sampling was continued until data saturation. All the interviews were recorded digitally and then they were transcribed word by word. The interviews were analyzed through Granheim and Lundman’s content analysis approach. The following steps was taken to analyze the data:

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

The objective of accuracy and consistency of data collection in qualitative studies is to ensure findings illustrate participants’ experiences, not the researcher personal interpretations of. Thus, in order to assess the validity of the findings, Guba and Lincoln’s evaluative criteria were used including credibility, transferability, dependability, and confirmability. In fact, in addition to close and longtime communication between researcher and participants in order to assess the acceptability of the review and evaluation (member check), external checks, and complementary comments of instructors were also
frequently used in different steps. Maximum case variance and external checks illustrated the accountability authentication and verification of the findings.

**Findings**

The participants included fifteen disabled individuals with national and international success (9 women and 6 men). The mean age of the participants was 28 years. Most of them have lived with SCI 12 years. The level of SCI varied from C7 to T12. Detailed and in-depth analysis of the interview and texts and concurrent comparison using field notes and memos illustrated two main themes in various periods and seven subcategories about disabled people's experiences and their families. Disabled individuals experienced the main theme. repressive viewpoint with four subcategories including “compassionate viewpoint”, “impotent viewpoint”, “being ignored” and “atonement viewpoint” before individual and social development and excellence. However, prior to the period of growth and development, they were exposed to experiences with main theme as “facing respectful shame”. This main theme contains three subcategories “impressive admirable viewpoint”, “disbelief encountering”, and “shame of past performance”. Table 1 illustrates the main themes and subcategories.

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Subcategories</th>
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<tr>
<td>Repressive viewpoint</td>
<td>Compassionate viewpoint</td>
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<td></td>
<td>Unable viewpoint</td>
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<td>Being ignored</td>
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<td>Facing respectful shame</td>
<td>Atonement viewpoint</td>
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<td>Impressive admirable viewpoint</td>
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<td>Encountering disbelief</td>
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<td>Shame of the past performance</td>
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**Repressive viewpoint**

"repressive viewpoint" of the society was one of the main themes before personal and social growth and development. According to the participants, person needs more acceptance, support, and understanding from the community in this challenging period - early years of SCI. While, confronting with such dysfunctional attitudes, especially from society's patterns such as educated class, had a very pernicious and harmful effect on their physical and psychological rehabilitation. Most participants reminded moments in which the impact of such attitudes made them to put an end to life and attempt suicide. This main theme contains four subcategories:

**Compassionate viewpoint**

One of the main concepts in disabled people's experiences was society's compassionate viewpoint towards them. According to participants, individual has tried to achieve a relative stability over the early years after SCI. In this novel and challenging path, the disabled individual requires the approval and support of others, particularly the educated people and élite of the society. However, experiences show that traditional compassionate viewpoint toward disabled people not only is useless in many cases, but also induces a sense of helplessness, and fades the minute of enthusiasm and effort at the beginning of the path. For example: "When I was waiting in the bus station to go to the university with my wheelchair, two middle-aged women looked into my face and exclaimed with certain pathos: Oh, poor girl, she is beautiful and young, why she, what would she do?"; said the participant No. 3. In this regard, many disabled believed that having SCI is a lifestyle. Instead of compassion, we must teach people to accept different conditions of life seriously and courageously and try to enjoy their life in every situation with remaining gifts. This extreme sense of compassion, in some cases, has resulted in ignoring independence, their privacy to be violated unconsciously, and be upset due to people's immediate reactions. For example, participant No. 11 said: "In the street, or mostly at the university, when someone sees me, immediately comes for help, they think they should absolutely help me, I did not ask for help. Like others, I would like to express if I need help, they should know this, and helping to disabled without permission is an insult. It is a privacy invasion".

**Impotent viewpoint**

One of the emphasized concepts in interviews was society's impotent viewpoint towards disabled people. In this regards, participants believed that using wheelchair is a criterion and symbol of absolute disability among public especially people with higher qualifications. While, using wheelchair simply means motor
disability; mental abilities and analytic power remained unchanged. In many cases, individual can still be effective in his/her previous profession by providing an appropriate physical circumstance. For instance, participant No. 8 said: “When I go an office or an organization to find a job, they reject me before evaluating my abilities. They did not even ask about my education or experiences so that I can convince them”. In such circumstances, disabled people who have expertise or higher qualifications and believe in their abilities address such viewpoint seriously do not give up, convince the other individual as much as possible and get the job. However, there are lots of disabled people who made such encounters as their cornerstone of their abilities. For example: “I went to the newspaper office, and asked to write an article in the daily newspaper column. When they saw me on the wheelchair, they told me do I want really to be a journalist, in daily column? Do I know what does it mean? I gave them my articles and requested for their comments. I said I will work with no salary for a month. See whether or not I am to be able? Since then, I have been responsible for writing Disabled Column in the newspaper for several years, and I published a book from my articles”; said the participant No. 9. Participants believed that unawarness and poor cultural may cause such harmful attitudes. According to them, the most ideal reaction against such attitudes is continence, patience, ignoring the behaviors and trying for more interaction with the community despite difficulties. Such behaviors finally lead to more recognition of disabled abilities and fade misconceptions. Disabled often do not consider this matter and will rapidly choose isolation in the face of dysfunctional behaviors of the society.

Being ignored
The other finding of analysis of disabled people’s interviews was “being ignored” in daily functions by public and even people with higher qualification. Such behaviors were stronger before personal and social growth and development period and have been reported as one of the usual experiences of disabled people. They believed that most people ridicule the disabled alienable right for having an effective, diverse, and happy life. For example, the participant No. 4 said: “Once I went to visit a waterfall in Hamadan, there was a slope down and I was going down slowly with my wheelchair. I could hear people, who seemingly had distinguished appearance, said to each other: Is he forced to come to such place, it is very hard for us let alone for him, what is he doing here? He is so cheerful”. According to the participants, public believes and attitudes, even educated people, seem to be based on this belief that an individual with SCI and lack of motor ability should only pass his life and just be amused. He/she does not need to have a goal, growth, development and diversity of life. For example, participant No. 2 said: “My family took me to one of the most prominent physicians’ office 6 months after my accident. The physician had an overview on the graphs and my body, then told my family: Do not spend your time on him, leave him alone, do not go to different clinics, what do you want him to be with this condition? I was extremely desperate when heard that. “Such attitudes have led to inhumanity and destructive behaviors in some cases. For example, the participant No. 11 said: "My wife went abroad after my SCI and he left me alone with my kids, and occasionally visited us. We divorced five years later because of the problems; I had the responsibility of raising the children while my older son was twelve years old, now he is a physician”. Since such behaviors had been faded after the personal and social growth and excellence, many of the participants believed that instead of cultural ignorance and weakness, lack of self-esteem and poor performance of the disabled can also reinforce such attitudes.

Atonement viewpoint
According to participants’ vision, media had an important role in the promotion and development of the sharp “atonement” viewpoint, in addition to unfavorable cultural context and incorrect interpretation of religious teachings. Facing with these viewpoints is one of the most destructive and damaging experiences that has been reported by disabled. Most of them believed that bearing such interpretations and viewpoints is much more difficult than the incident. For example, the participant No. 1 said: “An interpretation that I could not understand after eight years and I am still annoyed too much was the atonement viewpoint, I mean others said: Look, what he has done that it happened to him in his youth. In other words, it means he had it coming and deserved it, the punishment is the result of his own actions”. Participants believed that they felt blame and obsessive viewpoint at the past performances after facing with such interpretations. These feelings led their confidence and self-esteem to be reduced over time. Most of them remember the challenging period with lamentation that their whole identity was questioned as a result of such viewpoints and interpretations.
Facing respectful shame

Facing respectful shame has been one of the main themes of disabled people's experiences after the personal and social growth and development. After a challenging period of frustration in micro and macro policies for support, having bewildered relatives without social support who express contradictory behaviors, disabled must boldly accept responsibility of their life and do their best in using their remaining abilities and enjoying life. Selecting this strong strategy based on self-reliance gradually resulted in integration of individual identity and remarkable social achievement. Disabled people's experience about facing with society in this period, was representative of facing respectful shame. This means that people not only treated with admiration and respect while dealing with disabled, but also were deeply ashamed of their past looks and actions. This main theme included three subcategories:

**Impressive admirable viewpoint**

After personal and social growth and development, the impressive admirable viewpoint was one of the important concepts for disabled people facing with community as a successful disabled person. Participants believed that having an objective, showing dominance over life conditions, integration of individual identity and achievement of notable successes resulted in to be respected in the community that has not been expected such level of performance from disabled. Most participants believed that the great motivation to continue this strategy and achieve more successes is summarized in receiving more positive feedbacks, engaging in society and good sense of being close to a normal life. For instance, participant No. 12 said: “When I decided not to be a loser anymore, I wrote a list of my abilities and disabilities and I saw that I had more abilities, and then I started designing sites and building weblogs that I knew a little bit about it before the trauma. I won the second grade as the blogger in the first weblog competition; I received a lot of good comments, others’ point of view suddenly changed, thereafter I have been seen more than my wheelchair”.

**Disbelief encountering**

One of the main concepts in disabled interactions was “disbelief encountering”. Participants believed that the frustration of micro and macro policies, serious decision to take responsibility for the quality of life after an accident and self-reliance caused a discipline, concentration and personal integrity. The achievements of these matters have been confidence growth, more relaxation, and discovering various paths of personal and social growth and development. These awards and their quality of performance often are far from the expectations of the society. More important point is that all the successful disabled people believed that they would have never experienced such concentration, targeted and personal integrity if the accident had not happened and they had not deeply involved in such problems and challenges. In fact, they did not really have such experiences in their life before the accident. For example, the participant No. 7 said: “Many people told me that when we saw you, we have hope toward life, how could you keep your life despite such problems? And to be successful, whenever held an exhibition of my works (paintings), I clearly feel that visitors leave the gallery with much wonder and many questions, gradually I seemed to be a hammer, to flip and awaken others”.

**Shame of the past performance**

One of the main concepts in disabled people's interactions was the concept of shame of the past performance. According to the interviews, this concept was more seen in people who had serious interactions with disabled according to the demands of work or family relationships or incidentally in daily life. Unfortunately, such people demonstrated inappropriate behaviors that affected by suppressing viewpoints. Many of the participants remembered that this shame in some cases forced the individual to explain and apologize for his/her behavior. However, in many cases, people have many reasons to justify their inappropriate actions. For example, the participant No. 10 said: "When the head coach of archery realized that I got the Paralympics quota, he called me, apologized and excused that we did not have resources to take you to the Korean championships, please come back, and catch us the quotas for the Olympics. I did not accept; I said I’m exercising the Paralympics. They realized whom they have already lost".

**Discussion**

The analysis of disabled people's experiences interactions showed that the main concepts and themes were made in two different periods of time. The first one is the period before personal and social growth and development with the repressive viewpoints as the main theme including compassionate viewpoint,
impotent viewpoint, being ignored, and atonement viewpoints as the subcategories. The other one is the period after personal and social growth and development with main theme of facing respectful shame including inspiring and admirable viewpoint, encountering disbelief, and shame of the past performance as the subcategories. The first question comes to our mind is that "what happens that the quality of public interactions is changed so much and so fast?" This is a question that will be answered through deeper analysis of the main themes and related subcategories in the period before personal and social growth and development. Repressive viewpoint is the main theme of disabled people's experiences. This theme with four subcategories had unpleasant consequences for them. The first subcategory was society's compassionate viewpoint. The results of various studies all over the world showed that involvement of SCI disabled in social activities will have noble and valuable impacts on their intellectual growth by providing an opportunity to explore the unique capabilities, meaningful companionship and communication establishment, contribute to a deeper understanding of accident and give meaning to life after the trauma. 18,27-29 Existence of such traditional compassionates toward disabled not only causes the person to be deprived from such valuable achievements, but also tend to be less active and ineffectively attend in the community. These issues in a vicious cycle will intensify their isolation problems. 4,7,18,29,30 According to the social model, one of the reasons of compassionate behaviors is that people are frequently witness of disabled people's efforts and help of others to them in order to perform the easiest daily functions such as their commute in the city and daily shopping. 30 While the disabled individual exists in a building with appropriate slopes (ramps), standard lifters and proper width of entrance doors, they easily have effective activities and would not feel any limitations and disabilities and as a result, people's sense of empathy will be less motivated. 1,25 Accordingly, if it is to fade this kind of empathy in the society, in addition to general culture and acquainting the society with disabled capabilities, public should learn that the disabled subjects operate independently in their daily performances and have no need to others. Unable viewpoint of public at disabled, particularly for job adoption, is one of the most important findings of the present study. In this regard, the matter which should be more attended by managers and policy makers is that despite the fact that Iran has joined to the International Convention on the Rights of Disabled, fragmentation and the indifference to the law enforcement still have led to having a physical health as the first requirement of hiring in public service which is strictly emphasized by organizations' managers despite the great skills of disabled. This approach means that wheelchair is an absolute disability symbol in public unconscious viewpoint and even among educated people. The usage of this instrument is a starting point of moving to capability development. These findings can be compared to the results of Murta et al. which indicated that the main issue in using wheelchair is to change the image of disabled people, reduction of physical attractiveness, and compromising the effectiveness of communication. 33 According to Garrett, confronting with such destructive attitudes and interactions impact tremendously on shaping disabled people's belief and abilities. 7 These findings are consistent with the findings of Deeron i.e. physical damage intensity in SCI has no connection with psychological well-being after trauma. However, disabled people psychological well-being is inversely related to their understanding of the extent of their physical functions loss. Such a comprehension (severity of disability) is formed through daily interactions of disabled with the environment and society. 34,35 Most importantly, the findings revealed that despite unable viewpoint of managers, disabled people who had considerable expertise or education and believed in their abilities often seriously questioned such viewpoints, do not give up and have finally found their desired jobs. These findings are consistent with the results of several studies that show high self-esteem, having positive attitudes and the ability to deal effectively with the challenges of life have effective role in improving the living conditions after accident, social corporation, and independence achievement. 29,36 However, many disabled people have surrendered to such circumstances and beliefs and never experienced their own capabilities and effectiveness after trauma. Ignoring disabled people in daily life affairs has been one of the important findings of the present study. According to the participants, the society questioned their right for having a meaningful, effective and happy life with their inappropriate reactions following SCI and loss of the ability to move. In this regard, symbolic interaction theorists believed that people regulate their interactions and behaviors based on the meanings assigned to incidents and events. Such meanings will be formed in daily interactions with society. 37 In Harrison's view, the interactions with frequently negative concepts will have severely detrimental impact on people's quality of life. 38 Ignorance and neglect of disabled people in our community are such adverse interactions that would result in unfortunate
consequences. One of the main themes of dealing with disabled community before personal and social growth and development was the extremely destructive and damaging atonement viewpoint. It means that general population and sometimes educated people points of view regarding disabled or an unwelcome event in life which accuses the person of certain indifference and considers the occurrence of such events as a result of the past actions are justifications which are not acceptable and are destructive logically and intensively. The participants believed that the cultural context of the society, mass media and especially television has an important role in such destructive believes promotion by playing special series in recent years. Encountering to such subjects is a flip for all of us and especially for media scholars. They should have special cautious for indirect messages of daily interactions and mass media on their audiences. They should not neglect the professional help of experts. Related to the consequences of such feelings, study results of Girbig suggested that SCI disabled in connection with feelings such as anger, guilt, failure, and especially self-blame regarding past performances cause many psychological disorders and finally will have a disadvantageous impact on their attitude towards life after trauma and his/her ability for effective rehabilitation. 39 Respectful shame exposure is the main theme of disabled interactions experiences after the personal and social growth and excellence. This theme with three subcategories had pleasant consequences for disabled people. The first subcategory was the impressive admirable viewpoint, which means people had often been admired and had respectful reactions towards successful and developing disables. It seems that such rapid and widespread changes in attitudes and society reactions, rather than being just because of achieving special successes, is due to observing the seriousness, stability, and self-reliance caused by self-responsibility strategy and accepting responsibility of the quality of life after trauma. Self-reliance strategy and taking responsibility of quality of life after trauma refer to the important structure of "focus of control" from the social learning theory. This structure means that how a person can believe in influencing his quality of life. This structure has two internal and external focus of control. Several studies showed a strong and positive relationship between the belief in internal focus of control and high self-confidence, self-esteem, motivation, creativity and problem solving. 40,41 Having such valuable features in addition to success in many fields will stimulate a sense of admiration and respect. The second subcategory of the main theme facing respectful shame is the society’s disbelief encountering. It means that disabled people’s internal changes have multiple external representations and achievements that inspire a sense of be astonishment and disbelief. Many psychologists consider focusing on inner thoughts, feelings, motivations and reactions as private self-conscious construct, which is one of human unique capabilities. 42-43 Jessica believes such conscious thinking results in more valuable and noble achievements such as facilitating adaptive behaviors and different responses to different events of life. 43 this matter explains the disbelief encountering of society in this regard. The “shame of the past performances” is one of the main themes of disabled people’s interactions experiences in the period after personal and social growth and development. This expression of has been seen in different social classes. All those who had destructive interactions with disabled in the past, will be regretful and feel shame after disabled national and international shining. The quality and quantity of their interactions had been concluded by cultural weakness and traditional attitudes. Some of them accepted their performances and tried to amend them; however, most of people tried to explain their performances through projection strategy. According to Allyson, people use defense mechanisms (projection) unconsciously for solving negative tensions in order to keep themselves away from psychological injuries and losing self-esteem. 34 However, this point should not be neglected that resorting to such approaches cause a sense of false comfort, and cause the main problems to remain still unsolved and gradually becomes deeper and more complex.

**Conclusion**

It can be concluded that personal and social growth and excellence develop when the person shifts from external reliance and hope to accepting responsibility and internal reliance. In fact, he/she organizes the inner world in consistent with the outside world as ideally and effectively as possible rather than waiting for basic changes. In addition, the quality of interactions with social class is modeled on the quality of interactions of that stratum with their class. Accordingly, the first step in improvement of interactions’ quality is changing individuals’ interactions with each other. The concept that has been less considered in the disabled educational content in Iran.
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