

Barriers and Facilitators to Emancipation Process in Persons with Physical Disability- A Grounded Theory

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ABSTRACT

BACKGROUND

The social model has considered the concept of emancipation in the field of social participation of people with disabilities that is less frequently investigated. This study aimed to explore the facilitators and barriers of emancipation process in persons with physical disability.

METHODS

This grounded theory study was conducted in the welfare originations of Tehran and Zanjan from October 2017 to September 2018. The study was conducted using semi-structured interviews of 12 participants with physical disabilities, two family members, one nurse, one physician, and two employees of the Welfare Organization. Purposeful sampling was performed with maximum variation. All interviews were transcribed verbatim and data were analysed using the Strauss and Corbin 2008. The study continued until data saturation occurred.

RESULTS

The analysis of the data led to the extraction of 2067 codes, 25 subcategories and 8 main categories. The study findings appeared in 4 main categories for barriers and 4 main categories for facilitators. Barrier categories include non-supportive community, unprotected interactions between family, person and self-disability. Facilitating categories includes flexible environment, supportive programs, emancipated family and individual competencies.

CONCLUSIONS

There are barriers and facilitators to the process of emancipation, the most important of which are individual factors. So individual motivational interventions with physical disabilities can be effective in achieving the emancipation process.

KEY WORDS

Emancipation, Persons with Physical Disability, Grounded Theory

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BACKGROUND

Disability is a part of human condition and any person may be temporarily or permanently disabled or impaired during the lifespan or at the end of his or her lifetime.⁽¹⁾ The prevalence of disability increased from 12.6 percent in 2010 to 13.2 percent in 2016⁽²⁾ According to the WHO, disability is described as a complex phenomenon that reflects the interaction between the individual's physical characteristics and the characteristics of the society in which the disabled person lives. In fact, disability is a complex set of conditions created by the society for the disabled person.⁽³⁾ In the social model, disability is considered as a social phenomenon and considers disability as a complex set of conditions, many of which are created through the social environment.⁽⁴⁾ The concept of emancipation in the field of disability research was first expressed by Oliver.⁽⁵⁾ Emancipation has various meanings and consequences. In the context of this study the emancipation as exposure of forces that prevent decision-makings by individuals and groups to increase their autonomy and significantly change people's lives.⁽⁵⁾ Emancipation promotes and improves the quality of life and participation of persons with disabilities in employment training and social participation.⁽⁶⁾ Considering the importance of the concept of emancipation in persons with disabilities, this process and influential factors are still vague for patients, nurses and other healthcare providers.⁽⁷⁾ Understanding and identifying factors affecting the emancipation process can help nurses, rehabilitation team professionals, and policy makers overcome barriers and strengthen facilitators.

METHODS

This study was a qualitative research of the type of grounded theory. Grounded theory approach was used to conduct the study, because the process of emancipation process in persons with physical disability is subject to sociocultural context and various factors interact with this process.⁽⁸⁻¹⁰⁾ This study was performed in Iran from October 2017 to September 2018. Participants included 12 physical disabled people who were identified as successful individuals by the Tehran and Zanjan social welfare organization. The inclusion criteria for the study were able to communicate verbally and experience success in social presence and had a willingness to collaborate in the study. The exclusion criteria were unwilling to participate in the interview. Purposeful sampling was used in this study and due to the nature of emancipation phenomena it was attempted to use emancipation and success experiences in different areas of society. gathering was conducted through in-depth semi-structured interviews. Interviews started with the question "Tell us about your experience in emancipation", "What factors, in your opinion, have been facilitating you to reach the emancipation process?",

What factors have prevented your emancipation? The interviews were audio taped and then transcribed verbatim. The study continued until occurred data saturation. Data were analysed using the proposed model of Strauss and corbin 2008.⁽¹¹⁾

Ethical considerations and volunteers' right to withdraw from the study were taken into account in this research, the interview started with no reference to the interviewee's name, and the participants were assured of the confidentiality of their identities in the publication of the results. Credibility and trustworthiness of the data were assessed by reviewing the codes by the participants, the review of external checker and the prolonged engagement with the participants. Sampling with maximum variance also contributed to the transfer and acceptance of data.⁽¹²⁾

RESULTS

The analysis of the data led to the extraction of 2067 codes, 25 subcategories and 8 main categories. The study findings appeared in 4 main categories for barriers and 4 main categories for facilitators, each of which had sub-classes (table 3).

1. Non-Supporting Community

Participants described the inappropriate transport system and the lack of suitable vehicles as one of the most important barriers to emancipation.

"I use a cane and I cannot climb a metal bus stair. Using the subway and the bus is very difficult for me" (p3).

The other obstacles mentioned in the interviews were the high cost of travel. Participants also stated that Suitability of urban spaces for the disabled person have not been met in many urban spaces. The use of inappropriate materials in buildings and public spaces, one of the other factors that prevented the social presence of people with disabilities.

There is a staircase to enter the shop and supermarket that a person with a wheelchair cannot enter "(p8)."

Participants stated that the media have a compassionate and derisive look at the disabled persons. "The pity of disability is highlighted in the movies that have an actor with disabilities" (p2). Some other participants interpreted the negative media's view of disability as the result of guilt. In some films, negative characters are punished for their bad deeds in life with a disability in middle age and old and unfortunately, this is not a good picture of the physical disability that is left in the mind of the audience. "In the film... The actress helped her with the pity and compassion toward the person with disabilities. This feeling is in many movies" (p11)". The other subtheme of this theme was inadequate attention to media supportive programs. Another obstacle is to show the imposition of others in cinema and media. Participants have said that most media programs have a stereotyped look at disabilities. This demonstration is in the form of a myth and superstar and incredible look. "A series of television programs that examine the lives of successful disabled people but it is broadcast at times that there is not much audience". (p10)

Regarding the disabling perspective, the participants stated that the society's view of the disabled, coupled with lack of trust, is a pessimistic and ridiculous attitude. Sometimes this view from the perspective of participant is seen as the burden of society and the punishment of sin.

No	Gender	Age	Education	Residential Place	Cause of Disability	Field of Activity	Level of Disability	No. Interviews	Interview Duration
p ₁	male	26	Bachelor	Zanjan	Congenital	Athlete	paraplegia	1	45
p ₂	male	45	Associate Degree	Zanjan	poliomyelitis	coach	paraplegia	2	90
p ₃	female	38	phd	Tehran	poliomyelitis	University professor	paraplegia	1	70
p ₄	male	43	diploma	Tehran	car accident	Craftsman	paraplegia	1	65
p ₅	male	27	master student	Zanjan	Congenital	Athlete	paraplegia	1	50
p ₆	female	26	master student	Tehran	car accident	Athlete	Hemiplegia	1	40
p ₇	male	33	master	Zanjan	burn	Entrepreneur	paraplegia	1	80
p ₈	male	33	Bachelor	Tehran	Congenital	inventor	paraplegia	1	75
p ₉	male	56	Bachelor	Zanjan	Maternal injury	Craftsman	paraplegia	1	60
p ₁₀	female	35	Doctor of Medicine	Zanjan	poliomyelitis	physician	Paraparsis	1	50
p ₁₁	female	30	Bachelor	Tehran	car accident	Athlete	paraplegia	1	65
p ₁₂	female	28	master student	Tehran	Congenital	painter	paraparsis	1	75

Table 1. Demographic Data of Disabled Persons Participating in the Study (N=12)

No	Gender	Age	Education	Residential Place	Field of Activity	No. of Interviews	Interview Duration
p ₁₃	male	47	master	Zanjan	Deputy Director of Welfare Organization	1	45
p ₁₄	female	44	bachelor	Zanjan	Expert of Welfare Organization	1	90
p ₁₅	female	38	master	Tehran	nurse	1	70
p ₁₆	female	35	Specialist	Tehran	Physical medicine	1	65
p ₁₇	female	43	diploma	Zanjan	family	1	50
p ₁₈	female	58	middle School	Tehran	family	1	40

Table 2. Demographic Characteristics of Other Participants (N=6)

Main Themes	Subthemes
Non-Supporting community	Inefficient transport
	Inappropriate urban spaces
	Negative media outlook
	Inadequate attention to supportive programs
	Disabling viewpoint
Passive organizations	Insufficient attention to the rights of persons with disabilities
	Inefficient legislation
	Executive slot
	Inefficient attitudes
	Non-supporting functions
Unprotected interactions between family and person	Abandoning the person in the umbrella of limitations
	Painful care
	Destructive look
	Incompatible response
Self-disability	Self-incapable
	Disabled Performance
	Positive engagement on social networks and the Internet
Flexible environment	Access to non- personal service
	Advancement of technology
Supportive Programs	Empowerment laws
	Dynamic Organizations
Emancipating Family	The Independent Family Approach
	Effective Family Interactions with Organizations
Individual Competencies	Intellectual capabilities
	Behavioral capabilities

Table 3. Main Themes and Subthemes of Effective Facilitators and Barriers to Emancipation Process in Persons with Physical Disability

"The society's view of the disabled, coupled with is lack of trust, compassionate and derisive attitude" (p1) ".

Pity look to the disabled community can be seen everywhere which is a barrier against the social presence of

the disabled person. They believed that the Iranian society had not accepted the disability and with a negative look, it has prevented the emancipation of these people.

Participants stated that disabled people have little role in policymaking. Disabled people have many needs that may be considered in the rules, but this was not enough attention.

One of the other obstacles mentioned was the lack of attention to the laws by the organizations. They stated that the relevant organizations do not pay enough attention to the rules of this field, in particular, the rules of suitability and employment.

2. Passive Organizations

Participants stated that "the community's view of the welfare organization and NGOs with mistrust and profits. This view affects the access of people with disabilities to these organizations.

"People think that anyone who goes to the welfare needs financially" (p1).

On the other hand, the plurality and density of welfare duties and the inadequate facilities of organizations were another barrier in the emancipation process. Participants also stated that rehabilitation managers are skeptical about the expected outcomes of rehabilitation programs." Several tasks have been given to the welfare. I think if there was an organization that was just for the disabled persons, it would be better able to help achieve the independence and empowerment of people with disabilities (p2)"

Participants believed that relevant organizations in the field of disabled persons, if working in partnership with activities and facilities, provides a favorable context for the emancipation of disabled people.

" At the meeting, the managers themselves were not believed in executive programs that were in the field of rehabilitation". (p2)". "The association of welfare organizations with NGOs is low and they do not essentially believe in the functionality of these organizations." (p10)

3. Unprotected Interactions between Family and Person.

Participants stated that the main obstacles to the emancipation are non-financial support, emotional exclusion and inclining a person's ineffectual sense in the family.

"My father did not pay for my school because he believed that my education was useless". (p1)". " Some parents differ in their love for a disabled child, and sometimes they dismiss the disabled child" (p2).

They also stated that families, by isolating a disabled person due to fear of harm to him, prevents the social presence of a disabled person. A participant said: "My mother did not let me go exercise because she was afraid something happened to me". (p5) They also stated that misleading love leads to an exacerbation of the sense of dependency in a disabled person. Families sometimes feel guilty and ashamed of having a disabled child, leading to a lack of social participation in the disabled person. Negative reactions of parents, including anger and aggression, followed by parental conflict, were the other barrier to emancipation.

I sometimes felt the shame of my mother when I came to school and it was painful for me" (p6)." I heard several times

when my mother prayed: O God, what did I do when my son became disabled" (p12)."

4. Self-Disability

This category was the most significant obstacle expressed by the participants. Participants have stated that the weakened self-concept with a sense of humiliation and weakness of will prevents the presence and participation of the individual.

"Persons with disabilities often feel humiliated for their disabilities and therefore they do not pay attention to their abilities and talents". (p7)

Participants also stated that Sometimes people with disabilities magnify their problems and do not pay attention to their abilities and talents, which makes them afraid of being in the community. On the other hand, because of the negative viewpoint that society has a disability are pessimistic to others and do not feel safety. Feeling of frustration was another barrier to emancipation. Disabled people sometimes do not enter the community due to fear of physical injury. Other barriers expressed in this regard were dependency on others, lack of effort to reach the goal, and lack of purpose in life.

"Some of my disabled friends are dependent on others in their routine, even a glass of water should be given to them by others. (p7)." I was dependent on others in all my life and that dependency was due to my fears and concerns". (p8)."

5. Flexible Environment

Participants stated that social networks and the Internet lead to the interaction of people with disabilities and the information they need.

"In a telegram group I met a disabled person who made money through art and getting information about it". (p12)

Participants stated that the Internet is a tool for identifying individuals' abilities, social and political participation and improving the sense of self-esteem of the disabled persons. Participants identified access to non-personal services as another facilitating factor for social participation and emancipation. These services in the field of distance learning, administrative and banking services can help in the realization of the emancipation process.

"We will be notified of the campaigns through social networks". (p10). "I do my banking work without wanting to get out of the house". (p2)

Participants stated that mobility assistance tools such as braces and orthoses came with the assistance of the disabled persons and has provided the conditions for their social emancipation. Participants stated that technology advances in software and hardware had a positive impact on the process of emancipation.

6. Supportive Programs

The most important protection law stated by the participants was the Comprehensive Disability Protection Act. They argued that comprehensive law seeks to human rights of persons with disabilities and their empowerment. The Partnership emphasized that the law addresses fundamental rights such as education, environmental adaptation, health and employment

of persons with disabilities. One participant in the field stated that:

"When the law says there is 3% employment for people with disabilities it helps to become an independent person". (p2).

Participants also emphasized the role of organizations such as the Welfare Organization and NGOs in the realization of the liberation process. Participants stated that being present in these organizations provides a greater opportunity for people with disabilities to interact with one another and this leads to a greater understanding of one's abilities and talents.

"I met a basketball player at meetings at the center and told me to go to the team". (p5)

7. Emancipating Family

Participants stated that the family's autonomous approach to Constructive hardening, enhancing potential talent, creating peace in the family environment, accepting the disabled persons and intention and seriousness of the family can play a useful role in the process of emancipating the disabled persons. Participants stated that family could encourage the disabled persons to do their own work to help her independence. A participant in the field stated, "My mother forced me to wear my own clothes". (p1)

Attention to the talents of the handicapped in the family and helping them flourish is another facilitator factor expressed by the participants.

"When my mom saw how much I love painting she took me to a painting class (p12)". "My mom would hug me every day and take me to school" (p2)

Encouragement and acceptance of the disabled persons is another factor that helps to emancipation. Effective family interaction with organizations is another facilitating factor. These interactions were manifested through the search for information resources, active participation in rehabilitation programs and the provision of motor assistance devices.

8. Individual Competencies

Individual competencies were the most important facilitators of the emancipation process in this study. One participant stated in this regard: "The most important thing is the person himself, nothing happens until you find yourself (p2)". Participants identified characteristics such as good thinking, belief in inner power and resiliency as the most important individual factors of emancipation.

"I always tell myself it could get worse". (p5) "I believe in the power that is within me" (p7)."

Participants also identified spirituality and perseverance as behavioral characteristics facilitating emancipation.

"I had a lot of failures early in my career, but I was not disappointed. I had to re-plan". (p12)

DISCUSSION

People with physical disabilities in the process of emancipation face individual environmental and social

barriers. urban transport systems around the world are generally designed for a healthy population and rarely consider the needs of people with disabilities, what the participants in this study also mentioned.⁽¹³⁾ In this study, participants also stated that they had to use personal vehicles because of problems with the public transportation system, which would impose additional costs on them. As a result, public transportation barriers are rapidly affecting the socio-economic participation of people with disabilities. The most important barrier to the physical activity of the disabled persons in society, the lack of a proper transportation system.⁽¹⁴⁾ Studies have argued that barriers to the transportation system have an impact on the social participation of people with disabilities and access to it will improve the quality of life and reduce social isolation.⁽¹⁵⁾ Then it can also facilitate the emancipation process. The structural barriers as one of the most important obstacles to participation in physical activity of people with disabilities.⁽¹⁶⁾ People with disabilities cannot perform their activities in urban areas because of disabilities in the city and they are not disabled. The results of studies in Iran show that not only small cities suffer from the lack of equipment for people with disabilities, but also the Iranian capital (Tehran) also has some psychological and physical barriers that can prevent the participation of people with disabilities.⁽¹⁷⁾

In today's modern world, media not only play a key role in reflecting society's attitudes and values towards people with disabilities, But also play a role in shaping disabilities.⁽¹⁸⁾ Quinlan and Bates (2009) argued that mass media have a great influence on the understanding of the community of people with disabilities.⁽¹⁹⁾ This was also expressed by the participants in this study. The negative image of the media affects the participation and emancipation of the disabled persons.⁽²⁰⁾ Some participants say that society considers their disability to be guilty of their own sin and their parents, which affects their participation and emancipation. It can be said that according to the findings of this study, despite the high level of disability in Iranian society, there is still insufficient attention paid to the rights of persons with disabilities. The society's discriminatory view prevents people with disabilities from socializing, economic and political participation of people with disabilities.⁽²¹⁾ Participation is formed in the interaction between individuals and their social and physical environment and this interaction takes place in the legal, ideological and organizational context.⁽²²⁾ Examining the status of disabled people from different aspects in Iran indicates that there are many inequalities in the enjoyment of favorable living conditions in them and indicates the inadequacy of laws and regulations with the right-wing approach to protecting people with disabilities.⁽²³⁾ Political barriers cause limited participation and activity for people with disabilities. Also, the lack of recognition of the needs of people with disabilities, by population and government, is a major obstacle to change. Iran, like many other countries, faces the challenge of defining the disability Which is another obstacle to the process of emancipation.⁽²⁴⁾

The lack of organizational facilities and lack of financial resources were another obstacle Which is in line with other studies.⁽²¹⁾ Ineffective interactions with the family were other barriers expressed in this study. Lack of financial support, Emotional deprivation of the disabled person, inclining a

person's ineffectiveness, isolation of the disabled person due to fear of injury to him, guilty of having a disabled child, anger and aggression, and conflict and Parental conflict were the most important barriers in the family Which is in line with the results of other studies.⁽²⁵⁾ Self-disability, expressed by all participants as the most important barrier, includes individual characteristics that prevent a successful social presence and the emancipation of a disabled person. Negative thought, feelings of humiliation, pessimism, lack of attention to abilities and disappointment were the barriers expressed by the participants. These characteristics lead to social anxiety and tend to depend on the individual and as a result of the failure to realize participation and emancipation.⁽²⁶⁾

Internet sites lead to greater communication between people with physical disabilities. Studies say that internet space provides a good opportunity for people with disabilities this will lead to the promotion of social protection through sharing information, guidance and friendship in social groups.⁽²⁷⁾ The Internet is also a useful tool for independent living. A person can access a lot of information without leaving home, use the electronic community, updates on the latest news about the disabled persons, use the benefits of e-learning and online to buy their books and supplies.⁽²⁸⁾ Supportive laws facilitated the emancipation of this study. Achieving human rights for people with disabilities is an example of social justice that needs to be addressed.⁽²⁸⁾ The main disability protection law in Iran is the comprehensive protection of the rights of persons with disabilities. Participants in this study identified the implementation of comprehensive law as a way of achieving the process of emancipation and social participation of people with disabilities, which justifies the need for faster enforcement.

According to our study findings the family plays an important role in the process of emancipation of people with physical disabilities. A study showed that the family contributes to social participation through supportive behaviors such as instrumental support, planning to participate in social activities, financial and emotional support, connecting with other family members, and helping the disabled person make decisions.⁽²⁹⁾ Which is consistent with the results of the present study.

Individual competencies expressed was positive thinking and optimism to improve conditions, filtering external negative attitudes thinking, disappointing from failures and attempts to reach goals, seriousness and perseverance. Another researcher reported that positive thinking leads to increased self-esteem and improving the quality of social life of disabled people.⁽³⁰⁾ Optimists have less negative thoughts, less likely to be miserable and more responding to positive events in life.⁽³¹⁾ During the interview, the effort was to make the interview in an environment that was completely calm and quiet but some of the interviews were at the veterans' and disabled sports organization, due to the proximity to the gym, the focus of the interviewees was somewhat disturbed. Setting up an interview with people with physical disabilities, especially athletes, due to lack of time and volume of training exercises for the tournament, was one of the other limitations of the study.

CONCLUSIONS

According to the results of the present study, improvement of conditions for emancipation of persons with disabilities can be achieved through reform of urban structure and furniture, attitudes of society and existing laws and regulations, as well as reform of families' approach. Given that the present study was conducted in a specific area and included only the experiences of participants in this location, it is recommended that similar studies be conducted in other settings to increase the generalizability and applicability of the results.

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