

## Exploring Facilitators of Regaining Autonomy in People with Spinal Cord Injury: A Qualitative Study

### Abstract

**Background:** One of the most important aims of rehabilitation in Spinal Cord Injuries (SCI) is regaining autonomy, which can affect individuals' Quality of Life (QOL). This study was conducted to understand the experiences of individuals with SCI in terms of regaining autonomy during transition from hospital to community. **Materials and Methods:** The present study was conducted using a qualitative research design. In this study, 15 semi-structured, in-depth interviews were conducted with individuals with SCI in Spinal Cord Injury (SCI) Association of Arak, Iran, from June 2018 to May 2019. The interviews were analyzed using the conventional content analysis method. **Results:** Data analysis emerged four core categories of "self-management" (adaptation to a new life, self-care, responsibility, and seeking information), "social support" (family and friends' support, health care providers' support, and peer support), "access to facilities and resources" (home modification, use of various rehabilitation techniques, and use of mobility equipment), and "spiritual and religious beliefs" (believing in divine destiny and performance of religious rites). **Conclusions:** The present study showed that several factors influenced the regaining of autonomy in individuals with SCI. It is important to consider the impact of these factors during transition from hospital to community. Health service providers can use the findings of this research to help these individuals regain their autonomy.

**Keywords:** Iran, personal autonomy, qualitative research, spinal cord injuries

### Introduction

The ultimate goal of Spinal Cord Injury (SCI) rehabilitation is to restore and retain the highest possible level of autonomy in order to maximize the patients' community participation.<sup>[1]</sup> SCI is a life-threatening condition that has a significant impact on the survivors and changes their daily lives, their autonomy, and their roles in the family and society.<sup>[2]</sup> The mean prevalence of SCI is 20-50 in million per year in the world. The prevalence of SCI is about 40-50 in million per year in Iran and more than 3,000 people suffer from SCI every year.<sup>[3]</sup> This disability often results in sensory and motor skills deficiencies, pain, pressure ulcers, and bladder and bowel dysfunction,<sup>[4]</sup> which limit the patients' ability to manage self-care activities and personal and occupational responsibilities.<sup>[5]</sup>

Personal autonomy is the functional capacity for self-management and engagement and

participation in activities of choice within one's community.<sup>[6]</sup> Some studies showed that regaining of autonomy after a SCI depends on multiple factors. Therefore, it is important that the health team be aware of these factors.<sup>[7]</sup> Research into SCI has shown that patients' participation in different activities increases their physical, psychological, and social adaptation after being discharged from the hospital.<sup>[8]</sup>

Some studies found that providing these individuals with training and needed information increased their awareness of self-care and made them more autonomous in decision-making.<sup>[7]</sup> Factors such as support from family, colleagues, and health workers are also important in motivating SCI patients and helping them to adapt to their new circumstances.<sup>[9]</sup> Several studies have shown that barriers to community participation and autonomy of SCI patients are related to sociocultural conditions, SCI outcomes, attitude of the rehabilitation staff or caregivers such as

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overprotection or depriving the patient of social activities, architectural structures, and access to public services.<sup>[1,10]</sup>

A prospective study of subjects with SCI showed that functional independence improved during inpatient rehabilitation, but deteriorated after discharge.<sup>[11]</sup> Nikbakht-Nasrabadi *et al.* showed that SCI patients need training and support from the healthcare team, and social support to achieve physical independence.<sup>[12]</sup> Babamohamadi *et al.* found that making efforts towards independence is an important coping strategy in Iranian SCI patients, which is showed through being productive, reducing caregiving burden, and removing the distress caused by the dependence on others.<sup>[13]</sup>

However, there is not sufficient, relevant information on factors influencing autonomy of individuals with SCI. The facilitators of regaining autonomy in individuals with SCI in Iranian sociocultural context are not clear, and quantitative research does not reveal the nature and details of the existing reality. This study was conducted to explore the experiences of individuals with SCI regarding facilitators of regaining autonomy during transition from hospital to community.

## Materials and Methods

The present study was conducted using qualitative content analysis to provide a comprehensive description of the perceptions and experiences of individuals with SCI regarding facilitators of regaining autonomy.<sup>[14]</sup> This approach is particularly appropriate for areas in which nurses have little theoretical or practical knowledge.<sup>[15]</sup>

This qualitative study was conducted from June 2018 to May 2019. The study participants were 15 individuals with SCI who were selected from Arak SCI Association, Arak, Iran, which is the main center for rehabilitation of individuals with SCI in Markazi Province. The inclusion criteria were having paraplegia and tetraplegia SCI diagnosed by a specialist, SCI for more than 2 months, age of over 18 years, and ability to speak Persian. Unwillingness to continue participation in the study was considered as the exclusion criterion. Eligible participants were selected through purposive sampling and with maximum variation in terms of age, gender, education level, marital status, and level, extent, and cause of injury.<sup>[16]</sup>

Data were collected through in-depth, semi-structured, face-to-face interviews held in either the study setting or participants' homes depending on participants' preferences. The authorities of the study setting were consulted in order to identify and select individuals with SCI with rich experiences of regaining autonomy. An interview guide with general and specific questions was used for the interviews. Examples of interview questions were "Can you please explain your experience after discharge from the hospital?", "What role did you have in regaining your autonomy?", "What problems did you face in

regaining autonomy in daily life?", and "What helped you achieve autonomy?" If needed, participants were asked to elaborate on their statements. Data collection lasted until data saturation, i.e., when no new conceptual codes were obtained from interviews and all aspects of the study subject matter were adequately explored. Saturation was achieved after 13 interviews with 13 individuals with SCI. Yet, 2 more interviews were conducted to ensure data saturation. Interviews lasted 35-60 minutes. All interviews were audio-recorded and transcribed verbatim.

Data were analyzed concurrently with data collection using conventional content analysis. Interview transcripts were read to grasp participants' perceptions, and then, meaning units were identified and coded with conceptual labels. Subsequently, codes were constantly compared in terms of their similarities and differences and were grouped into subcategories. Similar subcategories were also grouped into larger categories. At each step, the authors reviewed the work to reach consensus. The researcher tried to prevent her ideas and assumptions affect the analysis and interpretation of data.

The criteria of credibility, confirmability, dependability, and transferability were used to ensure trustworthiness. Credibility was established via member checking, peer checking, prolonged engagement with the data over 12 months, and sampling with maximum variation. For member checking, 4 participants were invited to verify whether our generated codes and categories were consistent with their experiences. During peer checking, the second and third authors of the article reviewed the study findings and approved the accuracy of data analysis. To ensure the dependability and confirmability of the findings, the whole process of the study was documented with as much details as possible. Transferability was also ensured through providing rich descriptions of the data collection and analysis processes and the findings. Moreover, study findings were provided to 2 additional individuals with SCI who confirmed the congruence between their experiences and the findings.

## Ethical considerations

This project was approved by the Ethics Committee of the University of Social Welfare and Rehabilitation Sciences, Iran-Tehran (IR.USWR.REC.1397.011). All the participants were informed of the purpose of the study, confidentiality of their identity and their shared information, no obligation to participate in the study, and the right to withdraw at any stage of the study. Their permission was obtained for audio recording during the interviews. The participants signed informed consent forms before entering the study.

## Results

The participants were 15 individuals with SCI (9 men and 6 women). Their mean age was 33.8 years. The demographic characteristics of the participants are

presented in Table 1. Through data analysis, the 4 main categories of self-management, social support, access to facilities and resources, and spiritual and religious beliefs were obtained [Table 2].

### Self-management

This category reflects the impact of self-management behaviors on the daily activities of individuals with SCI. These behaviors helped them maintain their physical and mental health and played an important role in regaining their autonomy. Its subcategories are adaptation to a new life, self-care, responsibility, and seeking information.

#### Adaptation to a new life

All participants experienced many emotional challenges after being injured and living with SCI, but were able to manage their condition through using personal resources. According to the participants, a positive attitude, avoiding bad thoughts, hope for recovery, accepting the disease, and ignoring limitations help a person adjust to a new life. *“When I was unemployed, I always thought and wondered why this happened to me? What should I do if I remain like this? But I entertained myself with different methods such as reading, watching movies, and listening to music .... I thought to myself my life is not over, I just cannot walk, but I can be useful for my family and society ..... Despite this condition, I was not desperate at all. Sometimes, I had bad feelings, but very soon I regained my hope, you can try and work better when you are hopeful and have motivation”* (p7).

*“When this happens, the person gets upset and depressed (saying that) I was on my own feet until yesterday, now I need others. It takes a while to find yourself and become motivated so as to cope with problems. I accepted that this happened, but I did not lose my self-confidence and I tried to improve my condition”* (p2).

### Self-care

Most participants helped maintain their health and improve their quality of life (QOL) by taking responsibility for their own care. Self-care behaviors such as following the doctor’s advice, consuming appropriate foods, drinking adequate water, taking care of their skin, and being cautious in daily activities were some of the topics expressed by most participants. *“I had set an alarm on my watch for every 30 minutes to remind me to change my position so as not to get bed sores, I take my medicines on time, I eat the foods that are good for me, and I try to consume more water and do my exercises regularly at home”* (p6).

*“I always make sure that the heat does not bother me when I am by the heater. When buying shoes, I pay attention to which shoes may hurt my feet, which clothes hurt or put pressure on my body, I try to observe these so as not to get hurt”* (p8).

### Responsibility

The sense of responsibility in individuals with SCI caused them to do their best to meet their needs and achieve recovery. Participants stated that when they were newly injured, they preferred to be cared for by their family due to feelings of weakness and inability, but their participation in activities increased after recovery. *“Just after the injury, I could not lift my head and they fed me with a straw. As soon as I could raise my hand a little, I tried to slowly eat by myself.... When I could sit up, I tried to do my own things, when I did my own work, I saw that everyone was happy, and I myself enjoyed it more and tried harder”* (p4).

*“I used to move in a wheelchair, I started occupational therapy with a lot of hope, I had to prove that I would get better and that my disease would not be permanent. I fell down with the brace many times, as I was not in balance,*

**Table 1: Demographic characteristics of the studied participants**

Participant	Age	Gender	Level of education	Marital status	Cause of SCI*	Level of SCI	Extent of SCI
1	28	Female	Diploma	Widowed	T/A**	T12***	Complete
2	30	Female	Diploma	Single	T/A	L1****	Incomplete
3	36	Female	Diploma	Married	T/A	L1	Incomplete
4	32	Female	Diploma	Married	T/A	T8	Incomplete
5	34	Male	Diploma	Married	T/A	C4*****	Complete
6	31	Male	Bachelor’s	Divorced	Falling	T8	Complete
7	42	Male	Master’s	Married	T/A	C4	Incomplete
8	40	Male	Diploma	Married	T/A	C4	Incomplete
9	34	Male	Bachelor’s	Married	T/A	C5	Incomplete
10	44	Male	Diploma	Married	T/A	C4	Incomplete
11	27	Male	Diploma	Divorced	Falling	L1	Complete
12	25	Male	Bachelor’s	Single	T/A	C4	Incomplete
13	38	Male	Diploma	Married	Falling	C5	Incomplete
14	34	Female	Diploma	Divorced	T/A	T12	Complete
15	32	Female	Bachelor’s	Divorced	Tumor	L1	Complete

\*SCI: Spinal cord injury; \*\*T/A: Traffic accident; \*\*\*T:thoracic cord; \*\*\*\*L: Lumbar cord; \*\*\*\*\*C:cervical cord

**Table 2: Categories and subcategories of facilitators of regaining autonomy**

Codes	Subcategories	Categories	Theme
Positive attitude	Adaptation to a new life	Self-management	Facilitators of regaining autonomy
Avoiding bad thoughts			
Hope for recovery			
Ignoring limitations			
Accepting the condition			
Applying doctor's recommendations	Self-care		
Consuming appropriate foods			
Drinking adequate water			
Skin care			
Avoiding exposure to hot objects			
Careful shopping			
Regular physical activities			
Participation in activities of daily living	Responsibility		
Participation in rehabilitation process			
Hard work and perseverance			
Getting information from the doctor	Seeking information		
Reading printed materials			
Web search			
Emotional support	Family and friends' support	Social support	
Taking care			
Informational support			
Informational support	Health care providers' support		
Giving hope			
Motivating			
Boosting spirit	Peer support		
Exchanging common experiences			
Learning from each other			
Encouraging each other			
Bathroom modification	Home modification	Access to facilities and resources	
Toilet modification			
Access to home appliances			
Occupational therapy	Use of various rehabilitation techniques		
Physiotherapy			
Hydrotherapy			
Using a wheelchair	Use of mobility equipment		
Using walkers, canes, and braces			
Believing in God	Belief in divine destiny	Spiritual and religious beliefs	
Belief in destiny			
Saying prayers	Performing religious rites		
Nozorat (Vows)			
Appealing to Imams			

*but I tried to get back up. I said I could. I got better with a lot of effort and I managed to walk again” (p12).*

**Seeking information**

Most individuals with SCI would increase their knowledge about the disease and care by visiting a doctor, reading books, and searching the Internet. According to the

participants’ experiences, seeking information raised their awareness of the disease and helped them manage their condition better. *“When I was discharged from the hospital, I knew nothing about my disease. I got most of the information I needed from my doctor. I studied SCI on the Internet and got information about what the disease was and what care it needed” (p2).*



*“After my accident, I started reading different books about this disease, which increased my knowledge .... It is very important to know what the symptoms of this disease are, what care it needs, what is good for you and what is bad. I learned how to take care of myself, what to eat, and what exercise to do, and I followed all recommendations”* (p9).

### **Social support**

Participants reported receiving extensive support from family and friends, health care providers, and peers, which helped them regain their autonomy. The 3 subcategories of this core category include family and friends' support, health care providers' support, and peer support.

#### **Family and friends' support**

Most individuals with SCI received emotional support, care support, and a great deal of information from their family and friends. Participants believed that SCI was a difficult and challenging condition for them, to the extent that they became dependent on others for their daily affairs. Under such circumstances, they considered the acceptance and support of the family as one of the most important factors in improving and regaining their autonomy. *“After my accident, I had urinary and defecation incontinence and was very sensitive on my health. My elder sister took good care of me, bathed me regularly, and gave me nutritious foods. She supported me by giving me hope that I would get better and asked me not to get upset. My main motivation was my parents, who enabled me to overcome all this pain and problems, and find myself again and come back to life. Without the support of my family, I had no motivation for living. They made me try and be able to achieve autonomy”* (p5).

*“My cousin is a nurse. Whenever I had questions about my disease or medical and nutritional care, I would ask her on the phone. Her guidance was a great help to me. Regaining my abilities were due to my efforts and the support of my friend, who always encouraged me. I would sit still most of the time, as soon as my friend would enter our house, he would slap my hands and ask me to open my hands, he would say: move your hands, that would make me more motivated for activity”* (p6).

#### **Health care providers support**

Participants stated that receiving information from health care providers is an important source of self-care and prevention of problems and complications caused by SCI. In addition, the support of health care providers created hope, motivation, and adaptation with SCI in patients. With this support, individuals with SCI were motivated to work harder for their recovery and independence. *“When I was in the hospital, the nurse asked me to move every half hour so as not to get bed sores and changed my bladder catheter every 2 weeks to avoid getting a urinary tract infection. This patient education helped me a lot. While*

*most people with SCI suffer from bed sores due to lack of information, and consequently, their rehabilitation program is delayed”* (p11).

*“The doctor said that I will be fine, it will take time, I have to make an effort myself, be in good spirits, go to physiotherapy and occupational therapy, and should not think that I cannot. This gave me hope”* (p8).

#### **Peer support**

According to the participants, exchanging experiences and learning from peers, and the raising of one's spirit and encouragement by peers were effective factors in gaining autonomy. According to the experiences of the participants, the SCI Association was an important place to meet individuals with SCI and learn how to function independently from one another. *“When I went to the SCI Association for occupational therapy, I saw that although the members of the association were in worse conditions than me, they were doing their own affairs and getting into bed from their wheelchair without the help of others. I tried to be like them so that I could move”* (p15).

*“In the SCI Association, other patients lifted my spirit. They described their experiences and said that they were like me at the beginning, and when they wanted to walk with a walker; their legs trembled, but with effort and practice, they were able to get rid of their wheelchairs, you can walk too if you practice .... Their words made me feel better”* (p7).

#### **Access to facilities and resources**

Participants reported having adequate access to mobility equipment and rehabilitation facilities, and that their home conditions were suitable for them. The use of these facilities was a great help in regaining their autonomy. The subcategories of this category were home modification, use of various rehabilitation techniques, and use of mobility equipment.

#### **Home modification**

Many participants believed that home modification had a significant effect on regaining their autonomy in daily activities. Participants stated that their families changed parts of the house for their better performance as suggested by the health staff, but some were forced to relocate for more comfortable mobility after living in difficult conditions for some time as they were in an apartment with no lift. *“Any changes recommended by my occupational therapist were made at home by my family like making the bathroom suitable for me so that I could do my affairs independently, and this really boosted my spirit. For our independency, the environment is very important, that is, the environment has a great role in us either regaining autonomy or remaining disabled ....., our apartment was on the second floor; my family used to take me up with a chair; but as they were hurt many times, we decided to change our apartment”* (p5).

### Use of various rehabilitation techniques

Almost all participants experienced rehabilitation with physiotherapy and occupational therapy. They believed that the use of various rehabilitation techniques such as occupational therapy, physiotherapy, and hydrotherapy had a significant effect on their recovery. *“When I was discharged from the hospital, the doctor prescribed me 20 sessions of physiotherapy, which were done at home. After that, my family took me to the SCI Association in the mornings for occupational therapy. In the evenings, I would go for physiotherapy and swimming. These exercises were very helpful, I was able to gradually achieve relative recovery with a lot of effort and the help of those around me, and do my daily affairs independently .... Using different treatment methods such as occupational therapy, physiotherapy, hydrotherapy all together is very helpful”* (p9).

### Use of mobility equipment

According to the participants, the use of mobility equipment had reduced their dependence on others and made them independent in life. Almost all participants used various assistive devices such as wheelchairs, walkers, canes, and braces at different stages of rehabilitation and recovery. *“After my accident, I could not move and I was in bed all the time. My family would take me to occupational therapy in a wheelchair and bring me back. After a while, with the help of those around me, I was able to stand on my feet. Then, they bought me a walker with which I could walk. But they tied my hands to the walker, because I could not hold on to it with my fingers. After a while, I could walk with a cane, these tools helped me move”* (p7).

### Spiritual and religious beliefs

Believing in God, believing in destiny, praying and saying prayers, and appealing to the Imams helped individuals with SCI tolerate stress, and thus, more easily cope with their disease and try to regain their autonomy. The most important role of spiritual and religious beliefs was to create peace and strengthen the spirit of individuals. Spiritual and religious beliefs include the 2 subcategories of belief in divine destiny and performance of religious rites.

#### Belief in divine destiny

Many participants believed that their disease was a divine destiny and a destiny that God had decided for them. They believed that everything in the world was done by the will of God, and they used this belief to accept their disease. This viewpoint was expressed many times by individuals with SCI and had prevented them from feeling frustration. *“Believing in God helps a lot in accepting the disease; nothing can be done before you accept the reality. Some patients say: Why has this happened to us? I say this is a divine destiny, God wanted us to be like this, and we have*

*to deal with it. This is our destiny, God decided that for us; I never have a complaint”* (p7).

### Performing religious rites

According to the participants' experiences, asking God for help, appealing to religious clergymen, and Nozorat (vows) played an important role in calming them, reducing suffering and unhappiness, increasing spiritual strength and hope for the future, and lifting their spirit. Praying and saying prayers were among important aspects of performing religious rites. Participants believed that prayer increased their strength and ability by reducing anxiety and improving their physical condition. *“At night, when I wanted to sleep, I was in a lot of pain and I sent so many prayers (peace upon prophet Mohammad), then, I calmed down and fell asleep. Although my condition was bad, I prayed while I was lying down. Their prayers are the first thing some people give up when something bad happens to them, but I do not despair and I believe that God will heal me”* (p1).

*“Most of the time, I prayed for Tawassul (appealing to God). I believe in Hazrat Abolfazl (the fifth son of the first Shia Imam) very strongly. I vowed that if I get well soon and be able to walk, I will celebrate Hazrat Abolfazl's birthday. If Hazrat Abolfazl fulfills my wish, I will pay for the celebration every year ..... People prayed for me a lot and I received God's grace, I started exercising and working hard, and all this helped me to be able to improve and progress”* (p5).

### Discussion

The findings of this study showed that various factors are effective in individuals with SCI regaining their autonomy. These factors included self-management, social support, access to facilities and resources, and spiritual and religious beliefs. The self-management category reflects the ability of individuals with SCI in terms of adaptation to a new life, self-care, responsibility, and seeking information to regain autonomy. The results of this study showed that individuals with SCI adapt to their new condition through a positive attitude, hope for recovery, and acceptance of the disease. In this regard, other studies showed that a positive attitude towards disability and having a boosted spirit help patients' mental health promotion and increase their adaptation to the disease.<sup>[9,17]</sup> In the present study, one of the self-management strategies of individuals with SCI was self-care behaviors to maintain health. In this regard, Ide-Okochi *et al.* showed that individuals with SCI feel responsible for maintaining their health and keep themselves healthy by performing self-care behaviors.<sup>[18]</sup> Self-care behaviors are one of the strategies that ensure the health of individuals with SCI. Therefore, health care providers should evaluate patient' self-care behaviors and encourage them to apply these behaviors in their lives.

In the present study, individuals with SCI strived to participate in daily activities and the rehabilitation process to their bests. Studies have shown that appropriate clinical conditions including incomplete SCI, intact cognitive ability, low incidence of complications, appropriate functional capacity, high self-efficacy and low levels of depressed mood, low fatigue and pain levels are essential for social activities participation of individuals with SCI.<sup>[1,19]</sup>

The present study findings showed that seeking information was another self-management strategy of individuals with SCI to regain autonomy. Boluki *et al.* also showed that personal knowledge, and learning and education about SCI and its prognosis are among the factors that contribute to patient independence.<sup>[7]</sup> Patients' unmet needs led them to seek information to increase their awareness. Seeking information shows the patient's need for more information, which should be obviated by the health care staff.

Social support was another important category in this study. According to the results, individuals with SCI received support from various sources. They received the most support from their families and friends. This support had given hope and reassurance to these individuals. In line with the present study findings, Munce *et al.* reported that emotional support from the family increased self-efficacy in individuals with SCI.<sup>[20]</sup> This finding shows the importance of the presence of family members in the interdisciplinary team for the rehabilitation of people with SCI. In the present study, in addition to family and friends' support, the support of health care providers and peers led to adaptation with the disease and increased motivation of individuals with SCI for recovery. Muller *et al.* also found that social support in individuals with SCI led to faster adaptation, greater performance, and physical and mental health, and a better QOL.<sup>[21]</sup> Other studies also showed that peers of these individuals act not only as mentors and role models for them through their emotional support, practical advice, and sharing of experiences, but also as a stimulus to improve their physical function and social and mental health.<sup>[9,22]</sup>

The category of access to facilities and resources shows the importance of early access to rehabilitation facilities and services in regaining autonomy. In this regard, Carver *et al.* stated that the use of mobility aids increases the accessibility of people with disabilities and helps them to be independent in walking and performing daily activities.<sup>[23]</sup> However, in the study by Guilcher *et al.*, individuals with SCI did not have access to rehabilitation services due to financial problems.<sup>[24]</sup> They struggled for access to mobility equipment and home modification, and long waits for rehabilitation services led to the development of bed sores and readmission.<sup>[24]</sup> This finding emphasizes the importance of the impact of adequate access to rehabilitation services in individuals with SCI on regaining autonomy.

Spiritual and religious beliefs were another major category. The present study showed that spiritual and religious beliefs

are one of the important strategies in Iranian individuals with SCI for improving their mental health and increasing their ability to deal with problems. Other results showed that spirituality is one of the most important adaptation mechanisms in chronic diseases such as SCI, and believing in God and worship makes people stronger and their lives more meaningful.<sup>[25]</sup> A limitation of this study was that health professional's experiences were not explored. It is highly recommended that further studies be conducted on valuable work experiences of SCI Rehabilitation team with these patients.

## Conclusion

The ultimate goal of rehabilitation in people with SCI is to achieve autonomy in their daily activities so that they are able to execute their roles in their family and community. The results of this study showed that multiple factors affected the regaining of autonomy in individuals with SCI during transition from hospital to community. Understanding and applying these factors can be effective in designing rehabilitation programs for these individuals. Strengthening individual, social, and religious factors, and access to facilities and resources, extracted from this study, can facilitate, and accelerate the process of autonomy restoration in individuals with SCI.

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## Conflicts of interest

Nothing to declare.

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