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**This is a pre print version of the following article:**

*Original Citation:*

*Availability:*

This version is available <http://hdl.handle.net/2318/1528193> since 2018-03-27T10:15:57Z

*Published version:*

DOI:10.3109/09638288.2015.1031287

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## **Informal caregivers' needs on discharge from the Spinal Cord Unit: analysis of perceptions and lived experiences**

**Purpose:** Spinal cord injuries are one of the most complex and disabling diseases, implying severe consequences on aspects of life of people affected by SCI and their caregivers. The aim of our study was to explore the situation of informal caregivers of persons with Spinal Cord Injury when discharged home from a Spinal Cord Injury Unit, in relation to needs, emotional experiences, difficulties and subsequent reactions to discharge.

**Methods:** A purposive sample of 11 caregivers were interviewed on patients' discharge home from the Spinal Injury Care Unit and at six months. The semi-structured interviews were analyzed using a qualitative phenomenological methodology as described by Giorgi.

**Results:** Five main themes emerged from the caregivers' experiences including their implicit and explicit needs. Problems concerning communication with healthcare professionals and the need for an adequate multidisciplinary taking charge of caregivers in order to support their new role emerged within all the themes.

**Conclusions:** Results suggest that greater caregiver involvement in the rehabilitation process and their preparation for discharge are required. Communication with healthcare professionals needs to be enhanced. It would be useful to organize follow up visits after discharge to assess intervention effectiveness.

**Keywords:** Spinal cord injuries, Caregivers, Needs assessment, Discharge

### IMPLICATIONS FOR REHABILITATION

- Understanding the importance of discharge from the SCU as a meaningful step of the rehabilitation path both for the patient and his informal caregiver
- Orientating healthcare professionals towards a better caregiver involvement during the rehabilitation process
- Promoting rehabilitation interventions addressed to the patients and their caregivers concerning supportive communication strategies as well as giving meaningful information, psychological and social support, educational intervention other than the physical aspects of care
- Understanding SCI survivors caregivers' needs can assist healthcare professionals to plan and improve taking charge of this core aspect of nursing care

## BACKGROUND

Spinal Cord Injuries (SCI) represent one of the most complex and disabling conditions. The consequences of SCI are severe and complex, affecting both the person with the injury, and the people who might act as caregivers. In Italy the incidence of post-traumatic SCI is estimated at 18-20 new cases per million population (1500-2000 people/year), with a prevalence of 70,000 people, of which about two-thirds are younger than 60. [1, 2] Individuals with SCI are more frequently male, young, and due to advances in medicine, they have a minimal reduction in life expectancy. [3]

Informal caregivers, mostly represented by spouses or other family members of the SCI survivor, in many cases, are the only source of support for people who are discharged home. They continue to live with the injured person and, sometimes they have to move residence if they cannot conform to the SCI survivor's requirements. [4] The caregiver is most often a woman aged between 45 and 55 years old. In the case of SCI the caregiver takes on the responsibility of looking after the SCI survivor in terms of personal care, mobilization, dressing, feeding and neurological bladder and bowel management. In most cases, people discharged home claimed that there would be no other person to assist them without an informal caregiver. [5, 6, 7]

Caregivers of individuals with SCI play a central role in the rehabilitation process and recovery within the social sphere. Moreover, it is widely recognized that becoming a caregiver implies considerable stress, social isolation and tensions within the family. [8] The high levels of stress which caregivers of individuals with SCI are subject to, the worry and the anxiety that derive from the individual being discharged home, frequently lead to the onset of depression and Burnout Syndrome. [9] To date, results of studies have shown that divorce rates in couples with one spouse affected by spinal cord injury is higher than in the overall population. This is due to a negative impact on the couple's pre-existent relationship dynamics. [10] Although partners share an overall sense of well-being which is acquired through a unique coping process. [11, 12] Occurrence of depression is related to social isolation and the amount of activities that caregivers must carry out to assist their relatives. It is also influenced by the level of the injury, that is to say, the higher the level of the injury the greater the likelihood of onset of depression-related symptoms'. [13]

Spinal Cord Injury leads to a real disruption within the reference world of those affected and to a profound change involving family members, loved ones and all those involved, who can experience several problems mainly regarding social integration and economic difficulties. [5, 14] In addition caregivers report a loss of their own personal space and privacy, [11, 15] describing themselves as: "*victims of events beyond their control*". [16] The changes in their daily habits is just as fatiguing as those experienced by their beloved. In the relationship with the SCI survivor they often cover the dual role of lover and care provider that leads to the loss of their previous identity. [2, 17]

Several studies have been carried out with people with SCI, above all regarding psychological adaptation processes resulting from hospital discharge. Despite expectations, coping processes seem to be positive and even improve over time. [18, 19] Nevertheless there are few studies which

aimed to explore the impact of SCI on caregivers. They are mainly focused on quality of life after discharge examined by quantitative methods, emphasizing that a caregiving role is destructive in terms of leading to degenerative diseases or depression and anxiety. [9, 12, 20] Moreover, it emerged that caregiver's functioning influences the possibility of the person with SCI to remain at home. [11]

In Italy there are 12 Spinal Cord Units (SCU), most of which are distributed in the northern and central part of the country. They represent a reference point for people with SCI even after discharge. On discharge, individuals with SCI have usually reached the maximum level of autonomy expected for that particular clinical situation. Owing to the severity of the disability caused by SCI, patients discharged home might need an informal caregiver to take care of them during the activities of daily living and general life management. In Italy individuals with SCI receive a public disability benefit. The amount depends on the level and causes of the SCI, for example it would be different if the SCI occurred during the working activity of the individual rather than during an outdoor activity or a car accident. If the individual has a private insurance the broker would quantify the damage and the amount of the fund. A special benefit for caregivers of people with SCI is not provided, apart from a Social Security Service disability benefit for the affected person to cover part of the costs deriving from the need for assistance in everyday life activities.

The purpose of this study is focused on caregivers of people with SCI lived experience after discharge from the Spinal Cord Unit - City Hospital Health and Science in Turin. The aim of the study was to explore the experience of caregivers of individuals with SCI analyzing the final phase of hospitalization and at six months from discharge, to highlight their needs during hospitalization as well as emotional experiences, reactions to difficulties resulting from being back home, and subsequent positive and negative aspects related to discharge.

## METHODS

### PARTICIPANTS

A purposive sample of 11 caregivers of individuals with traumatic and non-traumatic SCI, on discharge from the SCU - City Hospital Health and Science in Turin, were recruited from February to December 2012. Inclusion criteria were first degree kinship caregivers, aged 18 or older, of patients with spinal cord injury (SCI) who had a Modified Barthel Index (MBI) lower than or equal to 60. Further inclusion criteria were spoken Italian language and living with the assisted person at the time of discharge.

Participation was voluntary, caregivers who met the inclusion criteria were contacted and provided with a written informed consent form. Out of the 14 caregivers eligible for the study, 11 agreed to participate.

Participants were 8 females and 3 males, mean age= 57.4 (SD = 15.8), ranging between 28 to 80 years. Caregivers had different socio-economic conditions, 5 had retired while 3 had to interrupt their occupational activity to provide appropriate assistance to their relatives. The mean MBI of patients is 26.1(SD = 15.5) ranging from 2 to 49, while their length of stay at the SCU lasted 10 months on average.

### DATA COLLECTION

Semi-structured interviews were carried out. Data were collected in two separate phases, before discharge home and after six months. A narrative approach was adopted to get a deeper insight into caregivers' experiences and needs. [21]

The researcher encouraged respondents to recount tell their experiences spontaneously by means of an inductive process characterized by probing questions and thinking over the participants lived experience. The track for the semi-structured interview [Box 1] contains 7 open ended questions used by the interviewer to provide support during the participants' storytelling. [22] All interviews were audio-recorded and transcribed verbatim. Interviews were carried out in Italian and after transcription, they were translated into English.

At the beginning of every interview socio-demographic information and other useful data were gathered to describe the condition of caregivers and their relatives during the presentation of results. Interviews were transcribed in a suitable language and later brought to the attention of participants for further reading, accurate analysis and possible changes if necessary. Please insert Box 1 about here

## DATA ANALYSIS

Data analysis followed a qualitative phenomenological approach. The aim was to present the experiences of those who had lived the experience by accepting their point of view. [21, 23, 24, 25] The Giorgi method for qualitative data analysis was adopted. [26] Data were analyzed following a four-step method: i) reading the interviews to get the gist of the whole; ii) discriminating units from participants' description of the phenomenon being studied; iii) articulating the psychological insight in each of the discriminated units; iv) synthesizing the transformed meaning units into statements of the participants' experience.

Subsequently these meaning units were grouped into several key thematic areas, until no new themes or patterns had emerged thus reaching data saturation. Identified themes were coded manually.

Interviews were not analyzed separately according to the time in which they had been conducted, in order to allow main essences relating to the global lived experience to emerge.

Some meaningful sentences allowing the reader to reach a deeper immersion into the data were taken from the interviews and reported in the results section. By providing participants with a number code anonymity was guaranteed during data transcription and presentation. The caregivers' degree of kinship with the patient, the interview time, before or after discharge home are also reported in the results section.

The quality of the study was ensured using the Lincoln & Guba framework (credibility, dependability, conformability, transferability and authenticity) as described by Polit. [27] Credibility and dependability were ensured through the use of an audit trail, verbatim transcription and member checking. All phases of the analyses were conducted by the researchers (two registered nurses experts on spinal cord injury and rehabilitation) and an independent auditor, with a triangulation between them. The auditor was an assistant professor of nursing sciences indirectly involved in the study but an expert on the methodology. During all analysis phases, the researchers reflected on their own values and suspended judgment, knowledge, and ideas about the phenomenon under study (so-called bracketing).

## ETHICAL CONSIDERATIONS

The study design was submitted to the head office of City Hospital Health and Science in Turin – Orthopedic Traumatology Center (OTC) - and received approval for its fulfillment.

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

No external funding was requested.

## RESULTS

Interviews were conducted between February 2012 and June 2013. The first interview was conducted within the SCU at the time of discharge, the second interview was performed after a telephone agreement with caregivers, six months after discharge in conjunction with a follow-up appointment at the SCU's day hospital centre. Interviews, lasting about 40 minutes each, were conducted in a private setting in order to ensure privacy. Table 1 presents the socio-demographic characteristics of caregivers and related assisted people. Please insert Table 1 about here

Data analysis led to identify five thematic areas, which are summarized in Table 2 together with associated units of meaning and they provide a summary of manifold caregivers experiences. Some of these emerged during both phases of the data collection, before and after discharge, while others are distinctive of one of the phases. Please insert Table 2 about here

### Coping with changing perspective

The theme of the changing relationship between patients and informal caregivers strongly emerged from participants' narrations. The unexpected onset of the new situation is a traumatic event that causes a strong emotional impact and people interviewed had initially experienced a common sense of hopelessness.

*I was there when the accident happened, he fell 10 meters down the mountain, from about 2000 meters height, when I rushed to help him, he was conscious and the first words he said to me were "my life will change but yours too, I will never move again." It was a shock. (7, brother, discharge)*

This initial phase of the recovery process is characterized by impulsivity experienced by participants as a result of upsetting moments when they realize that the consequences of the injury are not limited to a solvable problem, but that it will also affect the existence of their reference world. It is the moment in which anger is sometimes experienced, also addressed to the assisted person, and generally to anyone who might be involved. Everyone will take the time needed to process entirely what has happened and to realize that, in most cases, no one is to blame for what happened.

*It was as if my world had turned upside down in one single moment. I remember moments of anger very well, even after several months, I wondered why he had been so careless at the time of the accident, in a place he knew very well. (11, wife, discharge)*

Participants narrate how the actual situation is not immediately assimilated, but rather elaborated by different timings. For example knowledge acquisition is part of an inductive process that slowly brings the caregiver to a global change, including the perception of their spouse and the relationship with him/her. There are few people who claim that the initial period was the most stressful, and that personal strength is necessary to overcome the difficulties that overturns certainties acquired during a lifetime.

*The experience led to a global change from a practical standpoint while, from the emotional point of view it led to adapting to a situation that moved slowly, if seen positively. This means that you come here with hopes and when you notice that they are not realized you slowly fit into this reality. Firstly you live it as a contingent condition and then you gradually realize that it is a definitive situation. At the beginning you hope that there may be a consistent improvement, if not a full recovery. I keep hoping every day and, as time passes by, I adapt myself to improvements that do not come. (1, husband, discharge)*

The deep impact that the SCI has on caregivers' personal lives, show the intensity of the changes in the relationship with their relatives and others. However, the most important change can be

observed mainly towards themselves. Caregivers undertake a personal journey that leads them to cope within everyday life, changing perspectives and habits. Difficulties experienced and the sadness resulting from the new condition lead them to experience loneliness, social isolation, often because of their tendency of not sharing their difficulties.

*I feel abandoned by everybody, not only by institutions but also friends: I have to think about everything, I take care of him and deal with the red tape issues... I understand his friends, they do not even have the pleasure of meeting him, there is no dialogue, no enthusiasm, so it is normal that they slowly go away. (10, wife, home)*

Caregivers state that they find themselves in a condition of absolute loneliness characterized by increased insecurity and feelings relating to the lack of support. On discharge all the trouble regarding social exclusion that will be experienced by people after leaving the rehabilitation center are already clear. In addition to centralization of responsibility towards themselves, the resignation for a condition that leaves no way out emerges in this phase.

*What I feel at this moment is that everything is on my own shoulders, because I even cannot find any help from my husband's family. So far I have reached physical and mental fatigue, anger and I am afraid I will explode, because I know I would be completely alone. We must go forward, we entered a tunnel where there is no coming back, there is no emergency exit and you just have to keep on going even if, for the moment, you cannot see any light, just darkness. (9, wife, discharge)*

Returning back home amplifies the feeling of fatigue, closely related to loneliness, that participants have already experienced before discharge. In most cases, caregivers are the only people able to manage people with SCI, therefore they experience a sense of total cancellation of their own time and their personal self.

*I feel very tired, more mentally than physically. I am stressed, my presence is needed 24 hours a day, I am his reference point and from morning till night he calls me all the time, every minute. I cannot find any spare time for myself. (11, wife, home)*

However, there are not only downsides related to the new condition of life. In some cases, the situation has actually helped caregivers to increase their sense of relevance, their autonomy, self-fulfillment and feelings of self-efficacy.

*I am satisfied with the progress I have made, this situation has been challenging, I never used to go out on my own, my husband has always worked and sorted out everything that was needed, now I realize I myself am necessary, I have adapted to the situation many times and I am surprised about my own strength, I have never believed in myself so much as I do now. (4, wife, home)*

#### Search for a reference

The experience in the SCU is reported several times in the caregivers' narration, deeply influencing the discharge process. A feeling of disorientation, typical of the acute phase, during which there is a big concern for the safety of their relative, is mitigated by hopes felt at the rehabilitation centre which is indeed seen as the starting point to retrieve autonomy.

*During the stay at the SCU, we saw the place in a perspective characterized by hope, we had a lot of expectations in this regard. (8, wife, discharge)*

The lack of a reference point and clarity as regards information received from healthcare professionals is widespread throughout the participants' stories resulting in several devastating consequences and common feelings such as frustration, feelings of impotence, lack of confidence, and total disorientation. Caregivers invest a lot of energy which in most cases, is associated with inadequate perceived results compared to efforts.

*I would rather they told us straight from the beginning that there was no clearly defined goal and that they would use all the possible energy to reach recovery. Psychologically it would have helped me a lot. (1, husband, discharge)*

Lack of proper communication is a common experience among participants and it can greatly worsen the caregiver's stress. Health care professionals are not described as lacking clinical reasoning, however, an important gap in information transmission is reported resulting in several misunderstandings.

*A definite step forward should be made regarding the two basic steps of hospitalization, that is, diagnosis communication and discharge management. I think that communication aspects should be more implemented by all professionals. I think that asking patients' relatives for a full support during daily care is wrong. I think this is wrong. I agree with the care training because we are supposed to guarantee safety to our relative once discharged home, but health care professionals should always keep in mind that patients [in the SCU] are patients here for the entire period of hospitalization. (9, wife, discharge)*

Caregivers involvement in the care plan, that is to say, the strong collaboration that is built between caregivers, health care professionals and patients is definitely a positive aspect related to the rehabilitation facility stay.

*I felt integrated and fully participant in the decision-making process, I loved the happiness and optimism of health care professionals. (2, mother, discharge)*

Psychological support for people with SCI is crucial, for this reason there is a multidisciplinary team able to accompany them in a holistic way through the discharge home. Participants' narrations highlighted support seeking experienced by caregivers, as they are not yet ready to accept the situation and afraid of possible mistakes within their relationships with family members, who recognize their extreme fragility.

*I also think that greater support should be provided for us psychologically. Sometimes we do not have enough answers to what they (SCI survivors) have asked us or we do not know how to treat or cope with some behaviors, or even we do not know where we can insist with them. (5, niece, discharge)*

There are not only negative aspects, the lack of a institutional reference point may be overcome by the onset of camaraderie among groups of people, patients and caregivers, within the SCU. The aspect of living with others definitely emerged as a strength considering the perspective of participants in emotional rehabilitation.

*The positive side of being in this place (SCU) is also the constant comparison with other people who live the same situation that we live, you realize that you can live despite the injury. You do not feel so different from others, however, you realize that is an affordable life condition, some things are over but others are to come, it is a different dimension. (1, husband, discharge)*

The importance of the SCU for caregivers involved in the study is reflected in their stories even after discharge. The rehabilitation center also remains a reference point for all the home care health professionals.

*I also think that health institutions should take charge of us, it is not easy to carry on like this. I would like the home care staff provided by the National Health Service to come to the SCU in order to be trained. In this way there would be fewer complications and problems. (9, wife, home)*

### Changing role identities

Spinal cord injury completely disrupts the reference world for those affected and for those who care for them. Caregivers' quality of life leads them to take on a totally different role within the family or in their relationship with the assisted person. This situation is described as a reversal of roles between two lives, a split between "before the SCI" and "after the SCI", nevertheless there are not only downsides. In some circumstances, the caregiver and the individual with SCI may even get closer than before.

*I believe that this situation has enhanced the relationship with my son, we talk much more, it is not just physical contact. Before the SCI our relationship was seconded, almost conflictual. I also*



*succumbed a little, putting myself in his shoes. A relationship of dependency was, re-created, after the SCI, I had the feeling of taking care of him again, even though I urge him to try to achieve goals with his own efforts, I made him to try. I lived this reconciliation really well, I came to think that maybe something positive had happened for us. (3, mother, discharge)*

Caregivers who were interviewed claimed they experienced a new role after the SCI of their beloved. The new role does not concern only the affective spheres. Essential things of everyday life take on a new shape, after the efforts made during the period of hospitalization and those planned for the return home it is hard to feel satisfied. Caregivers feel suspended between memories, feelings, hopes and what reality will be like in the near future.

*I think that the relationship with my husband has changed, but I do not know how to explain it, there is no difference in our affection for each other, I see him as being so different. I am the one who became the reference point, the stronger of the couple. Now I see him as the person I have to take care of, I share everything with him, he was, first of all, a friend and a confidant, it is very different now, I take the initiatives, but I think it is pretty normal, I do not want him to feel guilty towards me. Before the SCI he was my support, now I am his support. (8, wife, discharge)*

*Life is not over, but it has stopped. In terms of communication, of not being able to get on "normally", sexually, mentally because right now, in my head, there is the problem of how to organize the life of my husband and our two children on a practical level...therefore I now feel as if I am canceled from everything, I am the pivot around which everything revolves, but at the end I get nothing from this situation. (9, wife, discharge)*

Once back home, caregivers narrate how the situation remains similar to discharge from the SCU. They emphasize how their main purpose is to care for the assisted person. The close link established with the SCU facility tends to be preserved over time. It increases safety in caregivers and accompanies them through new challenges expected for the proper management of their relative with SCI.

*The situation has not changed since discharge. I am the person who takes care of my brother, my duty is to take care of him. We still attend the day hospital service because he still has a urinary catheter and he will possibly be using intermittent catheterization to empty his bladder soon. Clearly he will not be able to perform this on his own, not having the use of both hands, so I will have to do it. It will be another new experience in this adventure. However, right now, I cannot say too much. (7, brother, home)*

Some stories reveal the discomfort resulting from the difficult caregiving role, the amount of energy spent to encourage relatives towards independence. Sometimes frustration arises as there is a difference between the role they imagined they would cover before the discharge and what is actually happening back home during everyday life.

*In some way I am discouraged, after six months I still can not help him to understand how important it is to schedule his medication and empty his bladder, many times I get angry but I am also tired of it, right now I don't want to fight anymore because, in the end, he is an adult, and I would like him to learn a lesson. (3, mother, home)*

### Hope for the future

At the end of the rehabilitation path, just before discharge, the desire of going back to their lives is undermined by the increasing fear that accompanies participants during their hospital stay. This is driven by a sense of inadequacy and insecurity typical of this delicate phase.

*Now I know that when we will be back home I will be alone with my children, they are young and I cannot expect much from them. So I am afraid of what awaits me when I go back home, because my husband has got a lot of needs, if it were up to him I would always be tied to his bed, he does not give me the opportunity to organize myself for my own self, I have to calculate the minutes to have a shower. My fears concern the fact that I do not want to hurt him, but I am starting to get very*

*tired, and the main doubt that arises is that “will I be able to cover his needs once at home?”. (9, wife, discharge)*

Fear and insecurity experienced by assisted people once at home after discharge, that is to say, outside a safe environment as the SCU was, emerged from caregivers' stories: consequently there is, often, a sudden slowdown concerning the journey towards autonomy.

*As far as going out is concerned I try to do more and more, so that she learns to manage herself and to be more self confident, although I realize that she immediately experiences a crisis when I am not there, it is as if she has no support, then she says “I’ll try” but with poor results. The only significant change I noticed in her character is that she is generally increasingly afraid, much less self-confident, I find her very apprehensive. (1, husband, home)*

Hope is crucial in caregivers' motivations. In many cases although they give the impression of resigning to living this new condition, it is always present, even back home, the hope for a better future, or at least, the desire for a life which is very similar to the one lived before the SCU admission. Hope helps them to face the present too. The greatest concern for those who are the only relatives taking care of SCI survivors, is to keep healthy enough to be able to assist them.

*Even if there were not a full recovery, I hope that even in a wheelchair he would continue to stay with me, with a healthy attitude. If I need to find a positive aspect, I am sure that now that I am at home I will certainly have less anxiety, my husband will always be around. We must go forward, I cannot make many plans, I realize that I have to take every day as it comes. I am afraid of being sick, I feel a huge responsibility, if I were no longer here how could he survive if not in a health care facility? (2, wife, discharge)*

*Findings from the latest research give us a lot of confidence, and we keep hoping for new developments, we love hope. (1, husband, home)*

### Modifications to everyday life

Returning home is described by participants as a moment full of mixed emotions. There is happiness to restart a life that was interrupted by the SCI but, on the other hand, there are doubts about future uncertainties as well as bitterness for a condition that does not allow the couple to be as it was before the accident.

*Seeing him back home is a joy. I have him back here to keep me company, it is a great comfort to me. I always keep on having great hope, so I experienced this return back home as a liberation, although it is still studded with many concerns. (2, wife, home)*

Once back home caregivers find themselves in a situation of having to build a new balance with the assisted person. There are difficulties related to the physical sphere and sexuality, which is in contrast with the tendency to build a symbiotic relationship on a psychological and relational level. The complex situation experienced by participants leads them to naturally develop high emotional stress which only enhances their uncertainties .

*The relationship with my husband has definitely changed. We are in tune emotionally, we talk, we trust each other, however, there is little on the physical level, I feel I still have the typical needs of a young woman, it is very hard. Occasionally I realize my character has changed, sometimes I get angry and I blame him too and I feel very sorry about it afterwards, I do not even know why I have this kind of reaction but I think it derives from the frustration that I feel for this situation. (8, wife, home)*

It is clear that everyday life is not comparable to the one experienced before the SCI, habits and lifestyles must change, sometimes dramatically, with considerable difficulties involving a sense of oppression with the situation.

*At first it did not seem so hard...but a lot of things have changed, not only in terms of our relationship, but considering our entire daily routine. I was used to doing just the bare essential, especially at home, now I feel more tied, I have to be constantly present...I do what I have to do but*

*to be honest it burdens me a lot. Life is no longer as it was before, it has changed a lot. (6, husband, home)*

It appears that it is necessary for caregivers to receive helpful support to bear the complexity of the situation since doubts undermine certainties acquired up to that point. . Sometimes they consider external support as essential to relieve their enormous burden.

*It is hard to believe that this will be my life forever...sometimes I see fathers who take their children to school and I think about how our lives would be without the SCI, this accident has shocked everyone. I started talking with a psychologist about my problems, even though I decided to do it alone. I feel that it helps me not only to understand but also to express my deepest emotions. (8, wife, home)*

After six months from discharge most participants revealed some kind of acceptance of the situation, some of them feel confident they will returning to normality, to the life before the SCI, even if there is a sense of discouragement in many of their stories.

*Now I think that this is my life, you need to take it as it comes without despair, without looking for something that unfortunately no longer exists. You are in a constant state of unstable equilibrium, I always feel on the edge of a cliff. (9, wife, home)*

In some cases, participants are aware that they are living a new life, with physical ties that limit their pre-SCI independence. Participants feel their lack of freedom as imprisonment. In this case change is experienced with greater difficulty.

*I feel very tied to this situation, a physical connection. The only free time I can find for myself is when we receive visits from my daughter or close friends. In that case I spend the limited time I have for myself, even if past times are now a memory. The thing that I suffered most was the sudden transition from the old life to the present one, it is as if I started living another life which I did not know before. (6, husband, home)*

## DISCUSSION

The study emphasizes the challenging impact of spinal cord injury on caregivers, characterized in the early stages by negative feelings such as anger and even despair, as widely reported in the international literature. [2, 6, 17]

Discharge from the SCU is an important moment in the path taken by SCI survivors' caregivers. It means leaving a safe environment after several months. At this moment a dual emotional state coexists. On one hand, there is the desire to go back home, trying to start the process towards the highest possible degree of autonomy while, on the other hand, there is fear and concern for clinical, logistic and organizational issues. [2, 8, 20] Beyond these feelings there is a great sense of responsibility and caregivers are challenged with expectations in returning to a normal situation, although a change of perspective towards assisted people is already evident. It is clear that, at this stage, both explicit and implicit needs arise from the people involved.

Assuming that participants in our study were different as regards age, parental or emotional relationship with the SCI survivors, we were able to affirm that the afore-mentioned problems are substantially comparable, apart from physical and sexual aspects, where experiences narrated by spouses are surely different from other caregivers. Differently the relationship between mother and son encloses other interpersonal aspects, concerning the role redefinition.

From caregivers' narrations it seems evident that the phase of taking charge and the subsequent cohabitation with the assisted person involves using all the available resources, including high energy expenditure both physically and mentally, pushing participants beyond their own abilities. Caregivers feel they act as a link between the assisted person and the outside world, being squeezed between needs, bureaucratic issues and costs. It appears as if their satisfaction comes second place, after the assisted person's needs . [19] Common feelings emerge, that is, living in symbiosis with the injured person, and acting as a link in their lives. The multitude of actions taken to ensure the

needs of persons with SCI inevitably leads to a decrease in leisure time, progressive loss of interests, freedom, spontaneity which previously ensured caregivers' self-perception. [7]

The process of adjustment, the change in the relationship between the caregiver and the assisted person is a process that can take on different forms, with different timing. It reaches its completion on returning home with an initial loss of their role in a setting which had a different meaning before the SCI.

The analysis of participants' narrations illustrate the progressive loss of identity of those called to assist a person with SCI. Indeed, we are facing a redefinition of the partner's role, supported by a radical change in the couple's dynamics, and this is also reported in previous studies. [16, 17]

As revealed by participants, and as already stated by other studies, [6, 17, 28] we find that addressing the personal and physiological needs of an assisted person can decrease complicity and the intimate relationship of a marriage. Results highlight the feeling that there is a loss of spontaneity, romanticism, with little time to devote to the couple's intimacy. There is great difficulty in approaching sexuality, which leads to a change in the relationship, from people who love each other even just on a physical level, to a relationship of maternal dependency. [28, 29]

Despite many uncertainties involving challenges related to the new condition of life, many participants express a stronger emotional relationship with their relatives as a result of SCI. They claim that the bond between them is more intense. [17, 30] A sense of extreme satisfaction is expressed by participants as a result of maintaining their marriage union, describing the lived experience as the final confirmation of their love.

Results should alert healthcare professionals as to the need for constant assessment of caregivers' needs, which are constantly changing depending on the path they follow outside the rehabilitation center. Planning a six month to one year follow-up from discharge, during which health professionals would assess caregivers' unmet needs, progress and the degree of adjustment of the relationship between caregiver and assisted person, could facilitate people in the coping process. [17, 31]

Another key point to be considered during hospitalization is certainly the role that the caregiver has to play in the rehabilitation process. Participants' considerations about the period in the SCU highlighted that SCI survivors' caregivers should receive the necessary preparation to take on their new delicate role, or even a personalized support in order to maintain the level of competencies achieved. This underlines the need, already shown in previous studies, [6, 32] of greater caregiver involvement in the rehabilitation process. Moreover, healthcare professionals have to adopt specific educational strategies, such as problem solving and cognitive-behavioral therapy, which ensure the identification of specific needs at regular intervals to reduce their dissatisfaction and prevent the onset of depressive symptoms. [19, 33, 34] These strategies should be necessarily adopted by all healthcare professionals to provide a real multidisciplinary support to caregivers.

As far as hospitalization is concerned, the most common experienced problem reported by participants is the lack of communication with healthcare professionals and the unclear information regarding diagnosis and the path to follow. The great importance of receiving information, emerged very often from participants narrations and it is identified as a way to overcome the confusion and doubts brought on by the SCI. [15, 35]

In addition to already observed relational issues, during hospitalization, a lack of psychological support is detected, which would have a pivotal role in the rehabilitation process, both for the caregiver and the assisted person. It would help to re-elaborate emotions and accept the change of roles. As highlighted by previous studies, people who suffer high emotional stress are at risk for the onset of long-term anxiety and depression. [9, 19] Therefore, it is a clear priority for health care professionals to immediately identify and address people with SCI and their caregivers for proper treatment to help them to better manage the situation. Social support for caregivers has also been

indicated as a key factor [17, 29] for the maintenance of their well-being since it reduces the sense of social isolation and burden related to stress and depression.

Focusing on results obtained, we can affirm that the health condition of the caregiver must be safeguarded, his physical and mental balance is severely tested on returning home. In most cases he is the only one able to manage the assisted person, which makes him and even the patient feel extremely anxious. There is a fear the situation might precipitate with feelings of loneliness, frustration and abandonment. [2, 11, 18, 36] The great strength of willpower that emerges from stories clashes with the decline in mental and physical health resulting from the daily situation of caregivers. Some quantitative studies have shown that health status and physical function in caregivers worsen after returning home, in some cases the decline occurs after 3-6 months after discharge [8] and this is supported by narratives collected in our study.

In relating our data with the existing literature, we can also affirm that regular follow up visits supported by a psychologist should be extended to caregivers of SCI survivors since they are involved in the same way in the psychological process of adaptation to the new condition. [18, 37] Psychological support has a pivotal importance in the rehabilitation process since it contributes to emotional elaboration and acceptance of the changing role. [38]

Participants emphasize that closeness with other people experiencing the same situation of difficulty although at different moments of the rehabilitation program, may offer some interesting ideas in terms of motivation. A motivated person is, indeed, a person who is more confident in his own means and his own skills. Peer support is a crucial factor here since it plays a key role in activity promotion and identity development. [29] Support groups have been shown to give caregivers the opportunity to express their emotions, to find positive aspects in their situation and they are effective in reducing feelings of loneliness and social isolation. [39]

Tiredness, uncertainty as to what the future might bring, a feeling of helplessness concerning the disease are important factors that heavily contribute to the perception of the substantial difference which exists between what should be guaranteed by institutions and what is actually available for caregivers. [2, 5, 14]

The lack of an adequate number of highly specialized centers for the management of individuals with SCI makes it difficult to ensure continuity of care, estimated internationally in 15-30 days post-discharge hospitalization per year, resulting in further disruption for the caregiver.

From participants' narratives the perception of loneliness emerges at the time of discharge, along with lack of liaison between hospital and community services. The protection and the sense of absolute availability perceived during hospitalization decline when one becomes aware of the difference with home care and the shortcomings of the support system. This often shows that the will of both caregivers and the assisted persons is to stay in touch with the rehabilitation center. The assessment of caregivers' needs should also be extended to local services which have the duty to track needs of people involved in the care of the person with SCI.

The implicit request is to remove the existing barriers between hospital and community services, [31] through the use of the most innovative communication channels which would allow the implementation of skills on a local basis. [40, 41]

Study limitations are related to bias in the recruitment of participants. It is possible that those who have decided to participate experienced substantially feelings, and have conflicting motivations and needs which are different from those who declined participation. Results obtained are generalizable with caution as regards the general population of caregivers of people with SCI, as obtained from a sample of assisted persons with a severe or total dependence inserted in a specific geographical regional and national level relating to the Italian National Health Service. Bearing in mind that the average period of hospitalization is different from other countries this may have influenced the experience lived by the participants. In addition, we considered the six month period

after discharge from the SCU as predictive, although we are aware that it is a very short period in the whole trajectory of relationship adjustments between individuals with SCI and their caregivers.

## CONCLUSION

Exploring the experience of a caregiver of a Spinal Cord Injury survivor has allowed us to highlight two key moments related to the process of caregiving, that is, the final phase of hospitalization before discharge and, the lived experience at home after six months.

Results of this paper suggest the importance of improved management of the discharge phase from the Spinal Cord Unit and caregivers' taking responsibility for the care of the individual. Caregivers' greater integration into the rehabilitation program, a structured assessment of needs during the early stage of returning home, an adequate taking responsibility for the care of the individual which includes improving health professionals' communication skills and psychological support and, finally, improved liaison between hospital and local services are some suggestions which we can conclude from our results.

Caregivers emphasize they only had a limited space, to date, in the rehabilitation process of their beloved. They ask for a leading role with greater support in decision making and care planning for people with SCI right from the admission to the rehabilitation facility. In light of the skills acquired over the years in the management of their relatives affected by SCI it is essential to consider caregivers' experience from the perspective of health policy for planning care for people with disabilities, that is, aiming to rationalize resources available and provide a customized offer to meet their needs.

In a rehabilitative setting, it is important for staff to note that changing the style of communication and transmission of accurate information can produce effective results in terms of therapeutic alliance and resilience of those involved. In light of the results obtained it would be useful to carry out further studies in this area.

Finally, future research should aim to assess the problem-solving abilities of people facing disability, which would be very useful for all the healthcare professionals concerned with the enhancement of self-efficacy of patients and their families during the rehabilitation path.

## DECLARATION OF INTEREST

None

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<b>Box 1</b>	<b>Interview Track</b>
1.	Reaction to SCI, feelings during the acute phase
2.	Entrance to SCU, admission time, hospitalization, satisfaction
3.	Relationship with institutions (health professional, social workers, community)
4.	Utilized resources, relationship with the assisted person
5.	Home care, everyday life (question for after six months group only)
6.	Expectations for the future

Table 1. Sample Characteristics

N°	CAREGIVER					PATIENT				
	Age	Gender	Kinship	Children	Perceived Health	Age	Gender	Injury level	Length of hospitalization	MBI.
1	48	M	Spouse	NO	Passable	36	F	C7 complete	18 months	24
2	80	F	Spouse	YES	Satisfactory	82	M	C4 incomplete	10 months	31
3	49	F	Parent	YES	Passable	19	M	C6 incomplete	9 months	44
4	62	F	Spouse	YES	Satisfactory	64	M	C5 incomplete	8 months	21
5	49	F	Niece	YES	Satisfactory	71	F	C6 incomplete	9 months	31
6	68	M	Spouse	YES	Passable	65	F	C5 incomplete	8 months	44
7	61	M	Brother	NO	Passable	55	M	C4 complete	12 months	21
8	28	F	Spouse	YES	Satisfactory	28	M	C5 complete	9 months	15
9	41	F	Spouse	YES	Unsatisfactory	52	M	C4 complete	13 months	5
10	73	F	Spouse	YES	Passable	75	M	T11 complete	7 months	49
11	73	F	Spouse	YES	Satisfactory	86	M	C5 incomplete	8 months	2

\*Modified Barthel Index

Table 2. Themes and Units of meaning	
Themes	Units of meaning
Coping with changing perspectives	<ul style="list-style-type: none"> <li>- desperation</li> <li>- anger</li> <li>- slow adaptation</li> <li>- loneliness / abandonment</li> <li>- fatigue</li> <li>- personal strength and growth</li> </ul>
Search for a reference	<ul style="list-style-type: none"> <li>- questions and expectations</li> <li>- communication and involvement</li> <li>- comparison with others</li> <li>- reference points</li> </ul>
Changing role identities	<ul style="list-style-type: none"> <li>- strengthen</li> <li>- role subverted</li> <li>- take care</li> <li>- promote the autonomy</li> </ul>
Hope for the future	<ul style="list-style-type: none"> <li>- fear</li> <li>- hope</li> </ul>
Modifications to everyday life	<ul style="list-style-type: none"> <li>- positivity</li> <li>- build a balance</li> <li>- external support</li> <li>- accepting the situation</li> <li>- freedom / imprisonment</li> </ul>