



UNIVERSITÀ DEGLI STUDI DI TORINO



## Educational pathway of people with Spinal Cord Injuries: a participatory research project starting from the illness narratives



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### The start of our journey

Spinal Cord Injuries (SCI), due to their disabling nature and complexity, lead to severe consequences in quality of life (QoL) of both the individuals and their carers (WHO & International Spinal Cord Society, 2013). People with SCI suffer from various issues comprehending the loss of the motor-sensory and the autonomic neurologic functions that result in loss of mobility, bowel, bladder and sexual independence (Alexander et al., 2009). Thus, the achievement of self-care behaviours is essential to people with SCI, lifetime, especially given the decrease in the length of stay in rehabilitation (National Spinal Cord Injury Statistical Center, 2016)

Between 250000 to 500000 people, nowadays, suffer a SCI annually: traumatic injuries are the majority, especially in developing countries, where working and roads safety programs are lacking (Lenahan et al., 2012). At the same time in developed countries, recent studies highlight an increase in the age of SCI onset and a progressive increment in the proportion of non-traumatic SCI, attributable to the ageing population (WHO & International Spinal Cord Society, 2013). It is esteemed that the direct and indirect costs of SCI exceed up to 20 times those related to other

disabling neurological diseases, such as dementia or sclerosis(DeVivo, Chen, Mennemeyer, & Deutsch, 2011), with a significant impact on expenses depending on the injury level and its completeness(WHO & International Spinal Cord Society, 2013). Direct costs may encompass hospital budget for acute care and rehabilitation and are higher during the first year after SCI onset(DeVivo et al., 2011). Indirect costs, which increase along the years, are connected to the lost productivity due to premature death or disability(Haeusler, Tobler, Arnet, Huesler, & Zimmermann, 2006; Munce et al., 2013).

SCI people have also to cope with a wide range of activity impairments as domestic, education and employment ones, together with important limitations in social participation social relationships and leisure activities(WHO, 2001). Moreover, despite the low average age in this population which presumably implies the return to their previous social condition, including work or study(Ullah, Fossey, & Stuckey, 2018), people with SCI are at high risk of secondary complications occurrence, which influences the long-term health, independence and QoL. This conditions can result mainly in higher morbidity and mortality(Biering-Sørensen, Bickenbach, El Masry, Officer, & Von Groote, 2011; Furlan, Kattail, & Fehlings, 2009), in rehospitalisation, and can limit the work participation further increasing the costs of healthcare for SCI survivors (Skelton, Hoffman, Reyes, & Burns, 2015).

In the light of all above, it seems clear how SCI assume the characteristics of a chronic disease. Skills required to maintain the highest level of performance have to be acquired during the rehabilitation process and, in order to ensure adequate standards in term of QoL or to prevent the any complications that can lead to clinical worsening or hospital readmissions, must be expressed at home by SCI people themselves or by their caregivers(Burkell, Wolfe, Potter, & Jutai, 2006). In this process of learning, healthcare professionals, and especially nurses, are viewed as the preferred source of valuable information(Matter et al., 2009). Healthcare professionals ground their educational intervention on the patient needs providing knowledges through an individualised approach. In this light, the educational pathway led in the Spinal Cord Injuries Unit (SCU) should be considered the preferred means to improve patients' self-care skills and to positively contribute to the improvement of their QoL. As such, this process implies, at first, the understanding of the patient needs and secondarily the renewal of the relational dynamics between the patients and his family, between the patients and the healthcare providers, as among the patients..

Given these premises, our research aimed to identify, through illness narratives, the educational needs of SCI people; to assess both pros and cons of the delivering of those information that

healthcare professionals perceive as essential to patients and caregivers to the improvement of self-care in order to reduce complications occurrence and the risk of hospital readmissions.

### **Planning the best route**

A qualitative descriptive study using the narratives of people with SCI, involving their caregivers and healthcare professionals was used.

The whole investigation was planned to occur in two separate moment of research: the first one involving the people with SCI discharged at least six months from SCU, and the second addressed to healthcare professionals, that involved 16 professional of four SCU in Italy.

The two phases were finally gathered in a Consensus Conference, combining and confirming the results of the two separate steps into a participatory process of summarization of the evidence produced.

The first step aimed to explore the perception that SCI people had about their health after the injury, highlighting positive or negative self-care behaviours, in order to identify any potential educational areas in which may have emerged the need of knowledges linked to self-management.

The second step was aimed at investigating the health providers' point of view regarding the conceptual and practical knowledges considered as crucial to people with SCI at the moment of discharge from SCU.

In both steps the sampling was purposive. Sample sizes wwere not fixed a priori.

The first phase included SCI people discharged within a minimum of six months and no more than five years, aged 18 or older and speaking Italian language, independently of their ethnic background; the level of injury and the functional independence was not use as an eligibility criteria but allowed intragroup omogeneity. People with mixed diagnoses, with cognitive impairments or discharged at any facilities, and not at home, were excluded.

Four different focus group interviews were conducted. In each of the three group a maximum of six participants was grouped homogenously, based on functional independence level. Data collection was driven by pre principle of data saturation. Group interviews followed a semi-structured interview track, eliciting questions and probes useful at fostering participants' discussion were also used when needed. Socio-demographic data (age, gender, working status, marital status, education) and clinical information (time and level of injury, level of independence, caregiver) were collected before the interview. All group interviews were audio recorded and narratives were manually

transcript verbatim. According to the qualitative methodology adopted, the data collection and analysis of every interview was performed as simultaneously as possible, in order to inform the subsequent interviews and reach the data saturation (Bender & Ewbank, 1994).

The second phase included healthcare professionals (as doctors, nurses, physiotherapists, occupational therapists, psychologists and social workers) working in SCU on the Italian territory and expert patients (as those having an active role in any SCI patients' associations).

This phase was conducted through the use of a Delphi process. The Delphi is an iterative research design in which participants, considered experts in the field of research, are involved individually and anonymously, to express their opinion about a topic: in our case the educational and the practical needs of people with SCI. Accordingly to the Delphi method, data were gathered through semi-structured e-mail questionnaires. The whole process was developed in three different rounds (Vernon, 2009). All data were processed in an aggregate anonymous form.

All the narrative data gathered were mainly textual and were analysed through a thematic analysis approach to Braun & Clarke principles (Braun & Clarke, 2006). Transcriptions were initially coded as general recurring themes by using the same words provided by participants or by using words which synthesised the unit of meaning, endeavouring to keep the original meaning. Subsequently, within each theme the words used by participants were categorised and condensed into codes in order to indicate needs, worries, practical issues, barriers, and so on. The whole analysis was supported by the use of a qualitative analysis software. The quality of the study was ensured using the Lincoln & Guba framework (credibility, dependability, conformability, transferability and authenticity) (Lincoln & Guba, 1985).

The study design was supported by the Head Office of Città della Salute e della Scienza Hospital of Turin, Orthopaedic Traumatological Centre, and was formally approved by Ethical Committee of The Città della Salute e della Scienza di Torino, (Resolution n° 0105785).

Participants signed an informed written consent before the interviews were performed.

### **Giving a voice to SCI people**

A total of 22 people with SCI were enrolled in four focus groups. Six of them were independent and not using a wheelchair, five were independent wheelchair users, six were partially independent wheelchair users, and five were totally dependent. Participants were mostly males, affected by

paraplegia for more than three years, with a mean age of 49 years, and only five of them maintained an active working role.

Three main themes emerged: essential preconditions to deal with the inward pathway and perform an effective self-care; the ways through which people with SCI take care of their health; the requisites to increase the effectiveness of the educational pathway.

SCI is a disrupting condition that generates a sense of fear in participants that does not completely understand the situation. In the acute phase of rehabilitation there is a lack of awareness of their effective health condition, and for this reason they referred that it is important to receive immediate clear and prompt information. When an improvement in the functional ability is seen, the approach of participants changes, banishing the concerns of the first times.

The injury aetiology introduces important differences in the way the educational and rehabilitation pathway is lived. Participants who suffer from a non-traumatic SCI consider the new acquire condition as a consequence of their disease, in which monitoring and management skills represent the main needs. To place themselves at the centre of their new life and starting from scratch, participants' narrations highlighted how the key factor of the process is the acceptance of the new condition, as a required step to find the strength to react. This turning point implies the consciousness to give up the hope of becoming functionally independent again. Participants told that the process of adaptation is partly mediated by the rationality of modifying their targets and partly unconscious.

The health perception is strictly connected to the level of independence reached. Participants declared that well-being is the essential component needed to move the frustration away. The psychological aspects are fundamental to deal with the situation and are a key factor, without which is impossible to engage in the rehabilitation process. Those aspects are essential to be more focused on the simpler aspects of the everyday life, especially giving some special values to social inclusion and relationships, increase the perceived well-being of participants.

The families play a leading role in maintaining the sense of perceived safe in people with SCI, allowing them support to face new challenges. On the other hand, families may become a barrier, especially when it does not promote the independence of SCI survivor, due to an excessive concern. To feel useful is another crucial element in the rehabilitation pathway, so participants highlighted that feel themselves a strain for others is a barrier to well-being. To feel useful is strictly connected with maintaining an active working role and help the peers who live the same life situation.

Participants declare that take care of their health means to take a special attention to a whole range of different aspects: this condition is perceived as struggling, and the self-care needs a lot of time to be performed. These aspects give more difficult the complete adherence to the prescriptions given by healthcare professionals, and in general, it seems complicated to follow the recommended behaviours. Participants who establish a daily routine are more satisfied and keep higher reliability in maintaining an effective self-care. The prevention is transversal to all the identified themes, and it implies the maintenance of a set of behaviours which make people with SCI free from complications. The self-care behaviours highlighted by participants are predominantly: physiotherapy exercises, use of assistive devices, pain and spasms control, sexuality, skin-care.

To know how to taking care of themselves means imply the learning of how to live differently and to acquire new knowledges and skills. Skills and knowledges can be learned through a complicated educational pathway that is time and energy consuming, that begins in the SCU and that continues after the discharge, at their home. This educational process implies that people have to learn to accomplish all the activities of daily living from the beginning, due to the completeness of SCI.

The precondition is the awareness of their condition, its acceptance, the psychological well-being and the balance between the support received by the families and the sensation of being useful. The education is reached by a high dose of commitment and motivation; moreover, to trust in the healthcare professionals is fundamental to this process. The targets of participants are different, and they vary based on their age, personal inclination and individual prospects. The knowledge and the skills considered more urgent are mainly: to learn to reach the more independence, to manage the bowel and bladder functions, to use the wheelchair, to perform the exercises to maintain their muscular function, to manage their sexuality.

The peer education is highlighted as the best method to learn how to manage their health condition; the peers give some advice, assistance, motivation and information. To learn from the everyday life is often cited as a method in which SCI survivors proceed by a trial and error process. An overarching theme during the focus group is the time needed for the education: participants perceived that they have to learn a lot in a short time. Instead they give some attention to the importance of learn slowly and with the right timing. The educational pathway is very long that proceed with short steps, and a relevant issue is that people with SCI are often not ready and responsive from the first stages of the rehabilitation process, due to the psychological stress and physical limitations.

From the narrations of participants, it emerges the importance of a proactive approach which is capable to stimulate them and make them in the condition to follow a routine, even with the involvement of expert patients, who serve as an example to follow. In this regard, the sport is a good ally in the rehabilitation, and the participants define it as an instrument to make them feel better, both in the psychological and physical spheres. Between the instruments used during the hospitalisation, some participants identified the week-end's licence at home or the training outdoors with the occupational therapists. Moreover, participants suggest the need of further instruments to sustain the rehabilitation pathway, especially at the discharge from the SCU, because that is the moment in which people with SCI and their families understand their needs effectively.

The potential barriers identified through our study are referred to the identity, the territory, the society, the bureaucracy, the architecture and the economy.

Identity barriers are defined as the way in which people with SCI define themselves about other people: disability means to pass unnoticed due to the limitation of mobility, or being labelled as unable people. Territorial barriers refer to the lack of social services on the national territory able to answer to the needs of people with SCI; in particular, some General Practitioners and healthcare facilities show a lack of knowledge on the clinical assistance of SCI individuals. Social and cultural barriers are defined as the discriminatory attitude of society perceived by people with SCI. The bureaucratic barriers imply obstacles in the funding and social support for people with disability, which do not allow people to reach the entire relief from the health policies. Architectural barriers are a real strain for people with SCI, especially for who has a bad independence level: leisure activities as moving around, going to holidays, visit friends become complicated, because of the lack of the accessibility of several places, starting from the health facilities. Economic barriers are referred to the difficulty of maintaining an active working role or a pension which offer an adequate income to SCI survivors, especially because the high costs which the condition implies on the families.

### **The healthcare professionals point of view**

A total of 16 participants took part to the Delphi. The process focused on the definition of the core knowledges people with SCI must have at discharge from the SCU, and that has to be reinforced during the outpatients' visits and the everyday life.

The sample was composed by two Psychiatrists, an Urologist, four Nurses, a Head Nurse, an Occupational Therapist, four Physiotherapists, a Social Worker, a Psychologist and an Expert Patient. The group performed a three-round study during which participants were asked to identify the core skills that people with SCI should acquire to perform an effective self-care.

Answers to the first round were organised into two main themes: the core skills to teach to people with SCI and the actions that healthcare professionals have to do in order to give an answer to the need for knowledges.

In the second Delphi round, the aim was to take into consideration exclusively the items of the educational area, as targeted to the aim of the research. This round used a semi-structured questionnaire, built on the first round occurrences. Participants were asked to give their opinion about the item through a five-point Likert scale, and were also asked to comment whether the listed skills were thorough and whether any new categories should have been included or eventually modified. The assigned scores were assessed through two measures: the consensus and the agreement.

A check-list designed to verify the level of performance assessed by people with SCI before the discharge at home from the SCU was finally produced through a third round of the Delphi. The whole set of items (the one obtained in the first and those added in the second round) were tested again using a five-point Likert scale. The aim of this third round was to show to participants the tentative items list, submitting them the items which did not reach the consensus of the 60% and the agreement of the 80%, and to obtain an evaluation on the new items deriving from the second round.

The third round resulted in a definitive list of items, divided into categories, useful to the creation of a check-list through which verify the acquisition of knowledges and skills provided to SCI people before the discharge from the SCU, in order to reduce the risk of occurrence of secondary complications. Into the instructions to the fulfilment of the third round, it was specified that the check-list was intended as an instrument given to people with SCI, independently from their level of injury or independence.

A total of 63 items distributed into 15 categories were included in the final version of the check-list, which has to be evaluated and corroborated by people with SCI and healthcare professionals.

**To be me in your shoes**

The natural end of our research was to put together the work of people with SCI and healthcare professionals. During a Consensus Conference conducted in the 2<sup>nd</sup> of May 2017, the results of the two phases were publicly discussed at the presence of an audience of 80 participants composed by people with SCI, their caregivers, and healthcare professionals. The most important part of the day was during the confirmatory process during which every item contained in the check-list was discussed and modified in case of disagreement between participants.

This event represents, to author knowledge, the first collaborative experience held in the Italian context, giving all the actors of the educational process the possibility of expressing their personal view. The final result is a check-list which can be used and evaluated, about the satisfaction of people with SCI, their families, the healthcare professionals, the perceived quality of life and the occurrence of secondary complications.

### **The last step is the first**

Our study have highlighted how SCI changes the individual representation of health: from the occurrence of the discharge at home, people with SCI live a stressful transition, redefining their self-care behaviours. Indeed, for SCI survivors is necessary to take care of themselves in a new way, putting themselves at the centre of their rehabilitation pathway.

Take care of themselves implies the learning of new self-care behaviours. Findings suggest that there are preconditions to learn these behaviours, in particular people, can take care of them if they have an awareness of their condition, accept themselves, whether they can count on a psycho-social balance, with the help of their families.

Self-care behaviours are time and energy consuming and is important to follow a routine to maintain the condition stable and free from complications. The educational process continues, and during its pathway is fundamental to learn again how to perform all the self-care behaviours to take care of the body, its primary needs and of the mind as well. And this process does not end with the discharge from the SCU, but continues lifetime, at home. Any educational interventions could be effective when SCI people are motivated, when they trust in the healthcare professionals and if they perceive to be ready to learn both physically than physiologically.

Peer education have shown to be a precious resource in the rehabilitation process of people with SCI, as the physical exercise or the sport.

The educational process was reported to be slow, and it implies that professionals take into account that timing is a fundamental resource to consider, in order to give a start to the process and to effectively proceed during the hospitalisation and, more importantly after the discharge.

A proactive approach, that motivates the people with SCI and involves them and their families in the design of the right pathway, will be also effective in increasing the satisfaction this people have of their health, of the psycho-social well-being and on the level of collaboration needed to face with the health policies. New instruments to evaluate the effectiveness of this approaches and a systems of surveillance, is highly needed in order to reinforce the education of people with SCI and to reduce undesired secondary health conditions.

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