

Statement on the quality of spinal cord injury rehabilitation and management

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Introduction and background

The 6th annual ESCIF Congress and Assembly of Delegates were held on 18 – 20 May 2011 in The Netherlands. The congress theme was: (Proven) Quality of SCI Rehabilitation.

There were around 90 participants; delegates from ESCIF member organisations, people with spinal cord injury (SCI), SCI professionals, congress sponsors, researchers and quality experts, from 22 countries in Europe and also from the USA.

The theme of the congress was/is an important and logical follow-up to several ESCIF projects such as the *Centralisation of the treatment, rehabilitation and life-long care of persons with spinal cord injury* and *Peer-counselling/support*. It addressed such topics as how to measure and evaluate quality in healthcare, the specific requirements of people with SCI, the knowledge and skills of SCI professionals and the accreditation of SCI facilities.

At the end of the congress, participants were challenged to formulate recommendations to assure the desired quality of SCI rehabilitation and the facilities required to achieve this. Three workshops were held where the input from the congress so far was discussed from three perspectives: people living with SCI, the SCI professional and the organisation providing SCI care. The main outcomes of these workshops, such as the importance of life-long follow-up (including professional management and self-management), support after discharge to ensure reintegration, and peer-counselling, have been considered in the writing of this report. The working group added the words 'and management' to the title of this statement to emphasise that this paper is not only about 'quality **during** SCI rehabilitation' but also about 'life-long quality when **living** with SCI'.

After the congress, during the Assembly of Delegates, the proposal of the ESCIF Executive to form a working group to formulate an ESCIF statement was approved. The working group had one year to formulate a draft statement on quality of SCI rehabilitation and management.

The ESCIF Assembly of Delegates endorsed this 'Statement on quality of SCI rehabilitation and management' in Italy on May 25, 2012.

There are many definitions of 'quality'. In this paper, quality is defined from the perspective of people living with SCI. But quality may mean different things to different people. This is why 'patient-oriented care' and 'self-management' by people with SCI are good starting points. Where baseline measurements of quality exist, these are used in this paper.

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Working group members: Jane Horsewell, Frans Penninx and Gunilla Åhrén

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Organisational and chronological perspective

Organisational perspective

In order to achieve quality in rehabilitation, a certain organisation needs to be in place. In the report on *Centralisation of the treatment, rehabilitation and life-long care of persons with spinal cord injury*, ESCIF defined what we mean by a Spinal Cord Injury Centre (SCIC), the stages of care provided by the SCIC and the necessary facilities. ESCIF believes that these demands must be fulfilled in order to achieve and maintain quality.

The cornerstone of a good rehabilitation programme is patient-centred and goal-oriented. An SCIC provides individualised rehabilitation in accordance with personal rehabilitation plans that focus on the motivation, integrity and dignity of the person with SCI and which are devised in consultation with him/her. The rehabilitation process encourages and empowers patients.

A seamless approach is required that addresses the medical, vocational, social/economic and the community effects of SCI. For the service to be optimal, it needs to be based in a centre of excellence with appropriate facilities and staff who are trained to manage people with SCI from the acute stage, through the process of rehabilitation and back into the community. The centre must be geared to provide lifetime specialist health support for persons with SCI.

However, it is important to remember that the mere fact that a certain organisation is in place does not automatically guarantee quality in rehabilitation. It is, therefore, crucial that rehabilitation outcomes are measured and evaluated to ensure continuous improvement of the rehabilitation programme.

Chronological perspective

Another way to approach the issues involved in the definition and monitoring of quality in the rehabilitation and management of SCI is to consider the various "care events" in the order in which they occur. In other words, starting with the injury or diagnosis of SCI and working through the events that follow chronologically – transportation to primary destination, transfer to a rehabilitation centre, return to the community, life-long follow-up and management. Each step requires a benchmarking procedure to define and describe standards. The benchmarks may define the minimum standards that are necessary for the provision of adequate care, but may also describe the goals for excellent care. In both instances, unacceptable practices should be listed.

If, for example, we consider the event of a suspected spinal cord injury in a road traffic accident, then it is possible to define certain "Do's and Don'ts" that will enhance the chances of survival of the accident victim, that will ensure that the injury is not exacerbated and that will promote the chances of successful treatment and rehabilitation. Minimum standards here would include the existence of an emergency response system (ambulance) that can be summoned on a publicly available and known telephone number. The next demand would be that the ambulance personnel are aware of and trained in the initial care of potential SCI patients, and that they have the equipment required e.g. a back board, and neck and head stabilisation aids. Finally, of course, there must be a hospital within driving distance. While the above standards may ensure a basic standard of care, further demands to quality can be made. In remote areas with difficult access by road, then helicopter ambulances with trained paramedics/medical personnel would improve site of injury care and speed of transfer. The initial destination of the SCI patient should be an SCIC that can offer state-of-the-art treatment and not just any nearby hospital.

Accreditation and evaluation

Accreditation of SCI units

Many hospitals and rehabilitation centres have already some kind of accreditation. Accreditation is a systematic approach designed to review and address performance. Surveyors come from outside the organisation, but should have expertise in the area being surveyed. A competent accreditation should be done by a third party, free of vested interest and ideally not-for-profit.

Most accreditation systems focus on the organisation and its procedures. Accreditation can be more useful as a quality strategy when the focus is on the person served and is SCI specific. Here optimal outcomes of services can be pursued through a consultative accreditation process that focuses on enhancing the lives of persons with SCI. The organisation and its staff will be forced to look for ways to better serve their clients and, preferably, in a more cost-effective manner. Staff will be more competent to help people with SCI to meet the goals defined as active participants in their rehabilitation process.

A good, person-centred, SCI specific accreditation process emphasises the person served, continuous performance improvement, business and service delivery aspects of human service and good management. There are accreditation systems available that meet these specifications.

Accreditation of SCI professionals

Organisations providing SCI care and (national) associations of SCI professionals must be committed to providing their SCI professionals/members with a high-quality, relevant and effective professional development and educational programme to enable them to become and/or remain up-to-date in their (clinical) practice.

But when is a professional qualified to call himself a SCI professional? National authorities and/or associations of SCI professionals must set standards for this, in consultation with associations of people with SCI. The next step is that this national authority and/or association of SCI professionals runs an audit system/quality visitation scheme to monitor that SCI professionals are fit to practise and are doing so in accordance with the relevant SCI professional standards. In some countries these audit/visitation systems for physical/rehabilitation medicine and/or SCI professionals are operational.

The ISCoS Education Committee mentions in its Strategic Plan some long term proposals for the implementation of its action plan. One of these proposals is that 'having a list of ISCoS approved/endorsed training centres may be considered'.

Patient evaluation

An organisation that 'wants to stay in business' regularly asks his clients about (the quality of) its products and/or services. This is also the key for SCI units when the focus is on the person served.

In many countries, patient evaluation systems for hospitals, wards, SCI units and/or on even the individual professional/staff member level are operational. When people with SCI are involved in setting and running these systems, there will also be more emphasis on client-based programmes for the improvement of SCI care and services.

Measuring outcomes

The concept of quality and its evaluation rests, ultimately, upon being able to measure the outcome of an intervention, procedure or process.

Individual level

Most SCI rehabilitation centres in Europe use the *spinal cord independence measure* (SCIM) to measure changes in how SCI patients function over time in tasks related to their everyday lives e.g. eating, dressing, personal hygiene and mobility. Typically, patients undergoing primary rehabilitation are assessed three times during the rehabilitation process.

While the SCIM score seems to provide a reliable measure when applied by multi-disciplinary teams, it takes no account of psychological or social factors.

One attempt to address this was introduced in 2010: the Boberg Quality Score. The “BobScore” claims to make it possible to determine the quality of a rehabilitation process by combining functional, psychological and cognitive parameters into a result score. The emphasis here is not functionality alone, but also psycho-social-economic factors that influence quality of life.

The ESCIF report on centralisation stresses the importance of motivation and the individual’s definitions of quality of life in devising patient-centred rehabilitation plans. As such, the ability to carry out tasks with a certain degree of independence may not be an adequate outcome measure.

Finally, it should be acknowledged that quality of life, in the long-term, rests on life-long care and follow-up; it is, therefore, essential that people living with SCI are offered life-long medical monitoring and psycho-social support from peer-counsellors and professionals.

Organisational level

More than 100 years ago Florence Nightingale suggested a health-related outcome measure for her patients: relieved, unrelieved and dead. Despite the developments in medical treatment and technology since then, attempts to measure the positive outcomes of health care have been slow in coming. On the organisational level it is not straightforward for an SCI unit to measure outcomes. Relevant standards have to be set and accurate and complete data must be available.

In some health care organisations systems are operational, for example Routine Outcome Monitoring (ROM), in order to measure and improve (the quality of) the health care process and management. Some ROM systems even support the health care professional by deploying a so-called patient-follow-system using also e-health tools. These are complex and expensive.

Maybe the only way to measure outcome on this level – in a practicable/useful way – is to keep it “simple” and small. In order to assess when an SCI unit delivers a high quality of services/ outcome, one must first agree on a ‘top 10 or 15’ of the most decisive performance targets for the SCI unit and start measuring the results against these targets. Examples of relevant SCI performance targets are: less than X % develop pressure sores/complications Y or Z during their stay on the SCI ward, more than X % successful discharge to a independent living condition, less than X % staff on sick-leave or % annual staff turnover. To these success criteria scores of patient satisfaction should also be added.

Such targets will be, of course, related to the national situation and possibilities. But, ultimately, whether people with SCI get the most out of these systems depends on the willingness of decision-makers to make tough decisions about services that are low-quality/ineffective and to promote practices that are high-quality/benefit patients the most.

Investment/costs: value-based

Since quality is a relative concept that means different things to different people we need to adopt other terms when we discuss the costs of the rehabilitation. Value is defined as the health outcomes relative to costs, and therefore encompasses efficiency. The payment system for healthcare should be value-based.

When costs are being considered we must refer to the total costs of the full care-cycle for the SCI consumer's medical condition, instead of the cost of individual services. Since SCI is a chronic condition, the care-cycle is life-long; this may be difficult to measure, but it is important to consider a care-cycle that stretches over a long enough period, say, a minimum of five years.

To reduce total costs, the best approach is often to spend more on some services in order to reduce the need for others.

Registries

Measuring, reporting, and comparing outcomes are perhaps the most important steps toward a rapid improvement in outcomes and – if needed – sound decisions about reducing costs. Outcomes should be reported in registries to best benefit patients and providers. Public reporting will accelerate innovation by motivating providers to improve relative to their peers.

Outcome measurements should include the health circumstances most relevant to patients. They should cover both short-term and long-term health issues, addressing a period long enough to encompass the ultimate results of care.

It is important that the outcome measurements can be compared and therefore the nomenclature and definitions used must be the same everywhere. Using the ISCoS Data Sets in the clinical setting and transferring the data to regional/national/international registries will enhance this process.

It is crucial that rehabilitation is not mainstreamed simply in order to fit a registry; rather, it is best practice derived from comparing outcome measurements that should mainstream rehabilitation.

Conclusions

The working group has investigated and considered the main points of the discussions at the ESCIF Congress 2011. The report may be regarded as an elaboration of those issues. It follows the ESCIF principle that people living with SCI must have a voice in setting the SCI agenda – including a discussion of quality and outcomes. As in other areas, SCI consumers rely on the expertise of others to guide and inform them – whether these experts are SCI professionals or health economists – but there are still many issues that demand, and will benefit from, the expertise that only consumers and their organisations can offer.

It is natural that many of the recommendations in the following statement are grounded in earlier work; we have, for instance, relied heavily on the report on centralisation. We also acknowledge that not all these recommendations can be implemented immediately in all ESCIF member countries; some will require a huge investment in facilities, others will demand further discussions with SCI professionals – some will require a total change in the mind-set that dictates doctor/patient relationships. We are certain, however, that the report and recommendations will contribute to discussions of how the quality of SCI treatment, rehabilitation and management can be improved, and how those improvements can be monitored.

ESCIF statement on the quality of spinal cord injury rehabilitation and management:

- Optimal quality in rehabilitation can only be achieved through a centralised system of SCI Centres
- Each event in the rehabilitation process should be monitored to ensure adherence to the latest clinical guidelines and clinical research
- SCI units must have an SCI specific accreditation
- The accreditation system used should focus on the 'person served perspective' i.e. on people with SCI
- People with SCI must be involved in the accreditation process; when the accreditation standards are set or revised and during the accreditation survey of a SCI unit
- Every country should have an accreditation system for SCI professionals devised and run in consultation with people with SCI and their representative organisations
- ESCIF recommends that ISCoS draws up and publishes a list of ISCoS approved/endorsed training centres for SCI professionals
- Every SCI unit must have a patient evaluation system devised and run in collaboration with experienced people with SCI and their representative organisations
- Individual outcome measures must take account of psycho-social-economic factors that impact quality of life
- SCI standards to measure outcomes on the organisational level should be devised and the results should be centrally recorded
- The payment system for health care should be value-based. We must consider total costs of the full care-cycle for the SCI consumer, instead of the cost of individual services
- Outcomes should be reported in regional/national/international registries using the nomenclature and definitions of the ISCoS Data Sets

References

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