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# Report
## on three-weeks visit to Midlands Centre for Spinal Injuries
## (November, 1st-21st, 1999)

At the beginning of this report, we apologise for our English as it proves difficult to express thoughts a foreign language. Being residents in Physical and Rehabilitation Medicine in Croatia and following 5 years of work in the area of Spinal injuries rehabilitation, a need for further training became apparent. Training in this speciality in Croatia takes 4 years of rotations, only 3 months of SCI rehabilitation included. Therefore, rehabilitation of spinal cord injured patients may be considered underestimated in Croatia, and majority of residents fail to conclude sufficient training in this particular area. Among other causes that we shall try to mention in this report, this might be relevant one for current status of SCI rehabilitation in Croatia.

Nevertheless, it might be useful to mention that Spinal Unit of Special Hospital for Medical Rehabilitation in Varazdinske Toplice has achieved certain recognition as a centre specialised in rehabilitation of persons with SCI serving near total population of Croatia and considerable part of neighbouring Bosnia and Herzegovina, and providing above mentioned training for residents in PM&R and physiotherapists. Spinal Unit serves as two well-connected wards, comprising approximately 100 beds. Unfortunately, being part of huge rehabilitation centre (1200 beds) has its drawbacks; there are times when more than half of these beds serve in purpose of rehabilitation after variety of other neurological, orthopaedic or rheumatologic disorders.

Having met Mr El Masry at several occasions and heard about extraordinary reputation of Midlands Centre for Spinal Injuries (MCSI) in Oswestry's Robert Jones and Agnes Hunt Orthopaedic Hospital, and being in obvious need to promote our knowledge in area of SCI rehabilitation, we applied for a visit. Our visit commenced on November 1st, 1999 with duration of three weeks.

In this report we shall try to go through the system we became familiar with in stages, relate its benefits to our personal training, compare it to training and system we achieved in Croatia, point to problems in SCI rehabilitation in Croatia, and, to the extent our current knowledge allows, recommend solutions for improving it.

Spinal injuries unit provides a system of emergency care and early referral, coordination of acute medical and surgical care, rehabilitation management beginning at the onset of acute care, vocational evaluation, counselling and placement and a system of lifetime follow-up care. All of these are provided in Midlands Centre, and even more important, all patient - centred activities are very well coordinated, giving a sense of quality care for patient and his/her relatives and an understanding among members of rehabilitation team.

1. Emergency department and coordination of acute medical and surgical care

Spinal injuries unit should be capable of admitting patients from the scene of accident, provided that paramedic services take all necessary precautions with respect to vertebral and spinal cord trauma. An early neurological assessment includes recording injury level and extent, as well as injuries of the vertebral column. Associated injuries of the head, chest, abdomen and extremities should be checked and treated accordingly. Respiratory, cardiovascular, gastrointestinal and genitourinary compromises secondary to neurological injury have to be addressed, and medical history should be taken.
Staff has to be familiar with possible early complication and an assessment should be made on hourly basis first 24 hours, and 4 hourly next 48 hours. Since 2 - 7 days are required before a person with SCI may truly be considered stable, first week monitoring is of paramount importance. Possible complications include spinal shock with bradicardia, hypotension, paralytic ileus, gastrointestinal bleeding, reduction in vital capacity, urine retention. Therefore, a comprehensive approach in stabilisation must be carried out, which includes:

a. monitoring of blood and electrolyte parameters
b. use of catheters with monitoring of liquid balance (input - output)
c. providing for bowel evacuation
d. use of iv. line (or central line if needed)
e. use of nasogastric tube (if needed)
f. provision of oxygen, tracheotomy and artificial ventilation (if needed)

It is necessary to coordinate assessment done by physicians in emergency units with respect to possible neurologic deterioration, and plan surgical intervention when there is a need. MRI or similar diagnostic procedure should be obtainable.

Relevance to Croatia: Croatia has well-built network of paramedic - emergency care centres that are located in all bigger cities, often next to hospitals. Every centre has predetermined number of vehicles sufficient to cover its area, and the staff includes physicians and paramedics. Fast boats and helicopter service are available in cases of emergency. If there is a case of road traffic injury, fall, violence or sport-related injury with apparent vertebral and/or spinal cord trauma, patient will be transferred to one of seven Neurosurgical centres throughout Croatia or Traumatology clinic in Zagreb. Unfortunately, in most cases patient would undergo surgical stabilisation regardless level, extent and stability of neurological status. Approximately 14th day following injury (that is postoperatively in a majority of cases) a patient is transferred to Spinal Injuries Unit of Special Hospital for Medical Rehabilitation in Varazdinske Toplice, and that is a standard procedure that all hospitals throughout country contribute in.
Croatia is small enough (5 million inhabitants) that one spinal injuries centre should be sufficient. Having in mind incidence of approximately 20 traumatic SCI/million (as derived from our database), that would add up with 100 new cases in whole Croatia every year, plus almost equal number of non-traumatic SCI. Midlands Centre (44 beds) itself serves an area that is bigger than Croatia, with 8 million inhabitants and incidence of 120/year. Simple logic with respect to figures recommends a 30 beds unit that should be sufficient for initial and subsequent admittance. A hundred beds facility, as it is now, is too big, with many resulting disadvantages, few already mentioned. However, at this stage of health economy in Croatia that seems to be a dream, therefore one possible thing to do is to convince medical professionals, surgeons in particular, to coordinate their actions with other experts in SCI area, to discuss each individual case with respect to type and extent of injury and provide a solution that would give the best chance for patient's recovery

and well-being. That could be carried out through Ministry of Health, conferencing or personal discussions, but the change of mind would probably be slow and difficult process. On the other hand, Spinal Unit should be able to provide necessary acute care, monitoring of vital function and have the possibility of fast intervention. The Unit itself has a ventilator, but no monitoring system. The nearest intensive care unit is in Varazdin, 15 kms away, and there is a good coordination between our two hospitals.

2. Rehabilitation management

Admittance

Patients with SCI admitted in MCSI are treated conservatively with 6 weeks of bedrest and traction, followed by 6 weeks of bracing. Immobilisation is achieved through Halo vest, SOMI (sterno-occipital-mandibular immobiliser), Philadelphia or Aspen collar, depending of level, extent and stability of vertebral column. In cases of neurological deterioration with unstable fracture surgery is recommended. Prolonged period of bed rest is promoted in order to avoid postural hypotension of central nervous system and spinal cord itself, as is shown that localised medullar hypotension might aggravate neurological recovery.

Relevance to Croatia: majority of patients admitted to Spinal Unit due to traumatic spinal cord injury have been operated on. Patients are transferred approximately two to three weeks following injury; some of them already elevated, even seated in a wheelchair. Jewet brace is used in most cases.
It would be worthwhile to delay elevation of patients until at least 6 weeks post injury, with weekly neurologic check-up.

Nursing care

Nursing care is carried out by fully qualified nursing staff; nurses have general and orthopaedic training and spinal injuries' course given at MCSI. Nurses are organised in teams; each team lead by most experienced and qualified nurse. A named nurse is allocated to every patient, with specific duty to provide a link between a patient and other members of rehabilitation team, to participate in goal planning meetings and to do a discharge. Nurses are responsible for feeding, dressing, grooming, moving and turning, bladder and bowel management and skin integrity. All mentioned activities provide excellent chance to promote trust between patients and staff, to learn more about persons inner thoughts and fears, that physicians can not achieve during ward rounds.

Moving and turning
Handling acute SCI patient is extremely sensitive and requires fully qualified personnel in order to keep good spinal alignment. If a patient with cervical injury is turned in bed, a minimum of 3 nurses is needed; in thoracic and lumbar at least 2. For transfer of a patient with cervical injury 5 nurses are required; 4 for patients with thoracic and lumbar injuries. Specially constructed hoist is used in transferring patients.

Bladder management
Patients are commenced on 4 hourly intermittent catheterisation as early as possible. Nurse's role is to take care of liquid balance (basic input - output), to perform sterile IC, and to teach patient self-catheterisation, if possible. If a patient undergoes suprapubic catheterisation, nurse shall check the

placement of catheter and look for signs of skin or orifice complications. As the reflex voiding appears, tapping is encouraged and residuals are being recorded.

Bowel management

As mentioned above, paralytic ileus is common first week post injury. Nurse should recognise an absence of bowel movements and order as follows: nil per os, nasogastric tube, aspiration of gastric contents and low suction treatment. Once bowel movements are restored, a bowel programme is established. Nurse should be familiar with premorbid patterns and consider post discharge activities and accordingly modify patterns. Irritant laxatives as long-term solutions should be avoided; instead glycerine types are recommended. According to lesion level, mobility of patient and presence of reflex voiding, suppository with digital stimulation or evacuation is done; eventually self-evacuation is pursued, preferably on an adjusted toilet seat. Dietician might be called for a consult.

Skin integrity

The skin and subcutaneous tissue in the anaesthetic area must be protected from abrasions and prolonged pressure at all times, and checked for complications twice daily. All pressure sores are preventable through frequent regular relief of pressure in bed and in the wheelchair. Egerton tilt-beds are used while on bed rest. Patient education is crucial in maintaining skin integrity throughout life, and nurse should teach patients ways of avoiding skin complications and protect skin over bony prominence in various activities of daily living. In case of pressure sore, a dressing is applied and changed daily; if necessary surgery (incision and closure) is done. Patient should remain on bed-rest with complete pressure relief as long as sore is present. A photograph is taken, and assessment is repeated on three-daily basis.

Relevance to Croatia: although there are no courses in SCI for nurses in Croatia, the knowledge is passed from experienced nurses to trainees. Nurses are skilled in feeding, grooming, dressing, bladder and bowel management, liquid balance monitoring and skin integrity maintenance. However, there is an obvious lack of self-confidence and autonomy. Due to serious shortage of staff it would be extremely difficult to attain proper management in moving and turning of patients if spinal alignment had not been established by surgical fixation. There are hydraulic beds with adequate mattresses, but no tilt-beds, turning frames or kinetic treatment tables.
At this point it should be possible to form teams lead by most experienced nurses, allocate named nurses to patients and encourage nurses to take more autonomy and responsibility in bladder, bowel and skin management. Ward managers could organise courses in nursing skills for trainees.

Physiotherapy

Physiotherapists are fully qualified to independently provide physical therapy, as well as hydrotherapy, electrotherapy, etc. During bed-rest period stretching, range of motion and respiratory training are carried out. Vital capacity is monitored in patients with compromised respiratory function; postural drainage, breathing exercises (incentive spirometer), chest vibration, percussion and assisted cough techniques are used. The load put on patients increases gradually. Neurologic check-ups are taken at weekly intervals and feed-back with other members of rehabilitation team is ensured. Following bed-rest period bracing is provided; tilt-table testing, transfer training, improvement of physical strength and stamina are carried out. Standing is maintained in standing frame, and wheelchair skills are promoted. Patients capable of ambulating

undergo specifically designed training, with use of orthoses, if needed. Physiotherapists ensure proper choice of wheelchair and cushion.

Relevance to Croatia: physiotherapists do not have adequate autonomy that is partly due to old-fashioned system, partly to lack of academic education. However, physiotherapists in Spinal Unit are very experienced and should be able to self-confidently, independently and with full responsibility organise and carry out physiotherapy of SCI patients. Their training in SCI rehabilitation should be permanent with more active participation in related courses and conferences. Instead of physicians, physiotherapists should be more involved in taking measures and prescribing wheelchairs.

Occupational therapy

As is the case with physiotherapists, occupational therapists are fully qualified in occupational therapy. The aim of their work is to restore, reinforce and enhance performance after disability, and to facilitate learning of those skills and functions essential for adaptation and best possible independence. For patients on bed-rest, occupational therapists apply splints and similar accessories helpful in grooming and feeding. Afterwards getting dressed, washing, toilet, bath, car (driver's seat and passenger`s seat), armchair/sofa and commode transfers are carried out. Writing and computer skills are taught and different workshops are available. Specifically adapted kitchen and flat enable training in independence of daily living prior to leaving hospital. OTs from MCSI work closely with community OTs and social services with respect to housing and work adaptations, paying a visit to every patient's home and work environment. OTs ensure driving licensing in Driving assessment centres. Occasional visits to pubs and restaurants as well as hill climbing and similar sports` and social activities assure patients in their socialising capabilities. Prevocational planning is carried out.

Relevance to Croatia: there is a shortage of occupational therapists in Croatia, and only few of them work in Special Hospital. Unfortunately, they do not coordinate their activities closely with Spinal Unit's rehabilitation team, majority of patients do not undergo proper assessment and treatment, and most of occupational therapy is carried out by physiotherapists. However, we believe that more effective coordination beneficial for patients could be attained. The shift of responsibility from physiotherapists to occupational therapists should be gradual as there must be no adverse effect on present quality of treatment. At this time, there are almost no possibility for home and work visits, although counselling is provided. There is an adapted kitchen, but no flat. Socialising events are scarce and sport activities are provided through recreational therapists and several sports` clubs, some on a competitive level. Prevocational planning is addressed by physicians, not OTs. Unfortunately, these attempts are usually hampered by community`s indolence towards persons with SCI wanting to carry on with professional life, as there is a trend of retiring them.

Resettlement

Within first week of admittance in MCSI, letters notifying GP, community physiotherapist, occupational therapist, district nurse and social worker are sent. Resettlement officer shall liase with community coordinators, ensure adequate housing (bungalows, council houses) and address specific needs of every patient. A carer is provided through social services, and if specific equipment is needed, direct communication with GP is ensured. Everyone is entitled to same level of care and payments are provided through social services or patients themselves. In order to

ensure social service benefits, a bank account record is demanded. Another provision could come from Independent living fund. Activities aim to enable home weekends' visits, 10-day visit and reduction of length of stay in hospital. Home weekends' visits give patient an opportunity to foresee possible complications regarding housing, mobility, community transportation, etc.

Relevance to Croatia: there are no resettlement officers in Croatia, and the closest position is the social worker`s. In our opinion, and that is also the opinion of Croatian association for persons with SCI, the link between Spinal Unit and community is the most lacking one. In most cases, community can not provide housings at all and any adaptations are carried out through direct efforts of family and relatives. Provisions of equipment through GPs are ensured, but there is substantial lack of coordination among district nurses, physiotherapists and social workers. Social services have no funding but for the most underprivileged, nursing homes are scarce, and persons with SCI are often accommodated inadequately. A carer is provided, but there is a tendency to register spouses as carers.
It should be possible to liase more with GPs, encourage them to coordinate their community teams, and provide feed-back to Spinal Unit. There should be strict determination to forbid relatives apply for carer position, as it has often been proved inadequate and disadvantageous. The Croatian association for persons with SCI should demand, through political means, more social support and involve in fund-raising activities.

Psychologist

The process of psychological adjustment begins quite early and early interventions make significant difference in both the short and long-term adjustment processes. Psychologist sees and follows every patient and ensures psychological training of staff and relatives. In case of premorbid psychiatric or addiction history or suicidal behaviour, psychiatric consult might be requested. Psychologist attends goal-setting meetings giving valuable estimates with respect to patient coping and motivation.

Relevance to Croatia: there are two psychologists working in our hospital, not specifically allocated to Spinal Unit. However, a lot of their work is focused on SCI patients that are obviously most in need of their attention. Feed-back with other members of rehabilitation team is maintained, and occasional written reports are provided. There is a tendency of refusing psychological consult among patients, since it is provided in separate offices of hospital, and patients have a feeling of being considered mentally ill, if referred. Also, in our opinion, and that might not be correct, too many tests are done instead of providing psychological support. There is no psychological training of staff, and occasional bursts of patients` anger is often misinterpreted, especially in less experienced staff members.
We believe that there are places for improvement in coordination, but that may prove extremely difficult with current disadvantageous psychologists/patients ratio. Having said that, it should be pointed out that actual work of psychologists is not covered in a contract our hospital has with health insurance, and their work is sustained from other hospital resources.

Social worker

From the first week following admittance social workers notify community and liase with colleagues there. Social benefits are addressed and proper link towards funding is established.
Relevance to Croatia: presently our social worker is most involved in addressing needs of patients that do not have family support. The link to community is inadequate. We believe that it should be

possible to improve coordination, but when it comes to terms of money the resources are quite limited. However, social worker in our hospital is a person most familiar with laws concerning persons with disabilities and is indispensable in rehabilitation process.

Keyworker

The keyworker is a staff member chosen from the team with the role of helping patient to make his/her way through rehabilitation system and to achieve maximum benefit from being in hospital. In a way the keyworker represents a bridge between patient and rest of the team, and through that link patient is able to express wishes, worries and concerns. The keyworker helps completing the Needs Assessment Checklist, and plans and runs goal setting meetings throughout rehabilitation.

Relevance to Croatia: it should be possible to allocate the keyworker in current settings of Spinal Unit.

Goal setting meeting and Progress meeting

Goal setting meeting provides an opportunity to discuss progress, difficulties and set goals to be attained in next two to three weeks. Meeting is run by keyworker, in presence of all members of rehabilitation team: patient, relatives, consultant, physician, named nurse, physiotherapist, occupational therapist, psychologist, resettlement officer and social worker. First meeting is usually commenced a week following admittance, and subsequent meetings are repeated in two-weekly intervals. At the end the keyworker writes a summary of agreed targets and everyone receives a copy.
With conclusion of bed-rest period, or around 4th week following injury, a consultant-patient meeting is done, sometimes with closest relatives present. It is up to consultant to discuss effects of lifelong paralysis, at most appropriate way.

Relevance to Croatia: at this point there are so-called team syntheses where all available members of team and the patient discuss various aspects of paralysis, but there is usually only one meeting for one patient during whole period of hospitalisation.
Actual progress is being discussed during ward rounds among physician, nurses, physiotherapists and patients on a daily basis. The effects of lifelong paralysis is discussed with the patient and relatives separately. Goal setting meeting, as seen in MCSI would require substantial increase in staff.

3. Outpatient

Outpatient department in MCSI reviews approximately 1500 outpatients every year, fulfilling the philosophy of care for patients from the first few hours following injury and for the remainder of the patients' life. All SCI patients are appointed periodically or in case of complications, and admitted to a ward if necessary. Appointments for basic and advanced diagnostics are ensured. Patients' and relatives' education are continued throughout rehabilitation and leaflets about various conditions following injury are provided.

Relevance to Croatia: there is no such outpatient department. Instead, SCI patients have the possibility to spend 3 weeks yearly in Spinal Unit, when their needs can be addressed, and limited

array of diagnostics is available. Although urodynamics device exists, due to decline in health economy we can not afford urology consult in our hospital any more. More absurd, if a patient is in need of consult because of complication and has already spent his 3 weeks, Spinal Unit can not admit him the same year. Result: persons with SCI feel abandoned because there is no facility to ensure prompt and adequate help and have substantial problems finding physicians familiar with their condition and resulting needs. In order to reverse this illogical pattern, a whole system of admittance of patients to rehabilitation centres should be questioned. On the other hand, such change should gain support from Croatian association for persons with SCI as this could affect their "right" to spend 3 weeks a year in our Unit, regardless needs. Patients` education is not provided through specific lectures and courses, but through direct staff-patient relationship. There is patients` manual in use.

4. Database

Midlands Centre for Spinal Injuries is maintaining a database of patients with spinal injuries, making records of every initial and subsequent admittance. Following general data, injury level and completeness are noted. Reports are being sent regularly to central register in National Spinal Injuries Centre in Stoke Mandeville.

Relevance to Croatia: we have been building digital database of persons with SCI admitted to our hospital since 1991. Besides general data, at least 30 other medical parameters are being recorded. Although it has not been completed yet, 3400 individual records were included, initial and subsequent. Since almost all patients with SCI in Croatia are admitted to our Spinal Unit, we have near-total population. This might prove helpful in organising preventative measures on a national level, give insight in incidence and perhaps serve as an argument in assuring government to finally form national Spinal Centre comprising all necessary services.

5. Stoke Mandeville

Our one day visit to National Spinal Injuries Centre took place November, 17th, 1999. We had a chance to walk through Centre, talk to colleagues and discuss similarities and differences in SCI management in Great Britain and Croatia. Handling ventilator-dependent patients was the most interesting part, as well as environment control unit used by high tetraplegics.

6. Orthotic Research and Locomotor Assessment Unit (O.R.L.A.U.)

During visit to O.R.L.A.U. we had a chance to see reciprocal walking in which paraplegic patients with complete lesion at or above L1 can ambulate by placing one leg in front of the other, by use of Parawalker. It provides low energy ambulation, easy putting on and off and transfer sitting and standing. Besides ambulation itself, use of Parawalker improves bowel function, urinary drainage and peripheral circulation. Bone fracture and pressure sore incidence are considerably reduced. Patients are advised to allow three weeks of expert training in O.R.L.A.U., starting once they are physically fit. For majority of patients, training should commence approximately 12 - 18 months following injury, and the highest applicable level is T7. Follow-up should be on 6 monthly basis, in O.R.L.A.U. or one of certificated centres.

Having seen so perfectly organised and coordinated facility such as Midlands Centre for Spinal Injuries, having met people so dedicated to their important work and following three weeks of intensive learning, moved us to contemplate Croatian position in SCI rehabilitation. The question is: is it possible to improve situation in current setting, or a complete new approach is necessary?
Unfortunately, we can not see much of dramatic changes in near future. Economic prospects of Croatia are not prosperous these days and health economy is going even worse. Spinal Unit does not have appropriate government support, and hospital resources are barely sufficient to carry on with current standards. An obvious need for forming of modern national Spinal Centre has not been recognised in government yet, and Croatian association for persons with SCI is not powerful enough, nor given much legal and political power. Community social services are not sufficiently developed, and links among Spinal Unit, community and Association are not established.
We believe that in present situation the best approach is to take small steps at a time as described in above report and coordinate activities with interested co-workers and community. At the same time, we should, through medical and lay associations promote an idea of dedicated spinal centre both in government and public. Once there is a change of mind of those who are in charge we might need professional support from internationally recognised subjects like IMSOP, and hopefully have one.

At the end we would like to thank all nice people we had privilege to meet, talk to, and observe their work. We are most grateful to Mr El Masry for kindly accepting us to Midlands Centre for Spinal Injuries and having done everything to make our visit both useful and pleasant. We believe our knowledge and understanding of spinal injuries enormously improved and now have a feeling that so much need to be addressed in Croatian SCI management.

We would like to thank the patrons and trustees of Spirit for making our visit possible.

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