

Integration and (Re-) Employment of People Living with Sequelae Post Spinal Cord Injury—successful Socioeconomic Evolution—from Cinderella, to the Wonder Princess

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Introduction

Traumatic Spinal Cord Injury (SCI) is an abruptly, major life-disrupting condition, with devastating usually permanent, effects on the patient's physical (neurological and functional) status, psychological and social well-being condition. Frequently SCI occur in a polytraumatic context. Slightly more than half of the subjects are tetraplegic, 40% of them have a complete (AIS-A) lesion [1,2]. Less than 1% succeed to completely recover (AIS-E) at discharge [1]. For both of the complete and incomplete SCI, most of recovery is achieved during the first year post-injury, but the "natural" healing progress can continue at a lower speed, with a relative plateau (reached by 12-18 months post-injury) [3,4]. Approximately 10-20% of the AIS-A lesions convert to incomplete ones [3].

Besides the neurosensory impairment, paraplegic or tetraplegic persons could have serious health challenges associated with infections, tissue trophicity (mainly pressure sores), metabolic, and cardiovascular problems [2]. In nowadays, life expectation after the catastrophic event is definitely longer [1], due to the improvements in medical care, multidisciplinary team approach, long-life medical supervision and social support. About 30% of persons with SCI are re-hospitalized [1] for a couple of times in the rehabilitation center, reassessed, and the basic program is enlarged, including a work-oriented occupational therapy and vocational counseling. In many countries, the length of vocational rehabilitation program is too short, or even absent [2].

Although SCI is a low-prevalence condition, it has an important socioeconomic impact for the health-care systems, whatever in a developed (high-income) or in a developing country. Epidemiologic data are non-homogenous and insufficient, in different continents or countries. Cripps et al. reported SCI global prevalence of 236–1009 per million inhabitants [5]. The highest was in the USA (906 per million in 2012, corresponding to 270,000 persons) [1,6]. In Europe, prevalence of people living with SCI (estimated in five studies) ranged between 250 to 520 per million) [6].

Theoretically, the resources allocated for social services and programs focused on a multidisciplinary vocational rehabilitation, should not represent an economic burden towards the European Union (grossly presuming the prevalence of traumatic SCI at 400,000 persons, under 0.1% of the total EU population). Return to productive work (paid or voluntary) is a domain of integration and participation extremely relevant for the quality of life (QoL) of a person living with SCI, and considered as primary outcome of comprehensive rehabilitation. Unfortunately, many persons living with long-term

sequelae after SCI are excluded from livelihood opportunities, marginalized and their families live in poverty (depending of the economic context and the geopolitical region).

Remunerative employment represents the "zenith" of rehabilitation, but it is not the first priority after SCI at least during the first year following the traumatic event. Employment of a person living with a disability is defined as having paid work for ≥ 12 h/week [7]. Return to a paid job occurs in 3-108 months (median 12) [8] in a chronically (medically stabilized) person with SCI, being "the final piece of the puzzle to fit in" [9]. Engaging with work has many advantages: it offers social inclusion, connectedness, a sense of self-worth, sustains and enhances mental capacities.

Return to work of persons living with SCI is very heterogeneous, ranging from 31 to 48% [7-9], even lower in the former communist-bloc countries (only 15% of the disabled persons are gainfully employed in Romania [10], or in the Czech Republic [11]). Return to work (paid or voluntary) of people with SCI is influenced by many external variables (environmental and attitudinal barriers, workplace-related and benefit system-related factors), integrated in a particular macro-social system (financial, legislative and geopolitical frames). The endogenous (personal) factors that modulate opportunities for reemployment are represented by demographic, present health status, psychological issues, education, skills and employment history (Table 1) [7-9,12-16].

Demographic variables (age at injury onset, respectively the chronological age, gender, ethnicity, marital status)
Injury-related factors (severity, time since the accident)
Health status (post-injury related medical problems)
Disability considerations (mobility, autonomy)
Psychological status (motivation, priorities)
Education (previous, actual)
Pre-injury professional experience
Training and vocational rehabilitation services, counselling
Environmental / architectural barriers
Employment type
Employer's attitude

Financial resources and social support (disability benefit status, health care issues)
Legislative frame

Table 1: Factors related to (re-) employment after SCI.

The injury characteristics and physical functional limitations are the most important predictors of employment in persons with SCI. Persons with incomplete tetraplegia are advantaged than those with complete paraplegia, also men vs. women [13,14]. Progression of body impairments (physical restrictions and mobility problems due to the evolution of complications and co-morbidities) represent endogenous barriers with negative repercussions on the activity, participation, employment and health related QoL [17]. Pre-/ and post-SCI psychological characteristics represent important pro and cons factors at individual level. Behavioral attitude towards work, positive expectations, concerns (for the family, for the children's future), motivation ("interested in becoming employed" [13]), the capacity to cope with distress and depression, represent a strong incentive for a person in wheelchair to upgrade from the (actual) "consumer" condition to the "producer" one (productive member of society).

SCI survivors could confront with different kind of external barriers in the community (outside the individual's control): architectural (limited accessibility in transportation and in the public institutions), psychological (negative attitudes in the community, discriminative or unhelpful attitudes of the employers and/or colleagues), low access to education and health care issues, financial and legislative contextual barriers. People who live in poor rural areas may not have access to educational opportunities, transportation, vocational counseling or employment, and confront with prejudice and ignorance. The nature of the job (the intensity of the physical, cognitive demands of the work process) could be a great hindrance to candidates who intent to return to work. The work-related requirements depend on the type and characteristics of the job (agrarian, industrial, transport, commercial, servicing, education, administrative, scientific or technical domains) impose specific educational levels and could represent objective restrictions.

Focussing on the actual working capabilities, discussing with professional specialists and consellers, as well as peers, about the demandings of the job, (reasonable) adaptations of the working schedule and place, trialing work-place, motivational protected units, represent main items in the endeavor to find, regain and maintain an adapted employment. Education is essential to modulate the general perception of the public and media, to eliminate prejudice, ignorance and discrimination towards disabled people, to induce positive changes in the attitudes of the employers, governments and political class. Supported employment integrated in multidisciplinary team interventions [2,18], counseling, legislative and fiscal/economical facilities for the employee and employer, facilitate successful work reinsertion of people living with SCI.

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