

Spinal Cord Injury in Portugal: Institutional and Personal Challenges

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Abstract

This article is dedicated to an analysis of the life trajectories of individuals with spinal cord injuries in Portugal. From a perspective that aims to understand the challenges faced in the different stages following the initial injury, it aims to relate corporeal, personal, and social impacts to medical, institutional, and political responses. Based on a total of 93 interviews, the analysis focuses on the period that starts with the event that caused the injury and extends to the present day, following the entire rehabilitation and integration process and identifying key structures, services, and institutions. In offering a critical reading of processes and structures that are capable of ensuring quality of life and social inclusion for persons with spinal cord injuries, it broadens the discussion to reveal the social exclusion widely experienced by persons with disabilities in Portugal.

Keywords

rehabilitation services, social services, self-determination, adult human services, health care, policy

The profound impact spinal cord injury has on individual lives puts the existing medical and institutional provisions in each society to the test. To understand the challenges faced by persons with spinal cord injuries in Portugal, this study aims to follow their paths at different times in their lives after the initial injury. It analyzes the processes of personal reconfiguration that follow on from an injury. In particular, it highlights how their expectations and experiences crucially depend on both the existing medical and institutional structures and the political and sociocultural framework that shapes their existence as persons with spinal cord injury. In this sense, the paths followed by these persons are heavily influenced by—and illustrative of—the broader social situation for persons with disabilities within the Portuguese context.

In Portugal, persons with disabilities experience blatant exclusion and a social context that oppresses their specific situation. Despite successive legislative proposals and the ongoing elaboration of social policies that have the stated aim of fostering social inclusion for this particularly vulnerable group, the social reality bears witness to the stubborn survival of this socially exclusive framework (Fontes, 2009; Martins, 2006). In conceptual terms, disability is an eminently modern category, established in opposition to the biomedical model of normality. It has therefore laid down a path in which those categorized as disabled have to adapt to normality, adopting a medicalized and narrow approach of the challenges posed to social inclusion. It is an approach which essentially accepts the norm and sees disability as an

individual challenge, preserving the boundaries of society intact (Stiker, 1999). Therefore, without calling into question appropriate medical interventions, such as diagnosis, stabilization of the clinical condition, and functional recovery, it is necessary to analyze the extent to which the consequences of such medical classifications can be far reaching and negative (Oliver, 1990). Particularly, attention should be given to the fact that this approach enshrines individualizing perspectives and practices in which “the effect of medicalizing social problems is their depoliticization” (Barnes, Mercer, & Shakespeare, 1999, p. 60).

It was only in the 1970s, with the development of Disability Studies, that the social exclusion to which persons with disabilities are subjected in Western societies began to be questioned. This new area of studies, established in countries such as the United Kingdom and the United States, was an offshoot of the politicization of disability that emerged in these countries in the 1960s and 1970s (Hahn, 2002; Oliver, 1996). The political struggle became more sensitive to the power relationships present in everyday life, the effect of cultural representations and body politics, and created new opportunities to give voice

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to the exclusion experienced by persons with disabilities. Thus, in various places around the world in the 1970s, organizational structures were created and reformulated to reveal the many forms of oppression faced by persons with disabilities.

Disability, Medicine, and Rehabilitation

Advances in modern medicine produced significant changes in the social understanding of health and sickness and the way in which society deals with this. As a result, we have witnessed the development of a scientifically based medical diagnosis which presents the “cure” as the main objective; the consolidation of a branch of knowledge which “determined the boundaries between ‘normal’ and ‘abnormal’ individuals, the sane and insane, healthy and sick people” (Barnes & Mercer, 2010, p. 18); the individualization and medicalization of disability (Oliver, 1990; Stone, 1984); the institutionalization and segregation of persons with disabilities (Goffman, 1987; Hughes, 2001); and the growing hegemony of the medical model of normality, as opposed to disability (Davis, 1995).

The emergence of politicized concepts of disability therefore denounced the “individual/medical model of disability,” recognized as hegemonic in Western societies. It is this social dimension that needs to be addressed in understanding the lives of persons with spinal cord injuries, particularly because the relevant literature in this area is often restricted to medical questions and individual medical rehabilitation in its narrowest sense (e.g., Klein & Karp, 2004; Somers, 2001).

After the Second World War, medical developments relating to treatments—involving the widespread use of antibiotics, anesthetic, antiseptics, sulfates, and so on—drastically reduced the high death rate for persons with spinal cord injuries. Medical advances, greater life expectancy, and the increasing numbers of patients, as a result of both the First and Second World Wars, transformed spinal cord injury into a social problem for which an answer needed to be found and, as a result, the first rehabilitation centers were opened. In Portugal, specialist institutions dedicated to the rehabilitation of individuals with spinal cord injuries were only created in the 1960s, with the founding of the Centro de Medicina de Reabilitação de Alcoitão (Center for Rehabilitation Medicine of Alcoitão). While the structures in Portugal that offer the most comprehensive medical responses emerged relatively late, the response to the challenge of social inclusion is still in its early stages today.

This article is based on the life stories of individuals with spinal cord injuries and aims to explore and analyze both their trajectories and the institutional and social provisions available in Portugal. The analysis therefore focuses on the period that starts with the event that caused the injury and extends to the present day, following the entire process of

rehabilitation and integration and identifying key structures, services, and institution within these processes. The main question framing this research was as follows:

Research Question 1: What are the challenges posed to persons with spinal cord injuries in Portugal?

To answer to this question, a set of secondary research questions were used:

Research Question 1a: What are the institutional paths and social policies framing the personal reappraisal processes imposed by spinal cord injuries and the personal experiences of medical rehabilitation?

Research Question 1b: How did persons with spinal cord injuries experienced the process of social integration?

Research Question 1c: How do persons with spinal cord injuries evaluate the medical resources and social services available for them?

Research Question 1d: What are the obstacles that undermine the lives of persons with spinal cord injuries?

Method

The study adopted a two-stage fieldwork process. Fieldwork I covered the initial phase of medical rehabilitation in Portuguese rehabilitation centers, and Fieldwork II focused on the process of reintegrating persons with spinal cord injuries into the community after the initial medical rehabilitation had been completed.

Fieldwork I involved qualitative methodologies and favored two data collection strategies: semistructured interviews and direct observation. Two groups of people were defined for Fieldwork I: individuals with spinal cord injuries who were in the initial stages of rehabilitation (Group 1), and professionals and managerial staff at the three rehabilitation centers (Group 2). A total of 10 days of direct observation per rehabilitation center have been conducted over a period of 4 months. Data deriving from direct observation (description of activities, reporting of interactions, and personal impressions) were daily registered and later analyzed to identify patterns and differences in the functioning of rehabilitation institutions and the rehabilitation protocols followed. Target groups (1 and 2) were then interviewed following a purposive sampling strategy. To assure the heterogeneity of Group 1, selection criteria included length of time at the rehabilitation center, gender, age, and country geographical origin of the person with spinal cord injuries. Group 2 interviewees were selected to have a balanced representation of the different professionals involved in the rehabilitation process at the rehabilitation centers. A total of 28 interviews with individuals with spinal cord injuries in the initial stages of rehabilitation (Group 1) and 22 interviews with professionals and managerial staff at the

three rehabilitation centers (Group 2) were carried out. Interviews were fully transcribed, coded, and analyzed in two different databases. A biographical chronology was created per interviewee (describing people's life events), and preliminary coding and analysis, drawn from initial research questions, was carried out. This preliminary analysis was crucial to identify and analyze major themes, moments, and challenges that were then cross-tabulated with biographical and institutional data collected through direct observation and secondary data analysis.

Fieldwork II involved qualitative and quantitative methodologies. Again, two groups of people were defined: individuals with spinal cord injuries living in the community (Group 3), and family and institutional support networks within the community (Group 4). To characterize local institutions involved in the rehabilitation and integration of persons with spinal cord injuries in the community, a survey was conducted to local institutions identified from national repositories as working in the rehabilitation and integration of persons with disabilities. Fieldwork II resumed then to interviewing people with spinal cord injuries living in the community in different regions of the country. Group 3 interviewees were selected with the support of rehabilitation centers, and selection criteria were defined to get a balanced sample of the persons with spinal cord injuries in terms of gender, age, and geographical area of residence (based on the seven Portuguese Statistical Regions and considering the urban/rural continuum). From the total of 29 interviews conducted in Group 3, five interviews were selected to be further analyzed. The selection responded to the need to represent the different challenges reported on the process of integration. For each case study, a map of local relevant actors was drawn which generated Group 4 interviews (relevant community actors for the rehabilitation and integration of the people with spinal cord injuries). A total of 14 interviews were conducted within Group 4. Again, all the interviews were fully transcribed and submitted to a systematic content analysis. Initial analytical codes derived from medical and sociological literature on the field and directly from the interviews. Different analytical codes were used for the content analysis in each group of interviews, identifying both key moments in the rehabilitation process/inclusion in the community (e.g., therapeutic itinerary before and after the rehabilitation center, discharge into the community, home adaptations) and prominent institutional and personal challenges (embodied experiences of spinal cord injury, community medical and social support). The study presented here complied with the American Psychological Association's (2010) ethical principles regarding research with human participants. The 93 interviews followed a strict protocol for informed consent, and the interviewees were provided with information on the objectives of the study, the use of the data that were gathered, anonymity

(all names used in this article are fictitious), and the option of withdrawing from the study at any time without having to justify their reasons.

The trustworthiness of the data collected has been established through the use of three triangulation methods: data triangulation, methodological triangulation, and investigator triangulation (Guion, Diehl, & McDonald, 2011). In Fieldwork I, data triangulation was accomplished through the use of different groups of interviewees (individuals with spinal cord injuries, professionals, and managerial staff), methodological triangulation consisted of the complementarity between the collection of interviews and direct observation, and investigator triangulation was achieved through the involvement of the team members in a process of peer debriefing and collective analysis. In Fieldwork II, data triangulation was supplemented with interviews to family members of individuals with spinal cord injuries, and methodological triangulation was complemented with quantitative data resulting from the survey conducted to local institutions. Furthermore, interview transcripts were returned by email or post to all the interviewees to verify the provided data. Interviewees were given 1 month to revise, clarify, or withdraw the content of the transcripts. Moreover, they were informed that in the event of no reply, it would be assumed that the data were correct and that the authorization given on the day of the interview was still valid.

Results

Institutional Paths

The Portuguese Health System, established in 1979, is formed by several public and private networks. Within public networks, health care services are provided by distinct health units classified according to the level of specialization of technical and human resources. Health centers correspond to the first line of health services provided to the community, offering mostly general practitioner appointments and nursing services, and referring to other specialized services. District hospitals correspond to Group II hospitals, providing medical and surgical services—of basic, intermediate, specialized, and exceptionally highly specialized level—to the population of their direct and non-direct area of influence. Central Hospitals correspond to Group III hospitals, that is, highly specialized hospitals in terms of human and technical resources, offering highly specialized medical and surgical services to the population at interregional and national levels.

In 2007, this public network was complemented by a National Network for Integrated Continuous Care (Rede Nacional Cuidados Continuados Integrados [RNCCI]; Law-Decree 101/2006, June 6) aiming to provide integrated continuous medical and social care to people who are in a dependency situation. This network results from partnerships

between public, private, and third sector organizations, and is structured around continuous inpatient and outpatient care units that assume different forms. Inpatient care units include Convalescent Units, Medium Term and Rehabilitation Units, Long Term and Maintenance Units, and Palliative Care Units. Outpatient care units include domiciliary support services: Day and Autonomy Promotion Units and Home Care Units.

The course of treatment for persons with spinal cord injuries involves various phases and several health care units from the different networks. The process begins at the scene of the accident, when the emergency services intervene. This is followed by a second phase of hospitalization, initially in the district hospital in the area where the emergency care is given, after which, on confirmation of spinal cord injury, the patient is transferred to a hospital which has multiple emergency departments and a neurotraumatology unit to undergo an operation on the spinal column and any other injuries. In some cases, identified from the outset as more serious, the individual is transported directly from the scene of the accident to this institution. When the postoperative recovery and physiological stabilization period is over, patients are transferred to other units (such as district hospitals, long-term care units, and, more unusually, their own home) where they wait for admission to an initial medical rehabilitation center for persons with spinal cord injuries.

With regard to this institutional response, an analysis of the interviews with both professionals and individuals with spinal cord injuries reveals a significant improvement in the services provided by emergency medical teams in the last 10 years. As far as we are able to determine, this is due primarily to more extensive and better training of emergency teams. However, the same cannot be said of the hospitalization period. As the great majority of interviewees stated, this phase is characterized by frequent hospital transfers and a lack of information on their clinical status and the reasons for the transfers. Shortcomings were also identified in the transition period between hospital units and rehabilitation centers. According to the majority of medical professionals interviewed, to ensure appropriate care for patients with spinal cord injuries, the transition from lying flat to using a wheelchair should ideally take place, either in acute care hospitals or in a convalescence unit within the RNCCI. However, in practice, due to the lack of RNCCI beds, this takes place earlier in general hospitals, which are often not fully prepared for this stage, or later in rehabilitation centers, which implies a longer stay in the centers, taking up time that should be devoted to medical rehabilitation and unnecessarily prolonging the waiting time for admissions.

Initial Medical Rehabilitation Centers

Portugal currently has four rehabilitation centers which specialize in spinal cord injury: Centro de Medicina de

Reabilitação de Alcoitão (Center for Rehabilitation Medicine of Alcoitão, opened in 1966); Centro de Medicina de Reabilitação da Região Centro—Rovisco Pais (CMRRC—the Central Region Medical Rehabilitation Center), whose spinal cord injury service opened in 2007; Centro de Medicina Física e Reabilitação do Sul (Southern Region Center for Physical Medicine and Rehabilitation); São Brás de Alportel (opened in 2007); and Centro de Reabilitação do Norte, in Gaia (Northern Region Rehabilitation Center, dating from 2014). This analysis did not include the Centro de Reabilitação do Norte as it has opened recently—2014.

As the research showed, the situation regarding rehabilitation centers is varied, with the CMRRC—Rovisco Pais presenting the longest waiting list for admissions. The reasons for this include the fact that this rehabilitation center covered the entire population of the Central and Northern regions and is the only one in the country that is fully integrated into the National Health System. This situation is particularly damaging given that a longer waiting time reduces the potential for medical rehabilitation, and this scenario can be extended to the entire country. As explained by the director of the CMRRC—Rovisco Pais Spinal Cord Injury Department,

At the moment [2012], we have, as you know, three rehabilitation centers in Portugal and ours is the only one that is an entirely public institution . . . Therefore, we have a certain obligation: although this is the rehabilitation center for the Central Region, . . . at the moment we are receiving patients from all over the country. As you can imagine, 30 beds isn't much for the whole country. At the moment, we have 22 patients waiting for their first stay in our center and another 30 waiting to return, so right now I have a waiting list of more than 52 patients. In terms of time, given that this always involves a lengthy period of hospitalization, it means that when a patient arrives here it's, let's say, very often past the minimal time we consider appropriate for starting their rehabilitation process but, unfortunately, this is the situation we face. We have 30 beds and five adapted dwellings, so a maximum of 35 patients. Given that the rehabilitation process as it should be carried out for a tetraplegic [*sic*] patient takes, on average, from five to eight months up to one year and for a paraplegic patient an absolute minimum of two to four months, both involve lengthy periods of hospitalization and because there are always new cases, we can't at the moment respond within the ideal prescribed time for admitting the patient. (Medical doctor)

The small number of rehabilitation centers in Portugal, the vast geographical area they cover, and the distance between these health care units and the communities where patients live all create significant obstacles to involving families in the recuperation and rehabilitation process.

Of course, when you first come here you've left your home behind, you're isolated, isolated from the persons you're used to being with. It's the changes in staff, nurses, auxiliaries, the

atmosphere is totally different, and then persons always miss their family, don't they? If you're closer to home, you always have that. Here, no; here, it's just at weekends and not always then . . . You end up being a bit far away from home. (Jorge, person with a spinal cord injury)

However, rehabilitation centers are the only institutional facilities that are properly equipped to deal with the specific nature of spinal cord injuries. After being discharged from the rehabilitation center, persons with spinal cord injuries return home where they may use the local domiciliary support services provided by the outpatient care units of the RNCCI or, for medical and/or social reasons, are referred to a long-term care and maintenance unit within the RNCCI or even a care home.

Returning Home

In the vast majority of cases, neither the Health Centers and outpatient care units of the RNCCI for persons with disabilities nor the general hospitals provide specialists in spinal cord injuries. Even in the institutions which do employ specialists, such as hospitals with multiple emergency departments and long-term convalescent units, there is a lack of specialist units capable of dealing comprehensively with spinal cord injuries. This situation is particularly acute in terms of community services. The institutional provision for persons with spinal cord injuries returning to the community is minimal, with regard to both the quality and the coverage of the existing support services and structures, as the different interviews with health care professionals, individuals with spinal cord injuries, and civil society organizations reveal. This scenario threatens much of the capacity-building work developed in the rehabilitation centers. In addition to issues concerning regression in functional gains, health complications (pressure sores, urinary infections, etc.) also have to be taken into consideration, often the result of shortcomings in the support structures outside the rehabilitation centers:

. . . because in the meantime there were some sores, due to lack of proper care. Because, although I have to be properly positioned, sometimes they aren't prepared to receive patients like us. For example, I've been hospitalized a few times in other departments in the Hospital São João [General Hospital, Oporto] and they aren't in the least bit prepared for patients with spinal cord injuries who are dependent on others to get up, lie down, turn over. People who have to have their position changed, who need a special mattress, they aren't in the least bit equipped for this. (João, person with a spinal cord injury)

In the more serious cases—patients with tetraplegia and with severe injuries requiring complex medical support—discharge from the rehabilitation center may signify a diminished life expectancy.

Because they are best designed to serve the everyday needs of persons with spinal cord injuries, the domiciliary support services provided by the outpatient care units of the RNCCI are crucial to the process of reintegration into the community. These services include medical and nursing care, physiotherapy, occupational and speech therapy, psychosocial support, rehabilitative and palliative care, and health education. The shortage of services is, however, a major obstacle to self-sufficiency for those with spinal cord injuries in Portugal, who almost invariably end up resorting to family help. This means that the majority becomes dependent on their families.

As is the case with other sectors of the population, for the majority of persons with spinal cord injuries, the deficiency of state provision is compensated by increased family responsibilities (Henriques, 2004). In accordance with this, our study reveals that families constitute the crucial economic, psychological, and social support for persons with spinal cord injuries. As one of the interviewees stated,

The support from your wife . . . For me, I think the greatest help was . . . she was unfailing, she was always by my side, always, always. I spent six months in hospital and she never missed a day, and it was 80 kilometers every day to get there and the same to get back . . . You have to be brave and when I looked at her I couldn't lose faith . . . because if someone is fighting and the other person goes under, they're not suffering on their own, they make the other person suffer too. (Luís, person with a spinal cord injury)

As this extract reveals, within the family, the role of the woman—primarily the mother and wife—as caregiver emerges as the norm (and is an even more significant factor in this analysis, given that spinal cord injury is much more common in men). Within the division of labor in Portuguese society, in which women are the mainstay of the “welfare society” (Santos, 1993; Wall, Aboim, Cunha, & Vasconcelos, 2001), mothers or wives very often give up their careers to look after a family member who has a spinal cord injury or combine being a care provider with their working life. Within this scenario, there is a tendency, even if temporary, for one of the members of the family, usually a woman, to make radical changes to organize their personal lives around this person. In these situations, family relations are then structured around the caregiver and the receiver of care, with the rest of the family operating in accordance with this core nucleus. The delegation of state responsibilities therefore has two main consequences. First, it demands remarkable efforts on the part of the family structure, frequently leading to exhaustion and personal tension: Moreover, if this structure does not exist, an individual with a spinal cord injury faces serious deprivation or the “alternative” of institutionalization (which very often means institutions such as residential care homes for the elderly, which are totally unsuitable, both in terms of the specific care required and

the age of the individuals concerned). Second, it reinforces the undervaluation of persons with disabilities, socially perceived as passive and dependent subjects, and consequently preventing them from achieving decision-making autonomy and control over their own lives.

As previously stated, in cases in which returning home is not a viable option for medical and/or social reasons, the solutions which exist in Portugal are limited, consisting of residential care homes for the elderly and medium- or long-term care units within the RNCCI. As is the case with social services and benefits, admission is once again not guaranteed and depends on vacancies, which are nonexistent in some regions of the country. In addition, it is not unusual for young people to find themselves in the extraordinary situation of being placed in an old people's home. This was explained to us by a social worker at one of the rehabilitation centers:

... these are the most serious situations and are very challenging for us because most of the solutions are not suitable, in social terms, for this population. Why? Because they are usually young and I don't think it's legitimate for us to send them to an old people's home, but sometimes it's the only solution we have . . . There are some residential centers for people with some level of dependency but they are in very, very, very short supply. It's impossible to find an answer . . . Even the homes . . . There isn't enough provision . . . There are also long-term care units but a patient has to have clinical criteria to be admitted, social reasons are not enough. And this places great restrictions on us and sometimes people are here a very long time before they are discharged. (Social worker)

One of the most significant consequences of spinal cord injury is the loss of mobility and/or feeling in the lower limbs and the need for patients to use a wheelchair. Given the lack of wheelchair access in most of the built environment in Portugal, being discharged from a hospital or rehabilitation center also raises the question of adapting the family dwelling to the new needs of the person who has a spinal cord injury and of wheelchair access within the community. As far as we could determine, home conversions are easier if the person with a spinal cord injury is covered by an insurance protection, given that funds are allocated for remodeling the home as part of the compensation paid for the accident. However, in the case of those who depend on the national health and social security systems, given the delays and difficulty in obtaining this kind of support, it will depend on the financial efforts of the family. Persons with spinal cord injuries who are covered only by the general social security system not only experience the sparse, nonuniversal nature of welfare benefits but also greater difficulty in accessing rehabilitation services, health care, medical supervision, technical assistance, and other factors, which facilitate social inclusion. Within the process of inclusion in the community, access

to certain essential services—such as domiciliary support services, physiotherapy and nursing, adapting homes to make them accessible, or even vacancies in long-term care units—is an extremely lengthy process that requires continuous and persistent efforts involving different entities. As an example of this, 19 of the 27 persons with spinal cord injuries who were interviewed and were already living in the community either had to have their homes adapted or else moved house, but only two cases received any direct support from the social security services. The local municipalities were particularly important in this process, in many cases offering building materials—and sometimes labor—for converting houses.

In the great majority of cases, it is necessary to adapt homes to the needs of persons with spinal cord injuries when they are discharged from a rehabilitation center. However, this is not the case during the waiting period between being discharged from hospital and being admitted to a rehabilitation center. This period is therefore defined by added setbacks that reflect just how inaccessible the vast majority of the built environment is in Portugal:

I lived in a first floor flat that only had stairs and wasn't suitable for me to go back to. And my parents, like the good people they are, did everything they could to change things as quickly as possible . . . So that was why getting discharged from the hospital in Coimbra after my condition had re-stabilized took a bit of time. Because they explained that I didn't have a house to go back to and they were understanding about it: "So, we'll let her stay here, until she gets into Alcoitão [Center for Rehabilitation Medicine of Alcoitão]." . . . It was a bit of a lengthy process getting admitted to Alcoitão . . . but I got in, I don't know, about eight months after the accident, I got there . . . And while I was there my parents dealt with the move. (Ana, person with a spinal cord injury)

The difficulties of the transition period between hospital and rehabilitation center are due, in this phase, not only to the physical condition of the patients—in most cases still confined to bed and not using a wheelchair—but also the existence of physical barriers, both in housing and in public spaces. This means that persons with spinal cord injuries are very often confined to their rooms, the period of hospitalization is extended, as in the case cited above, or, in other cases, stay in private clinics while awaiting admission to a rehabilitation center.

At different points in the relationship involving institutional provision and personal life, an analysis of the trajectories of persons with spinal cord injuries reveals the lack or inadequacy of responses that would maximize their rehabilitation and speed up the process of integration within the community. This lack of provision is even more serious given an environment which from many points of view—social, cultural, employment, architecture, planning—is, by default, ostensibly hostile to the social inclusion of persons

with spinal cord injuries (and persons with disabilities as a whole).

Spinal Cord Injury and Embodied Experience

The most common and obvious implications of spinal cord injury are paraplegia (loss of mobility and/or feeling in the lower limbs), tetraplegia (loss of mobility and/or feeling in all limbs), and possibly other dysfunctioning organs. However, from the time of the accident, followed by the period spent in a rehabilitation center, up to their integration within the community, individuals face difficult periods marked by challenges, changes, and pain which cannot be grasped by examining the medical and functional issues alone or the institutional responses to these questions.

On the basis of the data from the fieldwork, it may be said that the way in which persons with spinal cord injuries experience the changes and challenges depends on a number of crucial factors, namely, the time that has elapsed since the injury, socioeconomic structure, professional status, family and affective situation, the protection system activated at the time of the accident (namely, the existence of insurance), and the social environment in the area where they live.

However, although it is possible to list certain variables, which affect how subjects adjust to the need to live their lives in new terms after the injury, the personal and emotional impact of this experiential and existential reconfiguration is always inscribed within the particularities and contingencies of each individual life story. While not ignoring the very important social factors, it is still necessary to access the local experiences of subjects facing significant suffering and tribulation.

On the basis of the interviews, we may therefore agree with Oliver, Zarb, Silver, Moore, and Salisbury (1988) when they stated that, despite the social provisions and resources available, having a spinal cord injury will always be an extremely significant life event, which implies feelings of vulnerability and uncertainty. In fact, the initial period following the injury is frequently defined by deep anguish and ontological reflection in which life is divided between “before and after” the injury:

The hardest part is knowing that you had a job, you had a normal life and then suddenly your life falls apart. You go under. You feel very bad, very, very bad. You feel you are useless, you can't do anything, you depend on other people for everything. (Helena, person with a spinal cord injury)

Spinal cord injury therefore contains an awareness of the body via what Leder (1990) has named *dys-appearance*, understood as “the thematization of the body which accompanies dys-function and problematic states” (p. 86). Thus, *dys-appearance*—the affix *dys* comes from the Greek for

“bad”—denotes an increased awareness of the body as functioning via irregularity, loss, or excess. From the point of view of subjective perceptions of one's own body, a person with a spinal cord injury is confronted with a feeling of vulnerability in a body devoid of references from before the accident, what Martins (2006, 2008) referred elsewhere as the “anguish of corporal transgression.” This refers to an aspect of personal suffering that is eminently corporal and cannot be fully grasped in terms of social factors. We are therefore addressing the vulnerability that is the result of a “failing body” that transgresses the references for existence or the references for living in the world. Understood in this way, the anguish of corporal transgression makes us recognize the dimensions of the pain, suffering, and existential anxiety in which bodily experience, the incorporated knowledge of living in the world, and emotions become central.

This ontological anxiety tends to ease as greater adjustments are made to the condition imposed by the injury or as progress is made in the rehabilitation process. However, this path is accompanied by a complex adjustment of expectations which, to a great extent, involves constructing a more plausible prognosis than the possibility of “walking again”:

In the beginning, I was still thinking “this is just temporary, I'll go back to being the person I was, I'll walk again, I'll go back to my job,” but later on I began to realize it wouldn't be like that, and I spoke to the doctors and the nurses . . . the doctors also talked to my family and my family—mainly my mother—started to prepare me and I started facing up to reality. (Álvaro, person with a spinal cord injury)

Slowly, the personal anguish and sense of loss associated with physical subjectivity gives way to an awareness of the limitations, outside the body and the subject, which deny persons with spinal cord injuries the possibility of resignifying their existence by becoming as fully involved in society as possible.

Key Moments

Although it is relevant to refer to adverse events which leave indelible marks on people's lives as an ongoing experiential process, it is also true that the identity reconfiguration process for persons with spinal cord injuries is still defined by certain key moments. One example of this occurs in the initial period of hospitalization after the accident, when the individual becomes aware of the injury. At the time, the impact of this assaults the entire physical, emotional, and social structure of the subject. The sudden isolation from familiar environments, confinement to a hospital bed, physical suffering, feelings of alienation toward a changed body, and the need to confront the diagnosis are all

factors that create a framework of vulnerability and uncertainty. The difficult moment of facing up to a traumatic prognosis is frequently made worse by the circumstances in which it is delivered. In many cases, patients learn about their diagnosis accidentally or through hasty conversations that are distressingly brusque:

... the next day a doctor ... came up to me and said: "Leonardo, the operation went well but one thing is certain, you will never be able to walk again." It was a shock to me ... my hands went up to my face, I put my head in my hands and began to cry ... I started to cry and he was talking, talking and I wasn't paying attention any more to what he was saying. And he saw the state I was in and went away and the next day came back to apologize for what he had said. And I said: "Doctor, I'll never forgive you, because you are just tired of dealing with all these cases and you told me in such an offhand way." (Leonardo, person with a spinal cord injury)

The distress involved in the communication of the prognosis is due to a lack of preparation on the part of professionals, to the inexistence of an established procedure for imparting information, to the "vagrancy" through different structures and services in initial period of medical care, or even to the desire to put off a difficult conversation or to preclude misjudgments about the irreversibility of the injury. The second key moment involves the transition from hospital bed to wheelchair. This is the first milestone in the process of accepting the new condition. Whereas, from a functional point of view, moving to a wheelchair represents an important functional gain and a release from being confined to bed, it also involves a symbolic confrontation with a new identity and relationship with the use of space. The wheelchair prefigures a future in which it will serve as an extension of the body that is essential for mobility, whereas the bed reflects the transitory nature. Moreover, the wheelchair is the prime symbol of disability in our society (we need only think of the sign used to indicate reserved parking spaces), so that the transition to a wheelchair also implies the incorporation of the stigma hegemonically associated with disability. The struggle experienced by Sofia in using her own wheelchair clearly illustrates how this evokes the specter of a new life:

... the hardest part was when they ordered my wheelchair. Because I'd been using the hospital wheelchair and when my own arrived I didn't want it. For almost two weeks the nurse kept coming with my wheelchair and I sent him away. The hospital wheelchair was different ... it was like I was still thinking that I would be able to get out of it. Having my own chair meant that I'd be in it forever! And that's hard ... (Sofia, person with a spinal cord injury)

The third key moment involves the first time going home after experiencing a spinal cord injury. The significance of

this moment in relation to the process as a whole is due to two main factors: reencountering life before the injury and becoming aware of the physical, social, and cultural barriers that must be faced. In fact, returning home after a stay in a hospital or rehabilitation center frequently involves a shock encounter with the real world:

Alcoitão [Center for Rehabilitation Medicine of Alcoitão] was like the promised land for us, where you could turn left or right when you wanted, go to the bathroom in complete safety and now, the next moment, I'm out here and up against all possible and imaginary barriers, architectural barriers, human barriers, people who look at you and call you "poor thing," and "poor little soul," it hurts a bit to hear that. And then when you get to some building you just look at the steps, and when there aren't any architectural barriers—it can happen—it feels as if someone has "forgotten" about disability, but when you find them it's as if there's a little bell ringing ... That's how it was when I left Alcoitão, it messed me up a lot, it really did. (André, person with a spinal cord injury)

Leaving the rehabilitation center is the first test of self-sufficiency after the protective environment of an institution (Oliver et al., 1988). On one hand, depending on the resources available to them, people with spinal cord injury returning home may regain control of their lives and escape the strict medical controls (Hughes, 2001; Oliver, 1990; Turner, 1992), which invariably govern time and practices in hospitals and rehabilitation centers. On the other hand, returning home means being exposed to a hostile world that configures an individual with a spinal cord injury as an alien body. In a world constructed in terms of a much-vaunted normality (Davis, 1995), persons with disabilities are exposed to all kinds of obstacles, lack of understanding, and the threat of losing control over their lives. In addition, when returning home involves leaving the rehabilitation center where they have made friends with other people in the same condition, it may imply the reindividualization of experience.

The specified three key moments in the identity reconfiguration process are significantly telling of these hindrances, constituting moments of biographical experience in relation to which transformations of the institutional and political structures are crucial. As such, each key moment highlights the crucial dimensions of action that must be addressed to strengthen the institutional support network. Key Moment 1, concerning the information on the medical condition, reveals the importance of *specialization* in the medical intervention and communication. Key Moment 2, concerning the transition to the wheelchair, gives relevance to the need of *collectivization* of the experience of spinal cord injury and the identity of disability. Key Moment 3, concerning the return to home, underlines the significance of the *demedicalization* of the process of social inclusion. These dimensions of action translate into three action strategies defined to transform the

institutional and social panorama faced by individuals with spinal cord injuries.

Discussion

Disability remains a weakly politicized line of social inequality and exclusion in Portugal. One of the consequences of this reality is the perpetuation of the barriers preventing the inclusion of persons with disabilities in Portuguese society, thus fostering dependency on benefits and family support. In failing to present alternative models for disability, the low level of politicization of the question of disability in Portugal (Fontes, 2009, 2014) has also proved a significant constraint on the identity reconstruction process for persons with spinal cord injuries. The majority of our interviewees, despite remaining in contact with other persons with spinal cord injuries, mainly through social networks, stated that they were not involved in any political activities for the social inclusion of persons with disabilities. This leads to an individualization of the experience that has a disempowering impact for the challenges faced in the process of personal reconfiguration following a spinal cord injury. Based on the analysis of the life trajectories of individuals with spinal cord injuries in Portugal, three action strategies are outlined: specialization, collectivization, and demedicalization.

Specialization

Throughout this article, the importance of a specialized knowledge and intervention toward the individuals with spinal cord injuries is discussed. This specialization implies, first, increasing the availability of beds in the convalescence units and in the centers for initial medical rehabilitation, where waiting lists were identified. Second, the establishment of a protocol defining intervention procedures for the different services involved in the medical stabilization and rehabilitation process of persons with spinal cord injuries. This intervention protocol would need to set out the services, competencies, arrangements, and communication channels between the different institutional units. This would potentiate the delivery of a timely and resourceful rehabilitation process, optimizing the functional gains of persons with spinal cord injuries. Furthermore, this specialized approach will enable the definition of a communication procedure through which the prognosis can be delivered in a prompt, clear, and empathic manner (Key Moment 1).

Collectivization

The individualization of experience was emphasized for its negative impact in the subjective responses to the rehabilitation process. This issue was singularly exemplified by the symbolic weight of the transition to the wheelchair, a

moment that reifies the assumption of a socially devalued identity, creating a feeling of irredeemable destitution at a time when persons are deprived of empowering sociopolitical references (Key Moment 2). Rehabilitation institutions should allow and stimulate moments of biographic exchange between persons recently diagnosed and individuals who have long assumed a disability identity built on their experiences of spinal cord injury and enacted sociopolitical perspectives. This dimension of action must be translated into a strategy that proactively enables porosities between rehabilitation settings, the organizations of persons with disabilities, and the knowledge born of the daily experiences of living with a spinal cord injury in the outer world.

Demedicalization

Throughout this article, the limits of a medicalized and narrow approach to social inclusion have been emphasized. The shortcomings of such an approach are particularly conspicuous when considering the experience of returning home after the initial medical rehabilitation (Key Moment 3). This moment involves a first confrontation with a disabling environment. The *demedicalization* suggests that, besides appropriate medical interventions, the inclusion process of individuals with spinal cord injuries depends on a broader cultural and social transformation. The path toward wider social change must therefore support, and be supported by, the idea of destabilizing the dominant representations of disability and existing barriers to participation through democratic vigor. Therefore, Portuguese social policies toward persons with spinal cord injuries must transcend an individualized and medicalized approach.

There is a recursion between health complications—often resulting from inadequate care and a lack of resources—and the exclusion of persons with spinal cord injuries from public life and spaces. The shortcomings of the institutional support network for persons with spinal cord injuries, both in terms of health care structures and social provisions for their inclusion within family and community life, create an additional barrier to the identity reconfiguration process. This should result in the creation of an institutional network that is properly equipped to deal with primary care, rehabilitation, and inclusion within the community. It would also lead to changes in the rationale for medical care, providing persons with spinal cord injuries with better information and control over the various paths and phases of their treatment. The improvement of support services for persons with spinal cord injuries needs to encapsulate a politicized perspective on the rights of persons with disabilities and an acknowledgment of their capacities and aspirations. In this regard, it is vital to politicize the issue of disability in Portugal to offer alternative models for disability and a meaningful and inclusive life for persons with spinal cord injuries.

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