Care of patients after spinal cord injury in the Polish and English public health system

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Abstract

Background: In England and Poland there are completely different models of healthcare, which translates into the type and amount of the support received. The aim of the present article is to show the differences in healthcare systems and to compare the financial situation and access to medical services financed from public funds for people after spinal cord injuries in Poland and in England.

Main part: In England, a special commission assesses whether a patient needs a full package of continuous health care or assistance in the form of social care, including the provision of round-the-clock carers if necessary. In Poland, the National Health Fund provides medical assistance for the following household benefits: district nurses, long-term nursing care and rehabilitation. Only the families in a difficult situation are eligible for provision of carers. In England, occupational therapy is a highly developed field, while in Poland it is limited only to occupational therapy workshops.

Conclusion: It is advisable to conduct further financial analyses in order to assess the accurate scale of the problem and take action to improve the life situation of people after spinal cord injury. The English system ensures a higher standard of living for this group of people with disabilities.

Keywords: spinal cord injury, personal assistant, primary care, medical service, national health service

1. Introduction

Spinal cord injury is a serious trauma usually associated with irreversible loss of function, limitation of movements, deterioration of the material situation, social isolation and psychological problems, which significantly reduce the quality of life. Most people with spinal cord injuries are incapable of working and completely dependent on their families and help provided by health services. Studies show that the situation of people with disabilities depends on the country of residence. Many disabled people around the world, including Poland, do not have equal access to health care, education and employment [1]. Therefore, there is a need for a comparative analysis of the discussed issue in different countries, in order to present possible solutions and search for the best model of care for people with disabilities caused by spinal cord injuries [1,2].

About 40,000 people with spinal cord injuries live in England and each year the number increases by 800 new cases, which gives about 12 cases per 1 million inhabitants. In Poland, due to the lack of publication of comprehensive epidemiological statistics, it is difficult to determine the total number of people with spinal injuries. According to the study by Borzęcki et al., published in 2012, every year 25-35 people per 1 million of the population sustain spinal cord injuries [1]. Today the number of inhabitants in Poland is 38 million,, which gives in total about 950-1300 new spinal cord injury cases per year [3]. However, the numbers provided vary and the available data are often no longer valid. Therefore, there is a need to develop

an appropriate research strategy to provide reliable information, as much higher statistics in Poland can result only from unavailability of precise data [1,3,4].

The number of people with spinal cord injuries is quite high and the government needs to face a serious challenge to provide adequate care and a good standard of life.

The health care systems in England and Poland differ significantly, which results in differences in availability of public support, quality of life of people after spinal cord injury and possibilities of living independently of their families. Depending on the level of damage, the affected individuals are partially or completely dependent on the support received from the government and family. The amount of benefits, availability of free rehabilitation and occupational therapy, funding for medical equipment, architectural adjustments of places of residence and provision of permanent caregivers significantly affect the physical, mental and social dimensions of life of spinal cord injury individuals [2].

2. Aim

The aim of the present paper is to show the differences in health care systems, compare the financial situation and access to medical services financed from public funds for people after spinal cord injury in Poland and in England.

3. Main part

3.1. Consequences and complications of spinal cord injuries

The most obvious consequence of a spinal cord injury is tetraplegia or paraplegia. However, the loss of motor function and functional limitations depending on the level of injury are just one of many problems. Spinal cord discontinuity leads to urinary, intestinal, respiratory, cardiovascular and sexual dysfunctions [5]. Moreover, damage to the spinal cord has psychological, social and financial ramifications [6]. The urinary bladder is usually emptied using a suprapubic catheter, which increases the risk of urinary tract infections. Tetraplegic patients need help in defecation. Suppositories, enemas, and digital stimulation are used. Due to impaired intestinal peristalsis, they may suffer from constipation or diarrhoea. Prolonged lying or sitting can lead to pressure sores. According to the study by N.L. Liem et al. (2004), 47.9% of study patients developed constipation, 41.8% diarrhoea and 38.7% pressure sores. Lack of exercise significantly increases the risk of thromboembolism, pneumonia, and cardiovascular diseases. All these aspects together with social isolation can cause psychological disorders, e.g. depression [5].

Spinal cord injury is a serious trauma associated with many complications; the affected patients become totally dependent on others. Therefore, they require adequate support and assistance with everyday activities to help them cope with difficulties [2, 5, 6].

3.2. Health care system

From the economic point of view, health care is an activity dealing with health-related needs through physical means (medicines, equipment, medical devices) and work . i.e. medical services provided by doctors, nurses, paramedics, involving diagnostic tests, medical advice, psychological therapies, rehabilitation, health status adjudication, preventive measures, vaccinations and care [7].

In England, the funding of health care is based on the Beveridge model, which was designed after the Second World War. The government is responsible for health care ensuring access to the basic benefit package. The equivalent of the National Health Fund (in Polish Narodowy Fundusz Zdrowia -NFZ) operating in Poland is the National Health Service (NHS), whose sources of

Table 1. Expenditure on health care in Poland and Great Britain in 2010-2013.

State	Expenses for health protection per one person, USD			Expenses for health protection in relation to GDP, %		
	2010	2011	2013	2010	2011	2013
Great Britain	3422	3405	3235	9.6	9.4	8.5
Poland	1395	1452	1530	7.0	6.9	6.4

Source:
http://www.stat.gov.pl/cps/rde/xbcr/gus/ZO_narodowy_rachunek_zdrowia_2011.pdf
http://dx.doi.org/10.1787/health-data-en; WHO Global Health Expenditure Database

financing are taxes flowing into the state and local government budgets. The NHS provides only basic medical services; therefore, the voluntary health insurance is necessary [7].

In Poland, the Siemaszko model was in force until 1998; subsequently the state took full responsibility for the health of the society, and the only source of financing was the state budget [1]. All healthcare facilities were state-owned and centralized without the presence of the private sector. Since 1998, there has been a tendency to change towards the Bismarck model, which is the basis for functioning of the health system in Germany, Austria, Belgium, France and Switzerland. In this model, the compulsory insurance premiums paid by employees to independent health insurance funds and funds from the state budget became the source of financing. Instead of general taxation, the targeted funds were created. Currently, there are both public and private medical units. The Ministry of Health, the National Health Fund (NFZ) and local governments are responsible for the functioning of health care. The NFZ finances health services and signs contracts with public and non-public healthcare providers. The Ministry of Health supervises the activities of NFZ, while the Ministry of Finance supervises finances. Territorial self-governments are responsible for health promotion, planning of service supply and management of public institutions [7].

According to statistics, there is a significant disproportion between Poland and England in expenses for health protection. More than twice lower health expenses per 1 person in Poland may result from a lower level of economic development and a 2.5% lower share of health expenses in GDP. In 2010-2013, expenditure on health per person increased by 2.3% in Poland while decreased by 0.1 in the United Kingdom. This trend is not tantamount to the percentage share of expenditure in GDP, where a decline is observed. This is due to the general increase in GDP [7,8].

3.4. Financial situation: medical services and carers

The situation of people after spinal cord injuries in Poland is bad. However, in recent years, the government has been working on changes in the support system for disabled people and their carers. Numerous steps are taken to improve the quality of life of this social group. Some changes have already been implemented: funding for rehabilitation, orthopaedic facilities, elimination of architectural barriers and funding for employers hiring people with disabilities.

According to the study of B. Gąciarz and J. Bartkowski, conducted in 2014, only 20.9% of disabled people receive regular financial assistance. The basic financial sources of people after spinal cord injuries are retirements and disability pensions. People with disabilities can apply for a disability pension (an average of 345 Euros per month), for care allowance (36 Euros), and for housing allowance (about 47 Euros). Kaźmierczak

(2015) has demonstrated that almost half of people with spinal injury received disability pensions and/or benefits, and only 11% were employed and their job was the only source of income . The number of unemployed people in the analyzed group after trauma increased by 52% in comparison with the pre-accident situation. The amount of income was lower than the minimum wage. The financial support received is insufficient to cover even the basic costs of living, treatment and rehabilitation. More than half of respondents have net income of 235 Euros, 32% - of 235-350 Euros and only 21% more than 350 Euros [4, 9].

In Poland, the NFZ provides the following household benefits as medical assistance: district nurses, long-term nursing care and home rehabilitation. District nurses cooperating with a general practitioner carry out his/her recommendations in the patient's home. Based on the referral from the doctor and confirmation of the degree of disability, the patient may apply for nursing long-term care. The nurse visits the patient at least 4 times a week, performs hygienic tasks, dresses wounds, gives instructions to the patient, family and carers. Unfortunately, due to financial constraints, waiting for long-term nursing care is quite long. Home rehabilitation based on referrals from general practitioners is carried out by outpatient clinics that provide outpatient rehabilitation services. Referrals are valid for up to 30 days after issuing and the patient should report to an appropriate clinic during that period [10].

According to the regulation of the Minister of Health on guaranteed services in the field of medical rehabilitation of May 2017, the duration of rehabilitation carried out at home is up to 80 treatment days in a calendar year and includes no more than 5 treatments per day. There is a possibility of extending the benefits after obtaining the approval from the NFZ Department Director based on a justified request from the referring physician. Although physiotherapy is a much needed service on the Polish market and has many advantages for patients (including the absence of side effects as opposed to pharmacological treatment) and the state (limiting the number of disabled individuals and medical expenses), it is not appreciated by the healthcare policy makers and public payer. As a result, the waiting time for treatments is from a few weeks to several months. Due to long queues, more affluent patients are left to take advantage of private physiotherapy services, the availability of which increases due to growing demands for such services and increasing appreciation of the benefits and effects of physiotherapy [11].

Patients immediately after spinal cord injury and hospitalisation are referred urgently to neurological rehabilitation wards. The waiting period for admission is quite short and ranges from 2 to 4 weeks. As part of the NFZ services, patients may stay in such a ward for a few to several weeks, depending on their health condition. At that time, they should be under care of a team consisting of a physician, nurses, physiotherapists, a psychologist, and an ergotherapist. However, the therapeutic sessions with all the above-mentioned specialists are provided only in a few centres., As the experience of physiotherapists shows, in practice therapeutic teams do not exist and work of specialists is not coordinated. Based on the Act on Employment and Vocational Rehabilitation of People with Disabilities, adopted 27 years ago, the National Disabled Persons Rehabilitation Fund (in Polish PFRON) was established. It strives for stabilising the labour market of people with disabilities and supports non-governmental organizations and institutions. Thanks to its activities, about 24 thousand employers receive a subsidy to 250.000 employees with disabilities every month. Annually, 26 thousand people use 683 available occupational therapy workshops and 98 existing professional activity establishments

use 19mln Euro (6% of GDP) to employ 3.900 people with a disability certificate. Employers hiring people with disabilities may be reimbursed for adjusting workplaces and office space for employees, as well as for adaptation or purchase of specialized equipment**.** Annually, 60.000 people go with their carers for rehabilitation stays. PFRON also provides co-financing for the purchase of equipment and assistance necessary in everyday life and rehabilitation for 200.000 people with disabilities annually. Each year, it transfers 48 million Euro to non-governmental organizations for the implementation of rehabilitation projects. Thanks to co-financing, 200.000 people have the opportunity to take advantage of sports, cultural and recreational activities, while several thousand students with disabilities receive support in obtaining higher education. Until 2015, PFRON co-financed the purchase of around 100.000 computer sets, over 33.000 electrically powered wheelchairs, and more than 30 thousand drivers received financial assistance for purchasing or adapting cars and obtaining a driving license [13].

Within the assistance guaranteed by NFZ, you can apply for hygiene and rehabilitation equipment. Unfortunately, the funds are limited and patients are entitled to get only up to 60 auxiliary products such as nappy pants, underpads, and diapers monthly. The rest of the needs has to be covered from their own financial resources. Patients may apply to their family doctor for co-financing anti-bedsore mattresses, canes, balls, and to the specialist (rehabilitation specialist, orthopaedist, neurologist) for a wheelchair, which is financed to a certain price limit. If a more expensive wheelchair is chosen, it is necessary to pay the difference in price. The patient`s contribution to costs above the limit may also be covered by PFRON. The order can be executed in the shop with refunded equipment. As part of NFZ assistance, you can also ask the Family Support Centre for co-financing up to 95% of the costs of adaptive renovation aimed at removing architectural barriers, but this amount cannot exceed 13.5 thousand Euro [13,14].

People with spinal cord injuries often require 24-hour care. According to the study by Kaźmierczak (2015), 50% of people with spinal cord injuries in Poland benefit from family care. However, the results of the Khazaepiori study (2014) indicate that this percentage is even higher - family members provided care for 72% of the affected and nurses only for 5.9%.. The family members involved in care have to resign from their jobs. In Poland only families in a difficult living situation can apply for support in care activities in Social Welfare Centres. Depending on the financial situation, the care may be completely or only partially supported. A fully paid carer is provided only for a few hours a week. Families with the income per capita below 159 Euro (according to the data from June 2016) may apply for a special care allowance of 124 Euro [15]. Parents, grandparents, children, grandchildren, as well as siblings can apply for benefits. However, this amount is small compared to the minimum wage, which is 349 Euro netto and does not cover the necessary needs. There are schools in Poland preparing for the profession of "an assistant of a person with disabilities". Assistants are employed in social assistance units or non-public institutions. There is a high social demand for this form of support, which is something different than caring services [15]. People who want to continue their professional work must privately hire a carer for a family member who has suffered an accident. There are many companies on the market that offer 24-hour services, but there is no company specializing in the care of people after spinal cord injuries. The individual companies can employ people as an assistant to a person with disabilities and thus provide more personalized services. The cost of round-the-clock care is about 600 Euro per month [13]. According to the article 54, section 1 of the

Social Support Act, people with disabilities who can not function independently and who cannot be provided with care in another form, have the right to be placed in social nursing homes [16]. The number of places in such facilities is insufficient; moreover, the services and care provided leave a lot to be desired. Private institutions can be used only by some patients due to too low incomes (usually limited to social assistance benefits) and lack of family financial support.. In addition, in the Polish social assistance system people with disabilities are not eligible to any funding for living in private institutions [13,14,15, 16, 17].

In England, the Clinical Commissioning Groups (CCG), equipped with Decision Support Tools(DST), assess whether a patient needs a full package of continuing healthcare (CHC) or assistance in the form of social care. The CHC package, fully funded by the NHS, includes providing permanent care - financing of carers, visits to specialists, district nurses visiting patients at home, wheelchairs, hoists, medicines, hygiene measures and unlimited amount of medical supplies, physiotherapeutic consultations, and occupational therapists. In contrast to the CHC package, social assistance, depending on the health condition and financial situation, is financed only to a certain extent and the rest is covered by the patient. In addition, people with disabilities aged 16-64 years can apply for Personal Independence Payment (PIP), which is the equivalent of the Polish pension. Depending on the degree of disability, this amount ranges from approximately 111 to 634.5 Euro per month [18,19,20,21].

In England, within 4 hours after admission to hospital, a trauma centre consultant contacts the Spinal Cord Injury Centre (SCIC) to establish an optimal management plan for the patient. The time spent in SCIC is the beginning of a new stage in life. To provide the spinal cord injury patients with the most independent life, the adequate staff is needed. Outpatient assistance provides long-term support for people being treated in the centre after discharge. The process associated with provision of necessary help after discharge is started when patients who are still in hospital. The trauma centre staff designs a plan for skin or joint protection, pain management, proper functioning of the urinary bladder and defecation. The type of physiotherapeutic services depends on local possibilities near the patient's home, for example visits of physiotherapists, classes in rehabilitation centres. The financed services cover only a maximum of one visit / one class per week. As part of social care, patients can take advantage of visits of a specialist - case manager, who discusses their needs, dreams, well-being and advises on facilities and services available in the local environment, e.g. gym, swimming pool, sports groups, physiotherapy, which could help to activate them [18,19,20].

A team of physiotherapists specializing in neurorehabilitation is present at SCIC. Physiotherapy aims to achieve the maximum functional potential of each person individually, minimize complications and educate the patient, family and carers. Rehabilitation includes: respiratory physiotherapy, pain management, passive exercise, bed-wise training, tilting to erect positions, treadmill exercises for patients with incomplete trauma and walking potential, posture assessment, hydrotherapy, swimming, functional electrical stimulation (FES), orthotic aids, recommendations on the exercise programs. SCIC also has access to the ASPIRE centre, which offers sports and recreational activities as part of a rehabilitation program. On discharge from SCIC, further management and outpatient care are determined. The team specializing in skin protection provides special beds and anti-bedsore mattresses, assesses the wounds and advises how to protect them [22].

In England,, family members can practically lead a lifestyle as before the accident and continue to work professionally, being sure that the relative receives adequate care in their absence. Social security funds are designed to provide access to the help needed to achieve everyday tasks and goals. Two options available, i.e. provision of help or funds - (direct payment to organize independently the necessary help). The leading company that provides services for the care of people with the spinal cord injuries is the Active Assistance group. Individuals undergo specialist trainings where they acquire the necessary skills to take on the role of PA - Personal Assistant, e.g. manual removal of faeces, urine bag emptying, transfer from bed to wheelchair by hoist, education about spinal cord injuries and problems associated with them, first aid in emergencies (for instance episodes of autonomic dysreflexia). Depending on the commission's decision, these services are financed in 100% or partly by the NHS. A family member wishing to take up care may apply for a carer's allowance in the amount of 316 Euro per month. The condition of receiving the benefit is the care provided for a minimum of 35 hours per week [21].

3.5 Occupational Therapy

In Poland, since 2012, occupational therapy can be studied at the physical education universities in Wrocław, Gdańsk, Kraków, Warsaw and at the Poznań University of Medical Sciences.

According to the definition of K. Milanowska of 2003, occupational therapy is one of the forms of rehabilitation treatment through work and recreation in order to accelerate the restoration of lost functions and fitness or to develop substitute functions.

In Poland, the field of occupational therapy is just developing and is limited only to occupational therapy workshops. According to the regulation of the Minister of Labour and Social Policy of September 30, 2002, the workshops include occupational and social rehabilitation. Their aim is to acquire or restore the skills necessary to take up employment. The workshops offer classes in laboratories (household, computer, carpentry, art, tailoring), trainings in social skills and recreational activities [13,23,24].

In England, the concept of occupational therapy is associated with a comprehensive approach to the patient, covering all aspects of everyday life. This area is very well developed. The beginnings date back to 1930, when the first European school of occupational therapy was established. The patient is under the care of an occupational therapist from the moment of hospital admission until discharge from the centre; moreover, further outpatient support is offered. The main areas of occupational therapy in England are:

- developing everyday life skills: training in practical household activities, such as washing, dressing, cleaning;
- mobility in bed and moving around: use of a bed, wheelchair, shower chair, toilet, bathroom, elevator, car;
- wheelchair selection: assessment of the wheelchair allowing maximum independence, assessment of the right position, off-loading cushions; subsequently these services are provided by the local disability equipment service;
- upper limb therapy: maintaining the range of motion, evaluation of and exercises for the functional potential, providing orthoses to prevent deformities and maintain function;
- assistance in communication: orthoses for writing, advice on technological devices, for example a computer that reacts to eye movements, blinking;
- social life - help in getting back to work, driving a car, training in advanced skills of riding a wheelchair;

– assessment of necessary adaptations at school, workplace and home [22].

3.6 Supporting organizations

There are many organizations in England that support people after the spinal cord injuries. The most recognizable include: Back up, Aspire, Regain, and Spinal Injury Association (SIA). In Poland the network of this type of organizations is less developed and their work is less coordinated. The main ones include: the Foundation of Active Rehabilitation, Foundation for Persons with Spinal Cord Injury and "AXIS" association[10,24,25].

The best-known organization, i.e. the Foundation for Active Rehabilitation (FAR), supporting people after spinal cord injury in Poland was established in 1988. Its goal is physical and social mobilization by organizing trainings, training camps and classes where patients learn the skills necessary for independent functioning. E. Kamińska-Gwóźdź et al. (2015) has demonstrated that participation in such organized forms of active rehabilitation increases the number of people practicing sports by 13%. This is a very important aspect, as the results of the research show the positive effect of physical activity on the quality of life of patients after spinal injury. The foundation's activities are financed by the State Fund for the Rehabilitation of Disabled Persons and the Ministry of Sport and Tourism [26,27].

The Spinal Injury Association (SIA) is a charity organization that helps people with spinal cord injuries. SIA offers support for the injured and their families from the moment of injury throughout their lives, as well as provides necessary medical urological supplies, stomas, hygiene products (nappy, bed sheets, wipes, etc.), medicines and other necessary things. SIA enables cooperation of experienced people with patients with recently sustained spinal injuries. The organization encourages social activation, return to work, participation in volunteering, informs patients and families about the possibilities of financing care, helps to apply for funding. Membership in SIA is free [20].

The Back up organization provides support through the integration of people after the injury and through the activities of a group of volunteers who are themselves people with disabilities and understand perfectly the challenges associated with them. A telephone line is opened, which is available to both people suffering from spinal cord injury and families. Back up organizes trainings improving the skills of wheelchair-riding, trips with various sports activities: skiing, climbing, and integration trips.

4. Summary

The functioning of health care in England and Poland is different, starting from the method of financing to availability of medical services. The system in England financed from the state budget provides more extensive care, which most likely results from higher economic development and higher expenditures on health care. Thanks to adequate financial support and provision of 24-hour caregivers, a person suffering from spinal cord injury is able to live independently of the family. Otherwise,, in Poland the family is burdened with the responsibility for a decent life and care of an affected individual. The family members have to resign from work and completely reorganise their lives.

Further studies are necessary to provide more detailed statistical data in Poland, to accurately assess the scale of the problem and to take action to improve the life situation of people with spinal cord injuries. This task is extremely difficult, as the changes are not possible without specific regulations and acts of the Ministry of Health and increases in health expenditure in the state budget. Moreover, there is no specialized tool to accurately control and describe the actions undertaken for patients,

including those with spinal injuries. Currently, the government is working on improving the situation and some changes are being implemented based on assumptions for the new budget act. In England, spinal injury patients are provided with free medicines, the appropriate amount of means to maintain personal hygiene, advice on the selection of necessary equipment, housing (if necessary), round-the-clock caregivers and financial resources for life. In Poland, patients and their families have to care for themselves, and the pension is not enough to cover all needs. Moreover, there is the profession of an assistant to a disabled person, equivalent of the personal assistant in England. If more state support associated with provision of carers is guaranteed, there are people providing such services, which should markedly help to solve the existing problem [28,29].

The situation presented above clearly shows insufficient funds from health insurance or an inadequate financial management policy. The field of occupational therapy requires further development and the British model can prove extremely useful. Cooperation and gaining experience are essential

In both countries there are organizations and foundations that help people with spinal cord injuries, which are a huge support. In England, there are numerous such organisations and they are very popular; in Poland, they have just started to develop their activities. Noteworthy, the issues of people with disabilities are increasingly recognised and the society is willing to assist.

Both in Poland and in England, there is a need to provide physiotherapy services in a larger amount of hours and to develop this field,, which is very beneficial for patients.

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