

People with Disability due to Neurological Conditions at the Third Level of Attention

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Abstract

Disability is an important factor of discrimination and when combined with matters of gender, we find that women with disabilities face double discrimination which places them in an unequal position in relation to the general public and specifically to men with disabilities. Therefore, this article, following a deep analysis of the disability-gender pairing, as variables to be taken into account due to the double discrimination for women with disabilities, will explore the various policies carried out at the international, European and national level, pursuing a triple classification: Policies for people with disabilities; Policies of equal opportunities for women and men (with or without disabilities) and Policies for women with disabilities.

Keywords: disability, gender, public policies

Introduction

When talking about illnesses which require highly specialized approaches which impact the life of a person in not only one organ or part of the body, it is necessary to take into account the repercussions the condition has on mental health, both family and social. Therefore universalizing healthcare is necessary. Healthcare should not be conceived of as merchandise, nor as charity nor be available only to those with sufficient resources to cover the costs.

One's economic situation should not determine the access to care and thus the quality of life, of those with illnesses which cause some sort of disability. Public policies must be created which ensure quality inte-

gral health services and therefore it is important to have early diagnosis, correct treatment and medicine, wheelchairs, prosthesis and institutions available to all who need them. Due to the dearth of total coverage at all levels of attention, but especially at the third level, the intervention of healthcare professionals and society itself is necessary in making sure public policies directed towards social rights are complied with.

To include the people who do not have the basic satisfactors, to regionalize and decentralize in order to provide healthcare coverage and equality to these people often means having public services focused on these people who many times least expected it but now require a life with sup-



port, better job and educational opportunities and services which seek to improve their life quality. Thus, public awareness campaigns must be permanent, directed at professionals from all required areas as well as at the general public.

The definition of health of the World Health Organization (WHO, 2007) is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" with the objective of reaching the highest level of good health possible by means of promoting technical cooperation in healthcare among nations, the application of programs to fight and eradicate diseases and improve the quality of life. Among the objectives of WHO are to reduce the excess of mortality, mobility and disabilities with added emphasis on poor, marginalized people, to promote healthy lifestyles and reduce the risks to health and develop healthcare systems which are fairer and more efficient and financially equitable.

In the Mexican Constitution, Article 4 deals with the right to health as a right of all society, and compliance with this demand is the responsibility of the govern-

ment. In view of the numerous serious financial crises over the past years we have doubts about whether the government is in fact complying with this responsibility. A legal revision of this right and its becoming unequivocally universal and available should be a priority and the State and Society should proceed to complying with the objective of universal public healthcare and a fiscal policy which allows for quickly overcoming this serious financial weakness, both organizational and institutional, into which the State has fallen.

Within the processes of neurological illness, the sequelae which a person faces are disabling, since areas of the brain connected with motor coordination, memory and learning are affected. In many cases, these sequelae are treated like chronic, hereditary degenerative diseases which will also have an impact on the children of those suffering the disease later in life, impacting expenses in which the family will incur. Often people become ill during the productive years of their lives or when they are still taking care of young offspring. In these cases the disability which develops, besides being a biological

problem, is a social phenomenon, constructed in specific social contexts.

Disability is also a normative concept which reflects the ideas about what the class of human beings should be, mentally and physically, and the way in which society should be construed in order to treat all of its members equally, so that persons with these kinds of problems can find work, move around in public transport and have access to technology which improves their quality of life. It also implies catastrophic expenses which may ruin a family's economy and plunges them deeper into poverty.

In Mexico, in one out of every five households there is a person with a disability (González, 2013) and the socio-economic reality which predominates is not encouraging: socio-economic levels in which income is no greater than three minimum wages which must cover expenses that become permanent debt. Depending on the area where the house of a person with disability is located, there are various kinds of housing which due to their infrastructure make it difficult for a person to reach medical care or rehabilitation, or to simply cover his/her everyday needs, places far from the healthcare institution where the person will be attended. All of these factors, evidently, bring about drastic changes in family dynamics.

In this article the issue of access to neurological attention at the third level of attention is dealt with. The major neurological illness which result in disabling sequelae, situations of risk which patients with disabling neurological illnesses face, as well as the importance of financial protection in healthcare for persons with disabilities.

Access to neurological attention at the third level of attention

Given the complexity and diversity of existing illnesses, the healthcare sector has organized healthcare attention at three different levels, each provides attention to the population by carrying out specific functions. There should always be a direct relationship among the three levels in direct benefits for attention. In order to understand the importance of the third level of attention it is necessary to identify the specific characteristics of medical units, which are divided in the following manner.

First level: This is the first and most important link of the population with healthcare services. It is the entryway into public healthcare services, consisting of direct actions for the benefit of individual's, family's, community's and their surroundings. This area focuses mainly on preserving and maintaining health. It is made up of healthcare centers, medical offices, dispensaries and units of family medicine, in which outpatient care is provided. Its primary function is related to activities concerning health promotion, epidemiological overseeing, basic healthcare, specific protection and family planning, as well as timely treatment and rehabilitation, of those ailments which are frequent and whose solution is easily carried out through outpatient care based on a combination of not very complex resources.

Second level: This level constitutes more complex medical units where problems which require specialized outpatient services or hospitalization of patients who have passed through first level care or those which are spontaneous with medical-surgical emergencies, whose solution

requires a combination of mid-range and technical methods are taken care of, under the care of specialized personnel. Also at this level actions of epidemiological observation and healthcare promotion are carried out which support the actions of the first level.

Third level: The attention provided in these units of highly specialized national institutions and recently created regional hospitals where activities of restoration and rehabilitation of the health of the patients referred by the other levels are provided. Patients with complex illnesses with highly complex diagnosis and treatment are attended to at this level. Due to their high degree of specialization, these facilities are of great national and international importance in relation to investigation and medical equipment.

Here the population has access to operations, with specialized equipment, more economical than private medicine (determined by socio-economic studies carried out by social workers). Here patients from all over the country and sometimes foreign countries who seek specialized care are attended to.

In the healthcare system this division into three levels for attention exists, but coverage is not universal and does not assure cost-free medical attention to the entire population.

In Mexico social security is dealt with in the *Constitución Política de los Estados Unidos Mexicanos de 1917 (Political Constitution of the United Mexican States of 1917)*, with a social character. In 1929 the need for creating social security was foreseen, but it was not until 1942 that this system, divided into three sectors became

reality: social security for workers in general, for public workers and for the population not subject to a working situation (Díaz Limón, 2000). These sectors are under the charge of federal or local public agencies which seek to guarantee the right to healthcare, medical attention, protection of subsistence means and medical services, pensions and other social and economic benefits.

With respect to healthcare coverage up until 2012, 6 out of every 10 working people are not covered by care in healthcare institutions. 63.7% of persons in the work market are not registered in the Instituto Mexicano del Seguro Social (Mexican Institute of Social Security) (IMSS), Instituto de Servicios de Seguridad Social para los Trabajadores del Estado (Institute of Social Security Services for State Workers) (Centro de Estudios de las Finanzas Públicas).

In addition to this panorama faced by the population in relation to social security, chronic-degenerative diseases, besides in most cases being incapacitating, represent high economic and social costs and therefore, demand greater use of highly complex healthcare and technological services for their diagnosis, treatment and rehabilitation and often the institutions of social security (IMSS, ISSSTE) do not answer the needs of users in the question of attention or waiting periods, at times making it necessary for persons to seek help in other institutions such as the Secretaría de Salud (Healthcare Ministry), traditional medicine and at times self-medication, without taking into account the economic and social costs this may imply. People invest part of their personal assets in the search for medical attention and treatment, spending



their savings, or sometimes selling their belongings, but as the disease progresses, it becomes impossible for them to pay for studies, operations and medicine and visits to the doctor. Sometimes it becomes necessary for these people to renounce to their right to social security in order to continue with their treatment.

Neurological Illnesses and Disabilities

The term "disability" implies that those with disabilities lack essential human abilities or possibilities for being classified as persons (in the moral sense of the word) or for improving their quality of life. However, "disability" may be explained precisely through social and environmental factors, or biological factors which determine when a "disability" is in effect a concept describing society or the characteristics of some of its individuals. In both cases however, to have a "disability" implies an undesirable state of functioning or being of an individual in contrast to society (Shalock, 1999).

In Mexico, in 2010, there were 5,739,270 people with disabilities, which represents 5.1% of the total population. Of the people with some kind of disability, 49% were men and 51% women (INEGI, 2010).

Among the causes of disabilities, according to INEGI, are birth defects, illness, accidents and old age. Of every 100 persons with a disability, 39 have disabilities due to illness; 23 are affected by old age; 16 were born with the disability, inherited, during pregnancy or at the time of birth; 15 owe their disability to an accident; and 8% are due to other causes.

Dealing specifically with neurological illness requires medical attention at any age and for any gender; however, most of these

illnesses are chronic, bringing with them the high cost of medical attention. From studies on mortality, motives for visits to the doctor, hospital morbidity and population studies for neurological ailments, it was found that epilepsy is the number one cause for medical attention, followed by chronic illnesses, with is in concordance with more developed countries, where many communicable diseases have practically disappeared and there has been an increase in chronic illnesses (Jiménez, 2004).

Many neurological illnesses are incapacitating, and therefore it is important to learn about the ailments which cause a disability in order to decide on an approach to it, to obtain clear, concise information which both the patient and his/her family should know about, in order for the process of attention and rehabilitation to have better results, and also to learn to what extent rehabilitations will help the social and family needs which may be required.

In highly specialized institutions in the field of Neurology (Hernández, 2010), the main neurological illnesses attended to in rehabilitation and in which functional recuperation of the patient is sought may be divided into the following classification:

Muscular Dystrophy. A group of hereditary diseases that causes progressive weakness and loss of muscle mass. For every 100,000 people, there are three cases. After the age of 16 and for 13 years people are confined to wheelchairs. Death is due to cardiac arrest or respiratory failure. Age at death is between 20 and 60 years, depending on the kind of muscular dystrophy.

Back Pain. Caused by abnormalities in the anatomical structure of the spine and tissues such as the vertebrae, discs, ligaments and nerves. It produces consequences in the physical, psychological, social and job life of the person with the condition. It may appear at any stage of life and the impact may be social and economic due to absence from work and loss of functionality. Statistics show incidence of between 60% and 90% and almost 2% eventually need surgery.

Amyotrophic lateral sclerosis (ALS). This is a nervous system (neurological) disease that causes muscle weakness and impacts physical function. It is a neurodegenerative disease and is progressive and fatal and is characterized by gradual loss of upper and lower motor neurons in various regions of the central nervous system. The number of new cases is between 1 and 2.5 cases per 100,000 inhabitants and may increase to between four and eight. It may first appear between the ages of 40 and 70 and there are also cases of juvenile ALS diagnosed before the age of 25. The average age is 58 years. Survival is between 5 and 10 years after diagnosis.

Cerebral vascular disease. These diseases affect the functions of the brain, last more than 24 hours and lead to death with no apparent cause. This is the main cause of neurological disability in adults and there are a large number of persons with permanent disabilities with important impacts on the family economy and health services. 40% of survivors have some sequelae leading to partial or total dependency.

Neurological rehabilitation is part of a multi-disciplinary neurological team whose purpose is to promote the functional recovery of the patient with cerebral vascular disease.

Multiple Sclerosis. This is the most common chronic neurodegenerative disease in young adults, as well as the cause of the most serious physical disabilities. These are "demyelinating" diseases of the central nervous system (CNS). They are inflammatory: the cells of the immune system invade and destroy the myelin. The meaning of multiple sclerosis is "multiple hardened plaques." Disabilities range from moderate to severe; they may take 20 years to evolve and deteriorate. The average age for onset is around 30 years.

Guillain Barre Syndrome. This is a severe polychromic inflammatory demyelinating polyradiculoneuropathy which is ascending and progressive, characterized by weakness, paresthesias and hyporeflexia.

There are between one or two cases for every 100,000 inhabitants per year in both men and women, young adults and people over 55. While statistics show that 60% of the patients recover, 10% will not be able to walk without help and others will suffer some kind of residual disability. Patients present progressive weakness which usually starts in the feet and moves upwards towards the knees, hips, hands, wrists, elbows and shoulders. About 20 require mechanical ventilation.

Facial Paralysis. This is a unilateral affection of the face due to facial nerve dysfunction. The causes may be congenital or

acquired, an example of the latter is those associated with cerebral vascular disease. There are about 20 to 30 cases per every 100,000 inhabitants per year. The average age is 40 years. Most patients recover spontaneously and almost all achieve almost normal functions. 16% have permanent alteration in facial movement with secondary esthetic distortion and transitory or permanent psychological changes.

Parkinson's Disease. This is a neurodegenerative age-related disease. In its early stages, it produces movement-related alterations, later cognitive and dysfunctions in behavior are added such as: dementia, anxiety and depression.

The disability becomes more and more obvious when cognitive and behavior related alterations are added to the motor-related symptoms which lead to deteriorating functions of the patient. There is an incidence of between 5 and 20 cases in the susceptible population of between 20,000 and 100,000 per year.

There are many syndromes which imply deterioration of the memory, behavior and the abilities to carry out everyday activities which do not respond to rehabilitation treatment and this is one of the main causes of disabilities in the world with physical, social and economic impacts on the caregiver, family and society.

According to WHO there are 35.6 million people in the world with dementia, and each year 7.7 million new cases are registered. Alzheimer's disease, the most common cause of dementia, is responsible for between 60 and 70% of the cases (WHO, 2012). If we consider that life expectancy is increasing, in the coming years neurologi-

cal diseases will affect more and more people, and therefore the number of people with disabilities will increase. This leads us to think of measures to reduce the social, healthcare impact of this situation not only in states and the healthcare system, but also society as a whole, since there will be non-preventable situations which will require significant changes in persons' quality of life of.

Situations of Risk for Patients with Neurological, Debilitating diseases.

In one fifth of the households in Mexico there is a person with a disability, but the majority of persons with some kind of physical disability or illness are found to be living in poor homes, whose work-produced income is lower than what they receive from social programs said the National Institute of Statistics and Geography (INEGI, 2010).

It is estimated that in 2013, 6.6% of Mexicans have some kind of difficulty (disability) in carrying out at least one measured activity: walking, seeing, hearing, speaking, communicating, paying attention or learning, taking personal and mental care of him/herself. Of these, eight out of ten are over 29 years old and 7.3% are children under 14.

In the country there are 31.5 million households and of these 6.1% report having at least one person with disabilities: 19 out of every one hundred households. Of these, 78% have a person in these conditions, but in 18% live two people with disabilities and in 3% of these households there are three or more people with disabilities.

The National Institute of Neurology and Neuro-Surgery reports that up to 2013 among the main statistics reported, tumors stand out with 18% and vascular diseases account for

6.6%. (Table 1) In light of this panorama, some of the risks which patients and their families confront upon being diagnosed with a neurological illness which may produce disability may be multi-factorial, and some of the most common are:

- Dependency, understood as a state in which people find themselves due to the lack or loss of physical, psychological or intellectual autonomy and who need help for carrying out everyday activities. These may result in the wear and tear of the caregiver, exasperation and at times even lead to mistreatment due to the inability to provide constant, continuous support. If the disability takes place at an early age, care will probably have to continue for years.
- Psycho-social changes to the degree of maximizing and increasing the defense and crisis mechanisms, bringing on fear and anxiety, depression, aggression, negation, feelings of insecurity, guilt, compassion and uncertainty about care.
- The stage of negation may manifest itself through feelings of anxiety, fear, vulnerability, anger, protest and ire.
- Lack of organization: the illness breaks the adaptive resources for facing difficult situations; contradictory emotions and reactions are present, in family communications, handling of economic resources, physical and emotional exhaustion.
- Anxiety: hyperactive, irritable, intolerant behavior among the affected people, at times isolation of members of the household and refusal to speak about what is happening and what each member of the family is feeling.
- Emotional liability: ever-changing, superficial reactions when the capacity to contain, hold back and organize affective answers becomes insufficient.
- Insistent worrying: about future consequences and assigning roles (loneliness,

Table 1 Neurological Morbidity, 2013

Diagnosis	F	%
Malignant brain tumor	287	8.6
Other Vascular Diseases	218	6.6
Other congenital malformations of the circulatory system	170	5.1
Epilepsy	149	4.5
Benign tumors of other endocrine glands and non-specified	129	3.9
Subarachnoid hemorrhage	107	3.2
Benign meninges tumors	101	3.0
Recurrent Depressive Disorder	96	2.9
Malignant meninges tumors	88	2.6
Cerebral infarction	75	2.3
Others	1 907	57.3
Total:	3 327	100

Source: Statistics on Morbidity of the National Institute of Neurology and Neuro-Surgery Manuel Velasco Suárez, 2013; Dept. of Epidemiology, INNN.

economic problems and security in offspring's education).

- Loss of networks of family support: due to weariness for caring for or providing economic support, lack of time, change in everyday activities, work-related income or the formation of new families in the case of the offspring, leaving the person with a disability in the care of a primary caregiver.
- Economic depletion: due to the cost of treatments and transportation to third level healthcare institutions which are generally centralized, cost of medicine, medical equipment, purchase of such items as diapers, wheelchairs, special food and sometimes, when income is sufficient, the payment of caregivers by the hour or day to give relief to the caregiver.
- Changes in family dynamics which modify the relation of the sub-system and at times the expenses which can mean a decrease in basic needs which limit the quality of life of the family as a whole.
- Reduction in physical or psychological, or personal limitations in relation to the functions, activities and participation of the nature and implications of people and families (Shalock, 1999).

One of the strategies which lowers the risks of persons with disabilities and their families is to increase functionality and quality of life based on the emotional well-being which gives the patient security, respecting his spirituality and concept of happiness, strengthening interpersonal relationships of family intimacy, affection and confidence, which allows for creating

or strengthening material well-being with respect to his/her belongings, property, savings, security in housing and food, medicine, improving personal well-being with education, social abilities or personal fulfillment. The physical aspects of maintaining health, nutrition and ease in access to rehabilitation, are dimensions which jointly will support his/her independence and integration into the community and the respect of his/her rights.

Financial protection for persons with disabilities in healthcare services

Financial protection is based on three principles: a) assuring fair financing of health-care attention based on the premise that "he who has the most pays the most and he who has nothing pays nothing;" b) avoiding the possibility of families deferring or even cancelling health-care attention of some members of the family for financial reasons; c) avoiding households having to pay excessive amounts for caring for their health. These excessive expenses often force the family to use up their savings, go into debt, sell family property or go without other goods and basic services such as education, thus leaving themselves open to impoverishment. (Sesma-Vázquez, 2005).

WHO measures financial protection coverage using two indicators: a) incidence of catastrophic out-of-pocket spending¹, for example spending exceeding a threshold of a household's 'ability to pay' and b) incidence of 'impoverishment' arising from out-of-pocket spending. This organization

¹ A "household with catastrophic spending" is defined "as those in which health-care spending represents over 30% of their capacity to pay." (Sesma, 2005).

has developed methodology for estimating the financial protection in health-care: 1) measuring the ability to pay or the income which is available; and 2) the criteria for defining catastrophic spending.

Health-care expenses may represent between 3 and 5% of a household's spending in the poorest households where people with disabilities live. Most of their income goes for food and shelter. (González, 2013).

The first measurement of the percentage of households with catastrophic expenses was carried out by the Fundación Mexicana para la Salud (Mexican Fund for Health-Care) (FUNSALUD), and the findings were that 2.3% of Mexican households had incurred in excessive expenses to attend health-care needs in 1992.

FUNSALUD was one of the first institutions to carry out the concept of catastrophic expenses for reasons of health-care, according to figures of the Sistema de Cuentas Nacionales de Salud (System for National Accounts on Healthcare) (Sicuentas) which indicate that over 50% of the total expenses in health-care in Mexico is out-of-pocket expenses. The high incidence of these kinds of expenses is one of the factors which most influences the frequency of catastrophic expenses.

When evaluating the financial protection of a given population, besides the catastrophic expenses, we must add postponing medical attention for financial reasons. In the Encuesta Nacional de Salud (National Survey on Health-Care) (ENSA, 2000), it was found that 520,000 Mexican households postponed-for financial motives-the attention to healthcare of its member during that year. Spending on medication is a large proportion of out-of-



pocket spending, above all in the poorest households.

10% of the poorest households in the country spend over 70% of their out-of-pocket expenses on medicine; while the richest 10% spend about 56% of their out-of-pocket expenses. That is why it is not surprising that catastrophic expenses in families in the lower financial sphere are for medicine. Some authors have found that this type of expense in the lower 10% of Mexican homes generated 65.7% of the

catastrophic spending. In literature the condition of insurance, income and availability of services which require out-of-pocket payment are determiners of catastrophic spending. Other variables which influence the risk of incurring in catastrophic spending are the size of the family, place of residence, gender, education, age of the head of the household, as well as the presence of a family member with a disability. INEGI classifies the components of healthcare spending in three areas: medicine, out-patient care and hospitalization.

The ability to pay is defined as the money left over from the total expenditure of a household once the basic needs of food have been subtracted or a certain expense which defines the poverty level (two dollars per day per person). This concept is called the "effective income" by WHO.

Some research which was carried out in five states of Mexico attributes out-of-pocket spending to three factors: out-patient care, medicine and hospitalization. The risk of impoverishment at the national level occurred frequently in high-risk households; 20% are poor, live in rural areas and have no social security. It concludes that the implementation of local health-care policies should be based on evidence found at the state level.

In 2007 in Mexico, an exploratory study was carried out in which 26 patients who had been hospitalized between January 2004 and December 2005 at the Instituto Nacional de Neurología y Neurocirugía Manuel Velasco Suárez (National Institute of Neurology and Neurosurgery Manuel Velasco Suárez) were studied. The objective

was to determine the socio-economic factors which have a bearing on patients with a diagnosis of Epilepsy who were undergoing therapy. They concluded that these patients, regardless of whether they were at a reproductive and productive age or not, did not form a family, since they depended emotionally and economically on their family of origin. There are factors which limit their continuing with treatment, mainly economic, since their families spent on an average 62% of their monthly income on medicine, which is considered a catastrophic expense for health-care.

It is fundamental to make plans and programs as well as public policies which benefit the patient with a disability derived from neurological illnesses, as well as strengthening mechanisms which limit the out-of-pocket spending and avoiding the growth of deficiencies and poverty which, also, lead to further emotional and family problems.

Conclusions

Neurological illness causes limitations which interrupt personal, family, social and occupational roles, in terms of the quality of life of those suffering from the diseases, as well as their families. It is necessary to develop interdisciplinary processes of rehabilitation and attention in order to improve the functionality and reincorporation of the individual into his daily activities.

It is necessary to provide the useful services which reduce functional and psychological limitations of persons with disabilities aimed at easing, maintaining or returning the greatest degree of functionality and independence to the patient.

An analysis of public policies on the matter must be made, taking into account the evolution in the way we understand the changes in life expectancy and the explicative paradigms of disabilities.

It is essential to look at disabilities from the social sphere, where limitations in services should take into account the requirements of functioning (physical, psychical and sensorial) of all persons.

It is indispensable to create strategies for reducing the risks faced by patients, based on carrying out everyday activities, the physical and mental integrity of those who face these processes.

There are many diseases which may limit the performance of a human being, some are evident to society and some evolve silently; however, they exist, they are there, and it is not necessary for a person to have to undergo catastrophic expenses which limit the full development of his/her life of his/her social relationships.



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