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Ethical Implications and Social Exclusion of Severe Illness

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Abstract

This literature review highlights the social impact of various diseases, and more specifically their negative consequences to the patients. Stigma caused by these diseases is diachronic and leads all the sufferers, both adults and children, to social exclusion. Moreover, the measures that have to be taken for the prevention of these situations and the rehabilitation of the above mentioned patients are identified. At the end ethical aspects of stigmatization and social exclusion in health services are discussed.

1. Introduction

The definition and the interpretation of social exclusion involves a wide range of concepts such as economics, culture, job position, networks of personal relationships, the structure of personal identity and finally the participation to the social groups in which somebody belongs. The term is considered dynamic and not static, because it implies both a condition that cannot be incorporated and also different mechanisms that lead to this condition or are reproduced by it [1].

The meaning of social exclusion concerns groups who lack of civil rights or groups in which the civil rights have been removed and thus their access to the labor market and the process of consumption is prevented, and it is accompanied by the stigmatization of the suffering people [2]. Citizenship, although is considered inalienable right, it is not fully recognized for the sufferers, who are treated as "second class citizens" [3]. Social exclusion is also known as social marginalization. It is widespread and is often accompanied by verbal and physical violence against the marginalized persons [4].

There are many reasons for this inhuman behavior. Every human being feels safe in a familiar and intimate environment. So, when something is different from the usual causes him fear and it is faced like a threat that should be exterminated. However, the most important reason for this problem is the ignorance, the lack of education and the actions that allow developing phenomena of fanaticism and hatred [5]. In society, people with diseases are treated like "others", victims of stereotypes caused by stigmatized disease and prejudice, and as such they face discrimination and social exclusion. This study focuses on patients with diseases such as chronic diseases, mental illnesses and AIDS, who face social exclusion, and continually encounter obstacles in their social and personal life [6, 7].

2. Objective

The objective of this literature review is to highlight the negative impact of chronic diseases to patients, which result in their stigmatization and their social exclusion and the ethical issues that those diseases may arise.

3. Material and Method

An extensive review of the recent national and international literature in electronic databases (Pub med, Google Scholar) and in scientific journals was conducted using keywords such as chronic diseases, adverse effects, ethical issues and stigmatization. To achieve an interdisciplinary perspective, we also referenced a wide range of material from outside of medicine, drawing from the disciplines of psychology, sociology, and medical anthropology. Exclusion criteria were the language. The articles used were published in English and Greek language.

3.1. Chronic Diseases

As chronic are characterized diseases that have long duration, are severe and serious and individuals suffering by them are in need constant care from the health services. All these affect the range of skills and behaviors of the individual and induce alterations in social functionality or in the performance of his/her social roles. The psycho-social consequences of the chronic physical illness are also many. The appearance of these consequences in the family depends on the problems that the family faces, the type of the disease, the age and the maturity of the parents [8].

Studies have shown that children with chronic physical illnesses have psychological, learning and behavioral problems. But there are children who do not have such problems. This is related to the reactions of the child himself, his family and the wider social environment for the disease. Moreover, the mental health of the child depends on the personal and life experiences, on the quality of the relationships with his parents, and the personality and the relationships of his parents [9].

Additionally, these diseases affect the psycho-social development of the child. The separation of the child from his/her family for hospitalization reasons causes mental health problems during adolescence. Children feel frightened and thus become passive. They do not have physiological maturity and they cannot be independent. This impedes the proper participation of the child to education, because he /she is many times absent from school [10].

It is also supported in the literature that the brothers of the children with chronic physical illness are more likely to face themselves psycho-social difficulties. This happens because some parents neglect their healthy children and as a result they feel loneliness, anxiety, rejection and fears for their personal health [11, 12].

3.2. Disability

Disability is defined as the loss of health due to damage or disorder, inherent or acquired deficiency of the bodily, mental, or spiritual functions of the organism [13]. Among the students with disabilities and special educational needs are included especially those who are mentally disabled, or those who have vision-hearing sensory disabilities, physical disabilities, chronic incurable diseases, speech-language disorders, learning difficulties such as dyslexia, pervasive developmental disorders (autism spectrum), mental disorders and multiple other disabilities [14, 15].

Parent groups and organizations of persons with disabilities should be involved in all the levels of the educational process. In countries where the education is compulsory, it should be provided to all boys and girls, regardless the type and the severity of the disability, even those with severe case. Particular attention should be given to very young children with disabilities, preschoolers with special needs and adults with disabilities, especially to women [16].

Disability is internationally one of the most debated and constantly contemporary issues of the society. People with disabilities have the same rights as all the other citizens in their dealings, having the right of every legitimate use, reference, access and appeal to all the public institutions and authorities of the state. Many attempts are made to meet the needs of disabled people, particularly in the healthcare sector, a key sector for the care and treatment of persons with disabilities which generally contributes to their integration into society [17, 18].

3.3. HIV/AIDS

A particularly important group of social exclusion is the carriers of HIV. The virus and the disease are often together referred as HIV / AIDS. The disease is an enormous health problem in many parts of the world, and is considered pandemic, as an explosion of the disease affects a wide area and it actively spreads [19]. In 2010 about 34 million people were infected with HIV worldwide. Approximately 16.8 million of them are women and 3.4 million are under 15 years old. Approximately 1.8 million deaths occurred from AIDS in 2010, lower than 3.1 million deaths in 2001. Since 1981, when AIDS was first identified, until 2009, AIDS caused nearly 30 million deaths [20].

HIV is transmitted through three main routes:

- Sexual intercourse
- Exposure to infected body fluids, tissues, syringes and transfusion
- From mother to child (known as vertical transmission) during pregnancy, childbirth and breastfeeding. Contamination is also possible with several strains of HIV, which is known as HIV super infection.

3.4. Mental Illness

The preconceived negative perception about people with mental problems is based on some characteristic properties attributed to them, such as violence, dangerousness, irresponsibility, mental deprivation and the inability to work [21].

The discrimination remains even after the effective treatment of mental health problems and leads to relapse and ongoing problems. Many mentally ill hesitate to find work because they are afraid of the possibility of rejection [22, 23]. The nature and intensity of discrimination varies according with the diagnosis and the visibility of the mental health problems, while discriminatory actions combined with cultural events 'otherness', amplify the unfair behavior [24]. Discrimination can be expressed through laws, public policies, and private organizations or through the acts of the individuals [25].

Nowadays, the intense perceptions about the dangerousness of patients with schizophrenia still prevail, and push them everyday towards social exclusion in many areas of their lives. Additionally, despite the use of modern psychiatric clinics and specialized training of the staff, violence towards patients has not disappeared. The patients are also receiving medications to serve economic interests and social control [26, 27].

Social exclusion is in fact a creation of the society itself, since the different one is almost always treated as "defilement". This whole situation is reinforced by the fear caused by the lack of information and misinformation which is enhanced by the media [28, 29].

3.5. Epilepsy

The relationship of epilepsy with stigma is lost back in time and is influenced by many cultures. In ancient and primitive societies, people believed that epilepsy was from bad causes and people were possessed by demons and sins. Despite the significant clinical and therapeutic developments that took place over the last 100 years, people with epilepsy continue to suffer from discrimination and feel stigmatized, not only in the developing world, but also in the supposed updated Western world [30].

The consequences of stigma are important for people suffering from epilepsy. Bodies of such prejudices may be the person who suffers, but also his/her environment of either the direct family or the society, eg school, work. The fear of not being stigmatized and not experiencing the rejection, leads the person who suffers from epilepsy to delay or to avoid treatment , fact that results in negative consequences. The continuous effort of the person with epilepsy not to expose his condition creates to himself intense and chronic stress [31].

3.6. Leprosy

Leprosy, or otherwise Hansen's disease, is a human infectious disease and is one of the oldest recorded diseases. This microorganism was discovered by the doctor GA Hansen in 1873, and that's why leprosy officially called Hansen's disease. This is a disease known from the ancient times and in the past was causing stigma [32].

According to Holy Scripture, leprosy made the person ritually unclean and obliged him to move from the community. The lepers lived in separate homes and consorted with each other in the community. Characteristic part in the New Testament is the cure of the ten lepers by Jesus.

Since the middle ages, quarantine measures for the sufferers were introduced, as there were a lot of indications regarding the transmissibility of the disease. Patients were obliged to wear white clothes and big bells in order the healthy individuals to be notified of their arrival sound. In subsequent seasons, the leprosarium or Lazareta were created. From all the European countries, Norway plagued mostly by the disease in the 19th century, fact that led to an intensive research on the cause of leprosy and finally the discovery of the microbe from the Norwegian Hansen [33].

In Greece there were leper settlements, which were also called "muskiness" in city borders. In 1901, in an effort to limit the spread of leprosy, the Cretan State established the isolation of lepers on the small island of Spinalonga, Mirabella Bay in Crete. It has been estimated that in Crete from a total of 320,000 inhabitants, there were 600 lepers. Gradually sufferers from all over Greece and also from the Europe were transferred to the island and the population of the island reached 1,000 inhabitants. After the discovery of the treatment for the disease, the population of the island gradually reduced and finally Spinalonga closed in 1957 [34].

However, the word 'leper' remains a stigma until today and is one of the main reasons why some patients do not seek of medical help in the early stages of the disease.

3.7. Tuberculosis

Since antiquity tuberculosis has appeared in humans. Before the Industrial Revolution, there were beliefs in which tuberculosis was often linked with vampires. In case of death of a family member with tuberculosis, the other infected members would see a gradual deterioration of their health. There was the belief that the person affected initially from tuberculosis sucks life from the other members of the family [35]. Tuberculosis is a disease that mainly affects the poor. In 1882 the microbe which is responsible for it, the bacillus of Koch, was discovered, and its infectious (contagieux) character was found [36].

The "isolated" life of persons with tuberculosis extends the traditional exclusion of patients. However, the separation is no longer root. In sanatorium, patients receive visits. They start also to have hope that they will leave from there. Moreover, the sanatorium is a world in itself, a micro-society with its habits (treatment to fresh air, good nutrition), rules, rituals and relations [37].

4. Interventions

It is necessary, for the early diagnosis and treatment of psychosocial problems of people with chronic physical illness and their families, to raise awareness of the medical and nursing staff in issues regarding the mental health and psychosocial development of adults in general and particularly of children. It is also important to raise awareness of teachers in related subjects in order to provide to children and adolescents with chronic physical disease the help they need in their school life [21, 38].

It is also necessary to support, in general, the promotion of mental health through concrete actions to raise awareness of the community about mental health issues and psychosocial development. It is also important to change the negative social attitudes towards people with chronic physical illnesses in order to enhance their social integration [39, 40].

There are, however, many ways to deal with the psychosocial impact of chronic physical illness on child and family. One of the main objectives of the proper care of children with chronic physical illness is the minimization of the biological consequences of the disease, enhancing the normal growth and development. Other important objectives are the support of his potential at all levels and the prevention and treatment of the emotional and social impact of the disease on the child and family [27].

A thorough treatment of the effects of chronic physical illness, both on medical and psychosocial level, requires the provision of comprehensive care through coordinated medical, psychological, educational and social services [41]. The care provided to the child needs to be family-centered, because the effects of the disease are shared with the family. It should also be based on integrated services in the community in order to avoid the psychological effects of weakness and failure which lead the child to frequent visits to the hospitals [21, 42].

Regarding AIDS, the HIV prevention, primarily through safe sex and through exchange programs of pins and needles is a strategic key in controlling the disease. There is no cure treatment or preventive vaccine. However, antiretroviral treatment can slow disease progression and lead to a near-normal life expectancy [43].

Finally, it should be remembered that HIV is not transmitted from [44]:

- The daily, social contact, shaking hands, hugging, simple kiss, individuals' aggregation
- Living with someone seropositivite, sharing clothes, blankets, dishes, glasses and cutlery, phones
- Toilet, bath or shower
- Sweat or tears
- Pools or sea
- Mosquitoes or other insects
- Exposure to feces, nasal secretions, sputum, saliva or vomit of an infected person unless these materials contain blood.

The social rehabilitation of all these patients requires a lot of work in the field of education and the adoption of rules and behaviors [45].

The role of the family in addressing the stigma is catalytic in diseases such as epilepsy. It is very difficult a person with epilepsy to change attitudes towards stigma if they do not change the prejudices in the family. In the sensitive area of education, it is very significant to inform teachers and all relevant bodies regarding epilepsy issues through various news programs. The communication between the family and the teacher or lecturer is also of great importance in any effort to face the stigma [31].

Moreover, leprosy, although severely hampered, it is not completely disappeared. Individual cases are likely to continue to occur, but it is reassuring that this is a disease with low transmissivity and effective treatment [33].

5. Social Exclusion as an Ethical Issue in Health Care

The concept of stigmatization and social exclusion of certain population has a variety of ethical aspects. The main point that also opposes to human rights is identified as the public unjustified discrimination. Thus, it seems that not only the symptoms of the some medical condition but also the stigma associated are burdening the person as an individual and as a community member. The individual is facing a complex internal conflict that usually leads to feelings of guilt, helplessness, incompetence and reduced self-esteem [46]. Also, feelings like low self-confidence, self-blaming or shame are common. Individuals suffering those medical condition are usually put under a double test from the one hand facing the disease itself, all symptoms and difficulties that may arise and on the other hand the stigmatization and the social exclusion that those led to. Patients that are referred to health professional must be addressed as wholeness, taking into account all the needs and problems that may occur. It is health professional duty and moral obligation to address the patient not only his biological problem but as single psychosomatic entity with needs beyond the treatment [49].

Laws, statutes and deontology codes are governing all health professions. Their main concern is not only benefit and not harm the patients, but also a plenty of other items that promote equality in health services, information, respect of personality and human dignity.

The main concern of the health services should be to provide equal access and attitudes towards patients despite their health problems. Nowadays science has come forward in the field of screening; prevention and treatment of life threaten diseases but along with the progress came the ultimate need to maintain the person- centered approach to those conditions. Health care services must provide special training to their personnel in order to be capable to address those complex issues. Training programs in order the health care professional to be aware on issues of social exclusion. It is a vital social need that clinical staff must be able, to have effective communication with those people, to give proper instructions and guide those people to meet their needs [46-49].

6. Conclusions

Unfortunately, the history of mankind is full of incidents of stigma and discrimination not only of individuals, but also of social groups suffering from specific diseases such as those described above. It should not be forget the fact that these people have the same rights as other citizens in all departments and authorities of the country in which they belong.

The condition of smoothly social integration of these patients is to combat their social exclusion. In particular, it would be useful a close cooperation of all stakeholders, including the employment of trained professionals for the proper functioning of the structures of these institutions. Additionally, in case of students with such a disease, it is very important a close cooperation between health professionals and teachers with the family, in order a therapeutic relationship of trust to be established. Many efforts have to be done as to eliminate misconceptions and prejudices concerning risk, disability and dysfunctionality of these patients.

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