
Health and People with Disabilities. A Medical Anthropology View

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According to Shuttleworth and Kasnitz (2006), the past years have seen a burgeoning world political and academic interest in the study of impairment and disability. Although prior to the 1960s anthropologists addressed the issue of disability in cross-cultural terms, it was during the 1960s that the anthropological focus on people with cognitive, behavioural and physical differences emerged. Between the mid to late 1970s and early 1980s, a group of anthropologists and medical anthropologists including Joan Ablon (1981,1984), Gay Becker (1980), Louise Duval (1984), and Nancy Scheper-Hughes (1979), among others, began publishing their work on people with various kinds of impairment-disability experience. In the early 1980s, Duval founded the Disability Research Interest Group of the Society for Medical Anthropology, which sponsors scientific sessions on disability at the annual meetings of the American Anthropological Association (AAA). Disability is now seen through the wider lenses set by WHO, according to which health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. In this perspective, the rights of People With Disabilities (henceforth PWDs), their right to social reproduction among other things, should not be assigned as favours based on philanthropy, compassion or charity but in terms of their full citizenship.

Various aspects emerge as a result of this point of view. An important issue refers to the influence of the socio-economic environment and the class structure on the distribution of mortality and morbidity, and consequently on the reproductive value of the labour force. Another one concerns how to deal with health problems and the social production of medical care. In the capitalist system, the dominant problem is the contradiction between achieving health and pursuing profit. For the sake of profitability, the process of commodity production devalues the health of the low strata, aggravates the destruction of the environment and produces goods that are harmful to health. The model of therapeutic medicine, with its functional individualistic approach, serves the interests of the capitalist system, as it obscures the factors that cause disease and promotes individual responsibility, accusing the victim of lack of discipline, self-control and will, which are key personal characteristics in terms of productivity growth. On the other hand, to the extent that medical care improves the level of health, the state is involved in the financing and provision of health services with the aim of contributing to the ‘natural’ reproduction of the labour force and the exercise of social control. The contradiction between health and profit is reproduced in the health sector, where the process of capitalist accumulation results in more and more for-profit companies penetrating the field and expelling small-scale service providers. In this context, a ‘medical-industrial complex’ is formed; based on profit, it pursues the commercialization of medical care and the development of an entire health care industry. The consequences are rising costs, excessive

use of health resources, emphasis on technology expansion, insurance companies promoting risk-taking policies and creating a two-speed health care system regarding access to and quality of services.

In addition, I am thinking about the much-debated relation between doctor and patient. Doctors have power, and they claim a monopoly on the patient's body. Although patients may resist the doctors' prescriptions, they are faced with a double bond; on the one hand, they are those who judge and decide when to go to the doctor and, on the other hand, they have to follow his instructions. Every doctor is exposed during his undergraduate and postgraduate education to a set of values and rules of conduct that gradually compose his/her role as doctor. According to Robinson (1999), the physician, as a member of a special professional team and working in separate organizational formations (private practice, health centre, hospital, and so on), has professional and administrative restrictions that control his/her suitability and feasibility of the medical practice. In other words, the actions of the doctor are defined and limited by law, professional ethics, time, inter-professional relations and the organization of the exercise of legitimate power (Pardo 2000). On the other hand, the patient's behaviour, when s/he has already recognized her/his symptoms and adopted the role of the patient, depends on the perceptions of the origin and treatment of the disease, her/his socio-economic status and subjective characteristics. The various social institutions also play an important role in shaping the individual's perceptions about the origin of the disease and her/his attitude (and behaviour) towards the disease (and indirectly to the doctor). In this, family and school are the main actors.

On a similar line, it is important to take into account the role of lay health beliefs. We know that there are three main types of medical knowledge: professional, common (ordinary people) and alternative (traditional or non-Western). The second one focuses on the fact that professional knowledge has recognized that people's beliefs about their health are crucial to the course of the disease. Are there different lay health beliefs among different generations or different social classes? The basic sociological concept that helps us in our research on lay health beliefs is that of social representations. What are the social representations of everyday people about how they define health? In the 1970s, research highlighted the role of the metaphors people used to define health. The most basic were:

- Health as a destroyer, containing loss, isolation, disability;
- Health as a liberator, frees from obligations;
- Health as a stock that you inherit and protects you from disease;
- Health as balance and harmony.

I think this is important to understand that the way in which people interpret health has also moral dimensions; saying that someone is healthy is a moral discourse, because we mean that he is responsible, that he is capable of doing things (to work). Health, here, means that one has a responsibility not to give up, which may also be related to and derived from religious traditions.

However, social inequality regarding access to health care systems is extremely important. Health is considered a social good, so everyone should enjoy it and everyone should have access to the means to get it. But do they? The concept of health inequality refers to the idea that certain social groups have higher rates of good health and life expectancy than other social groups. Over the years, a theory has been developed of health as a social good according to which we should not focus on the individuality of patients and their bodies and health research and health policy should be directed to the economic, political and cultural institutions that produce illnesses. Thus, classifications of the disease are proposed based on the economic, cultural and social determinants of ill health and disease.

Inevitable inequalities focus mainly on the biological and hereditary background of each individual that brings about differences in health status and quality of life. Inequalities that appear to be unavoidable are also found in personal choices and attitudes toward health. On the other hand, the health inequalities that can be faced are centred on the social, economic and cultural factors of social differentiation that can be mitigated through appropriate policy measures. Recent anthropological approaches reject the notion of personal attitudes and behaviours as a cause of inevitable inequalities, as the former are directly dependent on external factors (economic, social, educational) that act as pockets of inequality and negatively affect personal choices, behaviours and appropriate information on health. The study of health inequalities is of practical and ethical interest to both health professionals and social anthropologists. By studying and explaining the phenomenon, they are able to identify several factors of good or bad level of health and help ethical philosophers to explore the ethical dimension of existing inequalities in health.

While the moral dimension of health inequalities should not be taken uncritically (Pardo and Prato 2019), the distribution of a population's health depends on the modern expansion and quality upgrade of health services, on social factors and on factors of individual/genetic inheritance and luck. Social inequalities in health are related to the life cycle of the individual as the former start from the accumulation of risk and vulnerability at birth and can be exacerbated or mitigated by the intervening life experiences. Related to these, are explanations of inequalities which can be summarized in three categories:

First, interpretations of choice due to health. From this viewpoint, the state of health decisively affects one's social position. Healthy individuals are more likely to have upward mobility, while those with poor health have a downward mobility; for example, those who had a serious illness in childhood have been shown to be statistically very likely to end up in a lower social class.

Second, cultural and behavioural interpretations. According to this approach, health is a dependent variable, in the sense that class differences cause health effects and not the other way around. Lifestyles differ according to social class, young people from lower social classes eat more unhealthily, while, as we move up the social hierarchy, the percentage of those who eat healthily and lead a healthy lifestyle increases.

Third, material interpretations. According to this approach, factors such as poverty, housing conditions, infection and working conditions determine health. Hence, inequalities related to health are not absolute and dependent on one but relative factor (for instance, income); that is, they depend on the coexistence of differences in power and status. Material inequality produces social differences that lead to stress, lack of self-esteem and insecurity, which undermine the state of health. The decisive factor is social cohesion, the higher it is the better health indicators.

Finally, a very significant issue relates to stigma. In Goffman's sense (1963), the Greek word stigma refers to a symbolic feature of people who are unable to maintain a respectable social identity because of this condition. There are three types of stigma: on the body, on the 'character or mind' (mental illness) and on an entire social group. The first two are about illness and disability and the third concerns groups that are considered 'contagious' such as drug addicts and prostitutes. Stigma emerges when there is a discrepancy between the potentially social identity and social identity as such, in the sense that the reactions of others 'vitiates' the social identity of the individual (spoiled identity). The probability of stigma depends on:

- The visibility of the symptoms and whether they are recognized by others;
- Whether others are aware of and know things about the disease (for instance, epilepsy);
- Whether daily interaction is hindered (for instance, stuttering).

Against this socio-medical background, PWDs are not only handicapped by physical barriers. They are also handicapped by social obstacles, such as the attitudes or beliefs held by other people (disabled or not), as well as by laws limiting their rights. A number of factors contribute to disability within a life course approach (Heller and Harris 2012), including, a) the age of onset of disability, b) whether disability is a condition that can come and go and, c) the fact that disability can also occur suddenly or gradually. In general, there are two approaches for theorizing disability culture, both with their respective key problems. Firstly, there are those who consider disability culture to be about challenging the cultural representations of disability that exist within a mainstream culture in order to achieve for disabled people the equal respect and value that is given to other members of society. Such a position clearly perceives that such cultural practices are not only about tackling stigma, but also about increasing equality of opportunity and outcomes for disabled people. The second approach to disability culture is about 'celebrating' disability as 'difference' (Shakespeare 2002). This notion of celebrating difference is very much connected with the idea of the positive 'disability identity', and as such is fully contested.

According to the Observatory for Disability Issues (2020), in practice people with disabilities face a number of obstacles as regards the health system and its services. In Greece, regarding the accessibility of hospitals, the obstacles that people with disabilities face concern the rooms of the hospitals but also the toilets for the patients, which are not adapted in such a way as to be accessible to persons with disabilities. In addition, there is no marking in Braille

for the blind or partially sighted, and there is also no design for how people with disabilities will evacuate the building in the event of an emergency. Although there are ramps, their use is mainly for stretchers and for the transfer of patients by the nursing staff. When it comes to elevators, there is rarely provision for sound floor announcement as well as buttons in Braille. In addition to barriers related to the built environment, there are barriers also in terms of communication of patients with disabilities with doctors, nursing and administrative staff of hospitals. In particular, the deaf or hard of hearing face limitations in their communication with doctors and nurses since there is no provision for communication between them in sign language. Equally, there are no documents available in Braille; for example, one's medical history is an important document containing sensitive personal information and it is available in print or in digital format but not in Braille. The same goes for patient consent forms regarding specific medical procedures. While it is generally good that access is available to persons without social security with or without disability, the negative facts remain that:

- There is a large percentage of people with severe disabilities whose needs for medical examination or treatment are not satisfied;
- There is a heavy financial burden on households with private expenses for health benefits;
- There are shortages of health personnel, supplies and consumables on health structures due to cuts in public health expenditure;
- There are obstacles faced by people with disabilities and/or chronic illnesses due to the inaccessibility of hospital buildings;
- There are barriers that people with disabilities face as far as their communication with hospital staff is concerned.

Based on these, it follows that people with disabilities experience barriers to accessing their right to social reproduction and of course to their well-being as the main aspect of their health status. This is a condition that they have not chosen and try to overcome, while being unprotected and can count on the sole support of their personal will and their family context. One needs to wonder who is really disabled, these people or the society that excludes them?

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