JOURNAL
of
APPLIED ETHICS
and
BIOLAW

ISSN 2501-529X
ISSN-L 2501-529X

JOURNAL of APPLIED ETHICS and BIOLAW

published by

the ASSOCIATION FOR EDUCATION AND RESEARCH IN ETHICS AND LAW - EDUCED

www.educed.ro

Subscription for hard copy:

100 Euros/year (4 issues) - including the shipping fees

Payment details: RO68INGB0000999905167265, ING Bank, Iaşi, Romania

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JOURNAL OF APPLIED ETHICS AND BIOLAW

Table of content

Journal of Applied Ethics and Biolaw 1(2), April - June 2016

The Cultural Challenge of Medical Care Providers. The Roma's Case

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Abstract: *Long ago the human being was using natural ways to treat diseases. The success or failure depended on some special people's medical knowledge. Since medication was extremely undeveloped, those "doctors" (shamans) focused their treatment on treating the soul. The body and soul were seen as a whole, working together to make the person a healthy human being. Making the soul comfortable (healthy) was supposed to make the body comfortable and able to fight properly against the illnesses. The technological development in medicine brought out new concepts in this field and ethical debates as well. The soul was set aside and the medical practice focused on the body as a system and not as a concept linked with personality. Indeed, the medical researches involving humans are oriented on dealing with a body but humans are complex systems. A human being is a very complex interlinked network of physical pieces, chemical phenomena, thoughts and soul. This paper focuses on the ethical issues in medicine when the subjects/ patients belong to a specific ethnic group. Since the researchers/doctors did not pay too much attention to the cultural background and personal beliefs, many frustrations came up among ethnical groups in terms of access to medical care or participation in medical research. The main point of this paper is the need of care providers to reshape their attitude towards the individuals belonging to specified cultures or vulnerable ethnical groups.*

Keywords: *cultural challenge, ethics, Roma group, Roma's health.*

Introduction

Long ago the doctor's interest focused on treating the illness and not the patient. The patient is a complex system, a human-body-soul-personal-feelings-specific culture puzzle. To treat any of those components forgetting about others would determine in the patient-doctor relationship a gap in communication in terms of trust in medical attitude and in the claimed medical intentions.

The tendency in the western culture is to treat the patient this way. That's why a patient is referred to so many doctors, sometimes for a simple illness. The problem is that after treating the illness, the patient sometimes feels depressed or develops side effects to the treatment. The medical attitude towards the patient is to use a much more "technical approach" to treat him. A

huge medical team works to pull him out from a specific medical condition even if it is not that bad.

The attitude of medical teams to treat a patient very often avoids considering his cultural patterns. A culture is defined as the total of human behavior patterns that includes thoughts, communication, actions, customs, beliefs, values and institutions of a racial, ethnic, religious or social group.

If in the past the doctor had a closer relation with his own patients, dealing with all socio-medical issues, today the same doctor seems to be or act like a machine, an intelligent one though, ready to read vital signs and to provide a diagnosis and a medical treatment. Anyway, the doctor's role today is "to fix" and not to treat. The medical technology developed during the last decades helps them use this kind of approach to deal with the patients.

Paternalism has been the main attitude in medical science since the beginnings of medicine in Ancient Greece. Given the fact that medicine was mainly based on a philosophical attitude of the doctors towards illnesses, and given the poor level of knowledge in this field, paternalism was encouraged broadly. The doctor was seen as a good representative, capable of doing everything to remove "the bad" from a body. Actually, the first doctors were much more religious than scientific.

Since the Second World War a bunch of ethical issues rose from the medical practice of the Nazi party. That practice facilitated the international ethical codes to come up framing the medical practice in researches on humans. During the last decades, medical research has become cross-national and cross-cultural, and international organizations developed sets of rules guiding doctors and investigators in the complex world of research on human subjects. With the intention to avoid abuses in medical research on human subjects, codes such as Nuremberg or the Declaration of Helsinki in 1964 (developed by the World Medical Association) were issued.

Even if there are codes and laws protecting the humans in terms of their implications in medical researches, the real problem of the cultural approach was not included in those documents.

Actually, the social attitude towards specific issues cannot be framed by codes. This is a matter of education- to learn how to deal with such problems. Culture is a phenomenon that can shape behaviors and beliefs. The cultural differences in medicine have a huge impact on the level and quality of care delivered to the patients. Up to a few years ago the Western culture

did not pay much attention to the "cultural patient" but to the "physical patient". The term "cultural competence" connected with the medical practice changed completely the picture of that old-fashion paternalistic doctor used to prescribe and to talk without questioning his/her patient. The cultural patient became a force in the Western culture and cannot be avoided anymore. Initially, the doctors treated the patient's social problems with pills (for instance, a depressed patient in the past would have been treated with drugs if he had presented such problem through a medical procedure for treating something else. These days the doctor would try to identify the cultural patterns, the root of the depression and after that he would provide the patient with care for both his physical and mental problems.

To get cultural competence, a medical professional should respect some general rules such as to listen with sympathy to the patient's standpoint and perception of the case and to understand it, to explain as well as possible his own perception on the case in order to make the patient understand the main point of the medical treatment and the medical procedure in progress, to discuss the differences between his own perceptions and the patient's perceptions, to recommend the appropriate treatment considering the patient's cultural background. In medical cases with patients coming from different cultures, the doctors must be able to negotiate the treatment and to achieve the consensus between different views based on the principle that the medical team should respect the patient's own values and standards. There are cases though, when it is very difficult to reach the consensus between the medical team and the patient or the patient's family. For instance, when the patient is a minor and belongs to Jehovah's Witnesses. The female circumcision can be interpreted in different ways by both medical team and patient. It is well known that in African tribes the female circumcision is a common practice and mainly the women accept it as a part of their African culture. Ethical dilemmas rise when an African patient asks a Western doctor to perform this kind of surgery. In USA this practice is forbidden since it is considered a body mutilation and without any benefits for the receiver. The great dilemma is ignited the moment a parent asks this surgery for a child, sometimes newborn. These cases are very delicate, and in the name of the so-called "golden rules" leading the case, the medical team sometimes acts in paternalistic ways refusing the procedure, for the patient's benefits any breach of autonomy or other

principles being well justified from legal and moral perspectives.

Identifying the cultural patterns plays an important role in improving the quality of communication with the patients. This asks for the medical team to have good communication and psychological skills. For instance, in some cultures it is an insult or seen as highly disrespectful to look a person in the eye, as it is to ask the patient certain questions.

Of course, there are some important barriers in doctor-patient communication when the patient belongs to a culture different from the doctor's or the country where he gets treated for various medical conditions. One of the most important aspects is the language. In USA, approximately 12% of the population speaks a different language than English. It is inevitable that some patients speak a foreign language or speak very poor English. In such condition, the physician is supposed to do his best to communicate with the patient or search for an interpreter because the language barrier may create very important issues in the medical care system. There are cases when the doctors, arguing that he/she informed the patient about the medical procedure (even if the patient did not understand him/her since he did not speak English) took the liberty to perform much more than usual medical procedures. Anyway, in order to reduce language barriers as much as possible, the medical team members should use a simple language, testing the level of the patient's connection to the news and information transmitted (by asking the patient to repeat the information with different words).

Ethnical and racial discrimination in health care as a result of cultural misunderstandings

The culture was not a factor to be well considered in the medical attitude showed to the patients by the care providers. The cultural challenge has risen issues in the last decades by the time of the increase in immigration all over the world. Populations from developing countries migrated to developed countries for various reasons. For instance, thousands of people leave their country every year hoping for a better life or for a better job in order to support the family left behind. At one point these persons may ask for medical care. Discrimination through and among those minority groups is not something new. Since long ago the social scientists have been trying to identify ways to decrease the gap in health care system in countries all over the world. The most important issues in health care discrimination rose in ethnical populations, mainly un-documented immigrants who do

not speak the language of the host country. Specific medical issues came up on each ethnical population to challenge the scientists.

Ethnicity is a heavy word used in medical research. This word has the meaning of identification of a person to a certain population. From the beginning, this term has hidden a basic form of discrimination. To say that a person belongs to a race or to an ethnical group sometimes creates frustrations among the members of the same group and isolates them formally from the majority population.

To identify a race group the phenotype characteristics, i.e. all physical features differentiating a person from other, are used. To identify an ethnical group, cultural patterns are used, much more than phenotype features.

In terms of phenotype characteristics I would split them into two classes: intrinsic (all physical features got by heritage) and extrinsic (those add-ons to the intrinsic human model such as tattoos or long hair specific style). The extrinsic model is directly correlated with the cultural patterns and usually when I talk about the extrinsic ethnical model I talk about those cultural backgrounds as well.

The health care systems in general are designed and developed to provide people with a minimal access to medical care. Even if the initial intentions are to avoid any kind of discrimination and any kind of issues that might would come up in medical procedures, the discrimination in medical system is a stringent problem at any time. There are injustices in health care systems in terms of racism and ethnicity. Some people from a specific race or ethnicity get much more medical attention. For instance, while the health status of populations in USA improved in the last decades after the Second World War, the differences between white and minorities (African American, Hispanics, Native Americans and Asians) have persisted. The rate of mortality and morbidity among those minorities increased so that we might say that they live sicker and die younger. Environmental factors such as social, physical, biological and economical, behavioral factors and the lack of access to medical care are the main reasons of such disparities and discriminations in medical health system.

USA is the country where the most ethnical issues can be found since here there is such prominent diversity in terms of ethnical populations. The base of such diversity is the immigration. In 1940 about 70% of immigrants came from Europe. By 1992 just 15% came from Europe, 33% from Asia and 44% from Latin

America and the Caribbean. Given such important amount of immigrants, the expectation of patients from minority cultures is about 40%.

Ethical issues in medical research on human subjects. Roma population example

In general, whatever would be the issue in a medical case, it addresses one of those four ethical basic principles, i.e. autonomy, beneficence, non-maleficence and justice. The involving of human subjects in medical research has implications for individuals, families and for the social groups.

In the context of medical care and medical research, autonomy addresses a very important issue. The informed consent and the access to the right information derive from the individual autonomy. Therefore, the individual should be informed about all medical procedures and treatment that would be performed on him. The decision of participating or not in a research should be up to each human subject. Medical ethics requires the patient to give his consent freely without any coercion.

A medical research is developed mainly to bring improvement to a medical procedure or to a treatment/medication. Unfortunately, there were reported cases of researches with much more harm toward the subjects (the Primum non nocere rule supposes that, above all, it shall not harm a patient/subject).

There are many requests for researches on ethnic minority populations.

Roma population. "Cultural phenotype"

Looking for this population's characteristics, both physical and cultural, patterns in terms of cultural attitude rather than physical can be observed (even if the main physical features are quite different from the majority of the populations).

It is not clear that Roma lived close to the Indian civilization, were members of Hindu castes, or belonged to different social classes and tribal groups. It seems that they lived in northern India. Their migration to Europe began in the 11th century when Muslims invaded this country. The majority immigrated to Greece and after 100 years there, they spread throughout Europe.

The Roma's culture is a nomad-based one. Basically they are people choosing to roam about without a specific place to settle. They do not spend too much time in a single place so that tracking them is quite difficult.

The Roma is a population that cannot be identified within a specific country. They are spread all over the world in many countries. They are

identifiable by their customs and habits. The Roma's culture varies considerably among various groups. A very important characteristic is their strong sense of group identity. In terms of culture, this minority cannot be identified with a specific country. They are spread all over the world. For instance, in Romania, there are 90% people with pure Romanian origin, 7% Hungarian and at least 2.5% Roma [1].

The organization of Roma is based on the tribal model (that can be found in Africa these days in some places). Various tribes are divided into clans, each one composed by families related by common descendent or historical association. Usually the head of a clan takes the title king or queen. These are not political positions but represent a sign of respect. As Zeanah and others say, "the elected Emperor of all Rroma worldwide lives in Romania" [1]

In Roma communities and any kind of ethnical communities using their own rules and regulations [2] (such as African tribal communities as well), the head gains considerable respect from the whole community.

Since the root of the Roma population is in Northern India, its language contains a number of dialects between Indo-Iranian and Indo-European languages. Most roma spoke a form of Romany languages, others dialects of local languages with strong borrowings from Romany. Romany language is more a spoken than a written language. Actually this fact is an important issue in working with this population. Since they do not write or transcript the spoken language into a written one, the majority cannot read. Or if they can read, they know just some basics, unhelpful in a higher level communication than their usual life.

Another cultural pattern is that the disputes among Roma are mediated by the Kris, a court that decides the punishment for the parts involved. Since one of the most important characteristics for this community is the sense of group, the worst one is the complete exclusion from the community.

In terms of religion, the Roma usually adopt the faith of the country where they are living. Some of them are Catholic, some Orthodox, Protestant or Islamic. Many of them have no religious affiliation.

Roma families are oriented on the elderly occupying position of respect and authority. They tend to marry at a young age. Many Roma women marry around 12-13 years old. In some countries this is an issue since the children are too young to get parental responsibilities and to create a family. But this is a case of a cultural issue and in some cases the

authorities agree with the marriage at such young ages. An argument against roma's marriage at very young ages is that it is usually arranged by the parents and usually reflects the desire to create alliances between families and clans. It is inappropriate to consider that the bride and the husband can really understand the facts and the reasons for them being married. They are just "objects" of a transaction. This sounds like selling people on a contemporary market for "human goods". I would not say that is "modem slavery" but it can be framed alike since usually the parts have not power of decision. Usually the groom's family pays an amount of money to the girl's family, as a compensation for the "loss" of the daughter.

The artistic history of Europe was influenced by the Roma culture. Many Roma are musicians and entertainers. The Romany folk has inspired many of Europe's composers, like Georges Bizet in France, George Enescu in Romania. Since they are prone to mobility, their artistic background varies very much because they tend to get influenced by the places where they live temporarily. The original dance flamenco originates in the Roma art [3]. Traditionally, their occupations are metalworkers and blacksmiths, basket makers and wood carvers.

To talk about an issue in terms of almost everything related to a population group means to talk about social relationships. An issue in general rose from a conflict. A conflict usually involves at least two actors on the scene. Primary issues are communication issues in any group. Mainly, any problem is based on a misunderstanding of language or on the lack of social skills.

The historical distrust

Many researches were conducted on Roma but every time the researchers had a hard time working with them. This community was generally well received all over the world but its strange, unfamiliar customs created frictions. Some governments even tried to restrict them by some regulations. For instance, between 1499 and 1783 the Spanish government enacted a set of laws restricting the Roma dress, language and custom. In France in 1539 took place first repression against Roma and in 1563 the Roma were commanded to leave England under the threat of death.

Starting with the 15th century, Hungarian and Romanian nobles enslaved Roma to work for them. In Romania the slavery of Roma ended in 1855.

Persecutions against Roma were realities all around Europe. During World War II, around 500000 Roma

disappeared in Nazi concentration camps [4], The Nazi period represents the base of all cultural issues that the researchers are meeting while dealing with Roma. The Nazi experimentations on humans were studying the freezing, genetics, infectious disease, surgery, etc. Very important medical researches were developed on genetics though. The Nazi's intentions to create the Arian race, is well known, a race that was supposed to be perfect (blond hair, blue eyes and many other physical and high intellectual skills). This was the reason of the holocaust in Europe. The Hispanics, Jews, Roma, Homosexuals and other races and minority groups that did not meet the "conditions of eligibility" to be super humans, were systematically exterminated.

So, history supports the Roma's fear in terms of being involved in research. One of the most known Nazi doctors, Joseph Mengele, conducted the research on the twins and Roma. Named "the Angel of death", this doctor conducted the most unbelievable experiments on this minority. Injections of hundreds of twins with deadly substances in the hearth, in order to see if the moment of death is the same was just one of the common practices at that time. The Roma population was studied in terms of the color of eyes or the anatomy of some organs. They were killed for harvesting organs which were sent in Germany to be analyzed.

This history makes that their fear against medical system to be still present. Papers were published about the involving of Roma in medical research and about the issues that these were facing through.

The cultural background and the life style make from Roma a very dynamic population in terms of the power of movement from a site to another. They are able to take off in less than 1 day. In this case it is quite difficult to be in touch with their community.

Many medical studies were conducted on Roma either against their wishes or without informing them about the nature of research procedures (for example, the case of Roma women's sterilization or Nazi's experiments on Roma) [5].

The biggest problems for the Roma arose in the developing countries, especially in Europe. Some reasons, such as an easier approach of minority populations in developing countries, gave the opportunity for many medical studies in such countries. An issue arising is that these populations in developing countries often lack the capacity of free consent of participation in a medical experiment.

The global differences among the countries in the world in terms of

economic development create differences in health care providing. The less developed a country is, the more health care issues.

Common practice such as Roma women involved in medical decision without understanding what they signed or what was the medical intervention were reported. There are known cases when these were sterilized without an informed consent at the baseline. Many women specified that the doctor asked them to sign some papers immediately after the birth of their last child. They said that they couldn't understand (the issue of communication and of use of a highly specialized language with a population displaying a low level of education) what they had signed (the issue of informed consent). In the name of good health the doctors acted freeway. After sterilization many of them were shocked to find out that they will not have children any more (the issue of restricting the liberty of having children). This situation becomes more problematic in Roma given that for them the number of children represents a reason for pride.

Explaining the cultural issues dealing with Roma populations

Cultural competence implies a set of academic and personal skills that allow the doctor to increase the level of understanding and appreciation of cultural differences between groups in order to make the best decision in a medical procedure.

The cultural issues that could rise in the interaction between Roma population and healthcare system have various causes both specific and social. Specific causes imply all those causes determined by the group's attitude, habits, customs and beliefs. For instance, the historical distrust is a very important reason of avoidance of involving the Roma populations in medical research.

The social causes are those related to the society and social environment where the Roma base their activities. The general social attitude is to isolate them, to reject them from the social life and from society in general.

Roma people have an ambiguous status since they cannot be related to a specific country or region. They cannot be defined as a nation because "the idea of a nation is closely aligned to the notion of a specific territory whether from the past, in the present or in the future. In the case of Roma- a travelling, semi-nomadic group, they cannot point to a geographically and nationally bound territory as an identity marker for nationalism" [6]. They are interlinked with the society where their occasional work is done for survival. Actually the Roma's status can be defined as one based on a surviving attitude. They work to

survive and not to gather belongings as others do.

A lack of a territory does not mean that they lack culture. On the contrary, the Roma's culture is quite diverse [7, 8]. Indeed they are majority bilingual since they speak Romany language and in the same time the language of the place where they live. The dynamic of this population is quite considerable. They are difficult to control by the state, in terms of taxes or medical mandatory programs (such as children vaccination). To involve it in any kind of research means to allocate a lot of resources in order to keep in touch with them. The researchers are supposed to use the same dynamic but many times this is very difficult to achieve. Indeed, a medical research is closely related to the environmental factors. If a medical research is started in order to detect the reasons for developing some illnesses in a Roma community, moving all the community would damage the data gathered until the moment they leave their location.

Another reason to avoid involving them in medical research is the difficulty to deal with the huge lack of education in this population. Education is a way to capture the next generation. The problem is that Roma's children are socialized by the parents, kin and neighbors. It is well known that the Roma would rather teach their children the "art of surviving" (fighting, identifying ways to get food or money) than to send them to school. School means fees and taxes, a regular schedule and much more time spent in a certain location. Even if school would be paid by someone else (the government, for instance) they would still prefer to teach their own values.

The attitude of the medical system towards minorities is to involve them in medical research because the ethnical minorities seemed to develop specific medical problems and specific approaches. Indeed, the ethnical minorities were rousing the researchers to develop trials on those minorities implying the most medical problems.

The cultural approach should be carefully considered before any other approach in working with ethnical minorities. The same medical procedure would be comfortable for some minorities but uncomfortable for others. To use the principlism approach is useful for some minorities but not for many others. The patient's autonomy principle would be a bedrock in a culture but not very important for many others. For instance, the patient's autonomy in Islamic culture evolved from a medical paternalism to a medical trust

in terms of patient-doctor relationship.

Let's refocus the discussion from a medical standpoint on a cultural one but medically related nonetheless. It is known that in medical sites the problems rose quite frequently in cases of ethnic or foreign patients.

A good example is the case of a three-month-old Hmong girl suffering from epilepsy. The doctor prescribed some medication to control her seizures. The parents considered that the illness was a faith problem. They considered that to give the medication to their child was not a good idea since there was a matter of losing her soul and not a physical one. They avoided the medication and they used the Hmong faith and beliefs to treat the child their way. They took her to a clan leader and shaman, where animals were sacrificed and bought expensive amulets get her soul back. The girl's doctors felt her parents were endangering her life by not giving her the medication so they called Child Protective Services and she was separated from her family and placed to foster care. At the end of the day the girl was the one who suffered the most. In this case the cultural issues created a social problem. The intentions of the doctors and of the social workers were good (to save her life) but the results were quite bad. The family was broken and the faith's community got to doubt the doctor.

This is just an example of cultural issue projected in medical situations. At a glance everybody surrounding a patient has the intention to save his/her life. The problem is that not every time the good intentions lead to a happy end. There are different concepts about the same medical procedure on both the doctor and the patient or patient's representative. For long ago the patient was seen as a simple "piece of meat" that had to be fixed in case of some damages. The technical advances and the opportunities that they provided the medical world and the humanity with, asked for a new type of doctor who is able to address cultural issues in medicine.

This example above is a clear case of a doctor having problems in dealing with a patient from a different culture. Technically speaking the doctor is a good specialist in his field but not necessarily equipped with social skills in terms of working with patients from different cultures. He has no cultural competence to treat such a patient as the girl in the abovementioned case. Such cases are not just about the patient; they are also about the patient's family and, not least, about their cultural background.

Conclusions

The cultural dimension in medicine came up with new challenges to the healthcare professionals. More and more new cases involving certain ethnics or race representatives were reported in terms of the cultural issues. Medicine ought to adapt the procedures and current practice in order to deal with such a big diversity of patients coming from so many different places, with different habits and customs.

I would say that in cases of patients from different ethnicities or races, the doctor should have much more than medical competence. Medical competence would help healthcare professionals to approach in appropriate ways the medical cases implying patients who belong to different ethnicities. However it is a real challenge for medical teams to adapt to different cultures and habits and to deal with different perceptions on the same medical procedures.

It is a real challenge for the medical teams to adapt to different cultures and habits and to deal with different perceptions on the same medical procedure.

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