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Abstract

Objective: This article examines culture-based particularities of communication between doctors and Romani chronic patients.

Methods: Qualitative study consisting of 48 semi-structured individual with Roma patients and their careers from two Romanian counties (Iași and Cluj) and 3 focus groups with health mediators. The interviews were analysed using Interpretative Phenomenological Analysis.

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Results: Answers varied according to participants' degree of acculturation. The family plays a central role in caring for the patient, accompanies him at doctor visits, and interferes to doctor-patient communication. Communicating with the patient must be tailored to the Roma patients.

Conclusion: To optimise communication, medical staff should be aware and respectful of cultural values, customs, and perceptions of the Roma regarding health and illness. Failure to observe these criteria may lead to breach of doctor-patient relationship, and possible failure of medical care. The degrees of individual Roma acculturation into the Romanian culture must be taken into consideration, and adjust the pattern of communication accordingly. The role of health mediators in the communication between medical staff and Romani patients are very important.

Practical implications: The dissemination of information regarding the Roma cultural values in regards to illness helps the health services adapt and create a holistic multicultural care model.

Keywords: *doctor-patient communication, Roma patient, ethnicity*

Introduction

Doctor-patient communication is a dynamic process, where communication partners must be adapted to patient's background, age, previous experience with illness, culture, ethnicity, education, pathology (acute, chronic, urgent), type of main clinical distress (physical, psychological, social), and coping, along with doctor's communication skills, personality, communication channel, and doctor/patient psychological profile (Schouten & Meeuwesen, 2006; Van Wieiringen, Harmsen & Bruijnyeels, 2002). The doctor must be the more dynamic and adaptable of the two, aiming to respect patient's dignity, which in turn cultivates his trust (Baile et al., 2000).

Many studies (Scheppersa et al., 2006; Bentacourt 2003; Schouten, 2006; Campbell, Ramsay & Green, 2001; Mitchell, 1998) proved that doctor-patient ethnical differences can create barriers in communication and patient's access to medical services. Ethnicity-related risk factors can lead to miscommunication due to language barriers, low socioeconomic status, lack of medical insurance, preference of traditional treatments, low educational level, etc. (Scheppersa et al., 2006). Schouten et al. identified five cultural factors predicting doctor-patient miscommunication: cultural differences in explaining health and illness

models, differences in cultural values, differences in perceived doctor-patient relationship model, racisms/stereotypes in ethnical perception, language barriers (Schouten, 2006).

Cultural factors have a special significance, making it so that if the socio-cultural differences that exist between the person who offers medical care and the one who receives it – the patient – are not acknowledged, explored and understood, it may lead to an inadequate approach of the patient, followed by the latter's dissatisfaction, a decrease in therapeutic compliance and a poor therapeutic outcome (Pakenham-Walsh, 2012; Betancourt, 2003; Campbell, Ramsay & Green, 2001; Van Weiringen et al, 2002).

The Romanian legislation and medical deontological norms (*The Patient's Rights Law*, 2003; *The Medical Deontology Code*, 2012) states that the patient has the right to be informed about his diagnosis and prognosis or to designate another person as a substitute decision maker. The patient's relatives and friends receive information regarding the patient's medical status only with patient's consent.

Of the few Romanian studies about doctor-patient communication, a nation-wide study with 244 physicians showed that 50% of them improved communications by learning from mistakes, and 96% consider that training and doctor-patient communication guidelines are useful (Mosoiu, 2009).

Another study involving 100 leukaemia patients (including ethnic minorities), showed that there is no standard practice of communicating with patient. The patients were most pleased when physicians communicated openly and spontaneously (Parvu, 2009).

This data is consistent with the European report “The power of European patients – options and implications”, showing that Romanian patients are among the least informed, ranking 30th in Europe (*Patient's rights*, 2010).

Roma cultural features relevant to the interaction with the medical staff

The Roma are a minority population in Romania, representing about 3.2% of population (*Population and lodging census*, 2012) being divided in numerous communities with different degrees of acculturation. The traditional Roma, with a low or absent level of

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acculturation live in a world filled with taboos, cultural values and laws. Their communities are resistant to change and influence from the majority Romanian population, considering tradition to be sacred and immovable (Cemlyn et al., 2009; Grigore, 2001a; Wamsiedel, Vincze E & Ionescu, 2001).

Roma culture influences the illness-related experience and behaviour, a phenomenon also present among other minorities or ethnic groups (Jesper, Griffiths & Smith, 2008; Ioan, 2012). Most Roma families are patriarchal, placing high value on family cohesion. Therefore, the family offers support when an individual experiences problems (disease, death, financial). For the Roma, caring towards the ill or the elderly within the family is considered a sacred duty. The Roma community promotes this care model, rejecting the idea of institutionalising the ill in chronic care units or hospices (Grigore, 2001b; "Health and the Roma community", 2009; Weyrauch, 2001; Földes, 2012; Hajioff & McKee, 2000). Roma patients prefer to remain in the family and the community, and it is recommended to accept the presence of members of the patient's community and extended family alongside the patient within medical facilities, an idea supported by Jasper, who has studied the English Gypsy Travellers (Jesper, 2008).

Additionally, the Roma have specific behaviours and beliefs about the interaction with the health system. They prefer curative medicine to the preventive branch, emergency services to outpatient care, and often lack health insurance.

Methods

This study is part of a qualitative research that aims to analyse perceptions and attitudes in regards to death, terminal status, and dignity of the Roma, in the context of Romania's health services.

This article analyses the specifics of the Roma chronic patient communication with medical staff, aiming to understand and interpret culture-specific communication problems and needs.

The investigating tools utilized were the individual phenomenological interview (with Roma patients with severe chronic illness and their relatives) and the group interview, in the form of focus groups, with health mediators from Roma communities.

The interviews were recorded and transcribed in Romanian. The data obtained was coded by demographic data, interview number, patient's caste, and socio-economic status. Data collected from the focus groups were coded by interview number and county where it was taken. The results were analysed using Interpretative Phenomenological Analysis which allowed us to identify ethnic particularities of doctor-patient communication.

The content of each transcript was processed with the aid of Nvivo qualitative data analysis software (QSR International LTD, version 8.0 for Windows), which facilitated the topic grouping, interview codification and thematic categorization.

This study was conducted with Roma subjects living in the Cluj and Iasi counties of Romania. Twenty-three interviews were conducted across 6 communities from Iasi and 25 across 3 communities from Cluj. Twenty-five chronic patients and 23 relatives were interviewed. There is variability within the Roma population, based on degree of acculturation and belonging caste. We conducted our interviews with subjects belonging to several different castes: bucketmakers (kalderash/caldarari), coppersmiths (aramari/spoitori), bear handlers (ursari), mine workers (boyash/rudari), goldsmiths (zlatari), silversmiths (argintari), spoon makers (lingurari), fiddlers (lautari), etc. Castes are named according to primary occupation.

In order to avoid psychological discomfort induced by unfamiliar surroundings, the interviews were conducted in the communities. We were provided with community mediators, such as Roma community leaders (bulibașii) or outsiders trusted by the community (physicians, health care providers, missionaries, etc.). The questions were presented in simple language, matching participants' education level. In order to avoid offending the Roma culture and customs, prior to conducting our interviews, an interview guide was reviewed by a representative of the Roma community.

We also organised 3 focus groups with 30 health mediators of Roma communities from Cluj and Iasi counties. We completed the information provided by the interviewed Roma subjects with information obtained from health mediators, who are knowledgeable of the Roma patients' communication.

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The criteria for including participants in the interviews were: age over 18 years old; mentally competent; suffering from serious chronic illness or caring for a chronic seriously ill.; Roma ethnicity; given consent to participate in the interview. In the case of focus groups, all active health care mediators from the two counties were invited.

Participation in the study was voluntary, without constraints or rewards. The participants signed our informed consent form after receiving information about the study. Participants had option to opt out of the interview whenever they wanted, or to not answer sensitive questions.

The study received the ethical approval of the Committee of Ethics of Research from the University of Medicine and Pharmacy from Iasi, Romania.

The limitations of this research arise from the fact that the data was collected using qualitative methods. Our results are relevant to the communities where this research took place, however, they should not be generalised to the entire Roma community of Romania.

Results

The data that was collected during the interviews and focus groups were analysed using a phenomenological approach, following two main themes: the persons involved in the doctor-Roma patient communication and the characteristics of this communication.

People participating in the doctor-Roma patient communication process

The Roma considers itself as a communicative ethnicity therefore communication is part of Roma's cultural model of explaining disease. As such, introversion and lack of communication play a part in pathogenesis, while promoting communication has a healing attribute:

the Roma are noisy! They constantly communicate!...they consume energy by communicating, they open their hearts at any given time. Others are closed off, judge, are consumed from the inside, and this is where many diseases come from. But a Roma, when he talks, he no longer thinks about the fact that it hurts!...and he forgets about that pain... SI.2-i18af1-rr

One of the most important aspects revealed by our study is the central role of family in offering spiritual and psychological support to

the patient. A characteristic aspect important to doctors treating Roma families is that within a Roma family disease is perceived as a family problem. The family relieves the patient of responsibilities, with healthy family members assuming those duties.

Therefore, when dealing with Roma patients, one cannot investigate the subject of medical communication without addressing the family's role in this process. One of the persons interviewed stated in regards to the family's role:

it gives you support, someone to talk to... if you were alone, you'd belong to no one. **SI.2-i34af1-cj**

When asked with whom they prefer to communicate during difficult moments pertaining to their illness, most Roma patients chose a family member. However, some, wishing to protect their family, chose their physician as psychological support person. A female cancer patient, aged 50, member of a large family, tells us that she communicated

With my doctor...That's it. **SI.2-i33pf2-cj**

The patient's daughter, on the other hand, when asked with whom she would prefer that her mother spoke the about disease, said, *With the family, just the family* **SI.2-i34af1-cj**, indicating a difference in opinions between the patient and the caretaker.

Regarding communication with the physician, we must first note that the Roma do not attend a medical practice alone. The ill Roma are accompanied by family and community members, who thus show their solidarity, dutifulness, obligation toward the patient. A record of compliance with this custom is observed in statements such as:

We are very united! Even strangers are obliged! If a stranger doesn't come, it means he bears hatred towards us! If I don't get involved in one of my sister's relatives' problems, when they arise, they won't get involved in mine. When we run into trouble, they'll say: 'When we were in the hospital or at the courthouse, you didn't come to us either!' **SI.2-i13af2-rr**

Our study reveals several explanations for this fact, such as: the desire to have someone close to them when facing bad news, solidarity, etc. The patients may be accompanied for their check-up by health mediators or by another person they trust. For example, in one community the mediator is a Pentecostal missionary who helps the Roma spiritually and financially. He facilitated access to medical care

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when they lacked health insurance, and urged the physician to tell a patient his diagnosis.

The people that accompany the patient to the doctor often interfere with the former's communication with the physician. Sometimes, a Roma that is experienced in communication with the public authorities acts as a middle-man in the process of communication. Within sheltered communities, communication takes place through their leader (bulibaşa). For example, a 40 year old patient belonging to the Kalderash caste, diagnosed with diabetes and chronic renal failure, recalls finding out his diagnosis from the bulibaşa, who spoke with the physician: *The doctor told bulibaşa.* **SI.2-i3pm1-cl**

This opinion is shared by a 66 year old relative of a patient, who explains that: *Doctors should discuss with a man in good health, not with the patient! The patient might have a breakdown, but relatives can calm him down, because they must laugh with him.* **SI.2-i13af2-rr**

This traditional spirit of solidarity, of dutifulness towards the patient, is not unanimous. Some expressed a desire for privacy and confidentiality during check-ups. For example, a 20 year old male Roma from the Kalderash caste stated:

... at the very least he should be alone when talking to the doctor! They come to the hospital in great numbers, but the person who is ill feels that this is not natural... He'd rather they distance themselves a bit, so he could have a private connection with the doctor without them breathing down his neck and listening to everything being said... **SI.2-i1am1-cl**

Several of the interviews conducted amongst traditionalist Roma reveal that they prefer that the physician first communicates with one of the patient's blood relatives and not the spouse or a relative by marriage. A patient that was operated for bladder cancer, who was not aware of her diagnosis and whose husband agreed to the intervention, expresses disapproval towards the fact that the physician did not consult her sisters (who were designated to take decisions in her place):

I had an argument with my sisters... I said that they shouldn't have allowed having me operated. Up until here she was your wife, from now on she is your sister.

The sisters should have told her husband.

Other patients had a hierarchy of people the physician should communicate with in case of the decision was taken that the patient had to be protected from certain information that could cause him distress:

So the patient won't be scared, so he won't have a heart attack... They should tell a son, brother, nephew, a close relative... Tell the wife, if no other member of the family is present. Then the family makes the decision in the patient's absence... then they tell the patient: 'look, you have this disease, this is what the doctor said you should do to get better' **SI.2-i22am1-bd.**

Note that after a delay, during which the family makes a decision, the patient is informed of his diagnosis.

A 71-year-old male, Roma bear-handler caring for his ill wife, shares the same opinion, that the family must know the truth about the patient's disease, and if the prognosis is severe, they should encourage the dying:

The family, not the patient! Like so, when they tell the brother, the sister, the father, mother: 'there is nothing left for us to do with her, take her home.' We have to encourage the patient: 'you're getting better, you're getting better!' We know she's dying, but... **SI.2-i24am3-ur**

The interviews conducted in Cluj County, which typically contains Roma with a higher degree of acculturation, reveal that most of them consider that the physician should communicate directly and solely with the patient. Some patients were firm in regards to knowing the truth about their disease and pleaded for direct doctor-patient communication. A male patient with cancer of the rhinopharynx with cerebral invasion states that he found out his diagnosis from his G.P. spoke to an American volunteer who came to the community to offer assistance to the needy. The man explains:

So the doctor told me (the diagnosis) after M. told her to tell me. This is fair? Talking sincerely! **SI.2-i35pm1-cj**

When asked how would he communicate with the patient if he were a physician, a 67-year old male Roma from Cluj, diagnosed with heart and neurological disease, states:

I say: 'look, mister, your heart's not doing well. If you want to get an operation... we fight, if not, it's your problem.' So that's how (we communicate), directly. **SI.2-i41pm2-cj**

The same interview reveals that the spouse should take decisions for a gravely ill patient who can no longer participate in the decision-

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making process. This practice exists throughout the Romanian population.

From the focus groups including health mediators of Roma communities we learned that the custom of accompanying a Roma patient and taking part in the conversation with the doctor may run the risk of breaching confidentiality, leading to stigmatisation and discrimination of the patient in the community. This is especially true with cancer patients.

The neighbours must never know. These days it's hard to find good neighbours.

SI.2-FG3-is or *There are Roma that avoid that, there are some who don't... they are afraid that they will be laughed at.* **SI.2-FG3-is**

Some participants tell us that they are asked by the patient not to reveal their diagnosis.

In our community they actually avoid that. I am asked to maintain discretion; there are people who ask me: what's wrong with him? What happened to him?

SI.2-FG3-is

The desire to hide a serious diagnosis from other members of the community does not appear in small, rural communities, perhaps because in these cases patients aren't marginalised or stigmatised. Health mediators compare these communities to a family:

They don't shy away. The people in the village generally know. Not like in the city, where no one must find out. Like, that guy was taken by ambulance

SI.2-FG3-is or *In our community, our Roma aren't ashamed of their disease. They help each other, they comfort each other.* **SI.2-FG3-is**

Given the great diversity in customs and beliefs in the Roma community, the usefulness of a health mediator familiar with the community and its unique subgroups in facilitating communication between patient and medical staff is obvious. For example, a mediator may share information about certain customs, or the specifics of a family. This is illustrated by a mediator who participated in a focus group:

An opinion that is shared by the entire community, there is no such thing. If they keep in touch with the health mediator, they'll be acquainted with the Roma customs, their culture, and everything that pertains to the Roma ethnicity. They'll know what they have to do in order to please everyone. **SI.2-FG2-is**

The specifics of communication between doctors and Roma patients

The language used by the physician in communicating with a Roma patient was an issue brought up by many participants. Some mentioned that they require additional explanations in order to understand how treatments are supposed to be administered. A father of a sick child recognises the fact that he has trouble understanding what the doctor is telling him:

We don't understand each other... They are having one conversation, we have a different interpretation. We misunderstand, I sometimes tell them: 'Doctor, say things clearly! SI.2-i17am1-rr

The health mediators explained to us the cause for the language barriers common in patient-doctor communication. Most Roma still use the Roma language, and lack mastery of Romanian:

Some of them don't know what to say when they visit their GP. If they constantly speak in Roma language, they don't understand. SI.2-FG2-is

Language barriers also arise from the Roma's low education level:
The majority of them are unschooled. The doctor tells them one thing, they understand something completely different SI.2-FG3-is.

The physician can overcome them by adapting his language to patient's intellectual level, by asking for feedback, or by asking a health mediator to provide clarification to the patient.

Health mediators have supported the idea that the tone of the communication indicates the quality of a physician:

When a doctor talks nicely to us, we consider him to be a good doctor. And maybe he doesn't know a thing SI.2-FG1-cj, or A good doctor, you can collaborate with. A bad one, he won't even look at you. When we go to an appointment, the minute we walk through the door, we want to see how he speaks to us. If he talks in a harsh manner, you don't feel like telling him what afflicts you. You ask for a prescription and you walk out. SI.2-FG3-is

The length of the interaction with the doctor is also important to Roma patients. Those who participated in the interviews said that they are typically offered short medical explanations "Two or three words-long," after which they are given prescriptions, but are not provided with meaningful doctor-patient communication. A Roma woman diagnosed with hemiparesis due to stroke explains:

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He should consult me for at least 10, 15 minutes, so he can see me, and believe me when I say something hurts. And for me, to tell him about all of my pains!

SI.2-i25pf2-cj. *For an appointment, at least 20 minutes are needed, so you can talk to them and explain. SI.2-i31pf2-cj*

The interviews also revealed that some Roma exhibited certain medically counterproductive beliefs and behaviours: use of expired medicine or prescribed to other individuals, not following prescriptions, refusing surgical interventions out of fear, making comparisons with other ill relatives, believing that all diseases are alike and require similar treatments, etc. To illustrate, we present the case of a female patient who received surgery for bladder cancer and was cured, but also states that, had she known the diagnosis, she would have refused the operation for fear she might have suffered the same fate as her cousin who died of pancreatic cancer. Due to such misconceptions, Roma patients may follow treatments that are unsuitable for their disease or may exhibit low therapeutic compliance. This is why physicians must become aware of these faulty beliefs, and offer additional explanations to Roma patients, in order to help them make the correct decision.

Discussion

According to the data obtained in our study, the Roma consider themselves to be a communicative ethnicity and desire an open relationship with their physicians. They believe that non-communicative individuals are predisposed to disease.

To the Roma, caring for the ill is a sacred duty fulfilled by the family. The interviews revealed that the family accompany the patients to doctors' appointments, participate in doctor-patient communication, and prefer to filter the medical information reaching the patient in order to protect him. Community leaders and health mediators can be useful communication facilitators between patient and physician. Within acculturated communities, we've encountered Roma who prefer the Anglo-Saxon communication model, which is centred on the patient's autonomy, a model which is also promoted by Romanian legislation. According to the data we've collected, during the doctor-Roma patient communication process, violations of the principles of ethics or patient's rights may occur (limiting autonomy, breaching confidentiality). These can be avoided by establishing a set of agreed-upon rules between

physician and patient, by finding out patient's communication preferences (direct or through intermediaries), by adjusting methodologies to meet the needs of each medical case (Deledda et al., 2012; Quirk, 2008; Pawlikowska, 2012).

Similarly to other authors (De Maesschalck, Deveugele & Willems, 2011; Mladovsky, 2007; Schenker, 2007), we have reached the conclusion that a doctor's language, which has to be adapted to the minority patient, is an important aspect of communication. Keeping in mind the Roma's typically low education level and limited knowledge of Romanian, Romania's official language, we found that in order to avoid language barriers it is necessary to avoid the use of scientific or medical terms. Note that despite their similar names, the Roma language is entirely different from the Romanian language.

Physicians should allocate more time to an appointment with a Roma patient, in order to provide complete medical explanations, to dispel biases, and to increase motivation to comply with treatment. Physicians must be aware that uninformed or misinformed patients will develop negative psychological reactions and an inefficient coping mechanism that will lead to difficulties in communication and diminished treatment compliance (Parvu, 2009). Thus, our study reinforces the conclusions of other authors in terms of lengthening the duration of an appointment with a patient belonging to a minority ethnicity, in order to increase understanding of the physician-provided information (Deledda, 2012; Mladovsky, 2007).

Efficient patient-tailored communication plays a central role in increasing treatment compliance. This idea was also highlighted by other researchers, who showed that 33% of doctors' appointments with ethnical minorities end without mutual understanding which then leads to low treatment compliance (Van Weiringen et al., 2002).

For optimising communication with Roma patients, doctors must be familiar with and respect the Roma's values, customs, and beliefs regarding health and sickness, and how they utilize health services. Failure to observe these factors can lead to injury of patient dignity and breach of doctor-patient trust, ultimately causing the failure of medical care, even when the recommended therapy was correct. This idea was also highlighted in other studies (Weyrauch, 2001; Deledda 2012).

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Nonetheless, it is not good practice to assume that all Roma patients share all values and beliefs specific to their ethnicity. Doctors must not consider *a priori* that all patients have the same preferences in regards to communication simply because they belong to the Roma ethnicity, an aspect that is highlighted within the scientific literature on other ethnicities (Ioan, 2012).

Taking into account all the aspects regarding doctor-Roma patient communication that we have previously described, a useful tool in communicating with the patient is the SPIKES protocol. This protocol complies with Romanian law and the Roma patients' general communication needs. It is an internationally accepted protocol consisting of six steps: preparing the setting where communication will take place, inviting the resource persons accepted by the patient, surveying patient's knowledge and preconceived ideas they might have about the disease, finding out the type of information the patient needs, the actual communication, offering psychological support depending on the patient's reaction, and finally, providing the patient with a perspective about the future (Baile, 2000).

Conclusion

Communication is a key element in developing a doctor-patient relationship based on trust. Communication with a patient belonging to an ethnic minority presents certain challenges, where the doctor has to adapt to factors pertaining to language, different cultural values, and a different way of interpreting disease.

The Roma are an ethnic minority with a specific system of values and beliefs. This fact is reflected in their preferences regarding communication with medical staff and in making medical decisions, preferences which often differ from those of the general population. The Roma population is heterogeneous with respect to cultural values, depending on their local community and degree of acculturation. Oftentimes, Roma's cultural specifics, as well as their heterogeneity, are unfamiliar to medical staff, which can lead to miscommunication, decreased patient trust, and poor therapeutic compliance.

Health mediators positively facilitate communication between physician and Roma patients, providing the doctor with essential community-specific information, and ultimately helping to raise the

efficacy of the therapeutic intervention. The participation of health mediators in medical care provided to the Roma is likely to create a sensible cultural model of providing medical care respectful of the Roma patients' values, customs, and dignity.

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