THE IMPACT OF CULTURE ON HEALTHCARE SEEKING BEHAVIOUR OF KALDERASH ROMA. A QUALITATIVE DESCRIPTIVE STUDY

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Abstract:
Some ethnic groups, as the Roma, are thought to have different healthcare seeking behaviour. This paper aims to provide findings on the attitudes, preferences, expectations and concerns of a Roma ethnic group (Kalderash) regarding inpatient hospitalization. The findings focus on a series of data analysed from semi-structured interviews with 23 Kalderash patients and caregivers from Zanea community (county of Iasi, north-eastern part of Romania). Kalderash people have negative attitudes towards hospitalization and report significant anxieties. The findings reveal specificities related to patients' ethnic background, cultural views and communication barriers. For their part, Roma are often suspicious of non-Roma people and institutions. Roma ideas about hospital are closely related to notions of purity and impurity. These basic concepts affect everyday life during inpatient hospitalization, including the way Roma deal with eating and washing, physicians and treatments, or coping with illness and death. When they seek medical care, Roma often come into conflict with medical personnel who find their behaviour confusing and demanding. Roma's cultural beliefs and attitudes underlie their behaviour when they are being confronted with a serious illness and are seeking inpatient medical care. Attention to cultural diversity does matter, as this should lead to different medical behavioural patterns.
Keywords: Roma, hospitalization, medical setting, illness, purity, customary law.

Rezumat:
Anumite grupuri etnice, precum romii, prezintă un comportament diferit atunci când caută asistenţă medicală. Această lucrare îşi propune să ofere date referitoare la atitudinile, preferinţele, aşteptările şi neliniştile unui grup de romi căldărari cu privire la internarea în spitale. Rezultatele cercetării se concentrează pe o serie de date analizate în urma unor interviuri semi-structurate cu 23 de pacienţi şi îngrijitori căldărari din comunitatea Zanea (judeţul Iaşi, nord-estul României). Romii căldărari prezintă atitudini negative la internare, fiind raportate stări semnificative de anxietate. Rezultatele dezvăluie

elemente specifice legate de trecutul etnic al pacienţilor, perspective culturale şi bariere comunicaţionale. În ceea ce îi priveşte, romii sunt adesea suspicioşi faţă de populaţia şi instituţiile non-rome. Ideile romilor despre spital sunt strâns legate de noţiunile de puritate şi impuritate. Aceste concepte de bază afectează viaţa de zi cu zi pe perioada spitalizării, inclusiv felul în care romii tratează modul de a mânca şi de a se spăla, medicii şi tratamentele, sau cum fac faţă bolii şi morţii. Atunci când caută asistenţă medicală, romii intră adesea în conflict cu cei din personalul medical, cărora comportamentul acestora li se pare confuz şi solicitant. Convingerile culturale şi atitudinea romilor stau la baza comportamentului lor atunci când se confruntă cu o boală gravă şi când au nevoie de asistenţă medicală la internare. Atenţia faţă de diversitatea culturală contează într-adevăr, căci acest lucru ar trebui să conducă la modele diferite de comportament medical.
Cuvinte-cheie: populaţia romă, spitalizare, cadru medical, boală, puritate, drept cutumiar.

Introduction

We live in a culturally pluralistic society, therefore it is essential to understand the cultural heritage of other communities. Moreover, we should recognize that some minorities who are on the border between two cultures may have fears about the risks involved in adapting to the value and institutional system of the majority.

Patients belonging to groups with sundry ethnic backgrounds have been shown to vary in regard to pain response, perception and interpretation of symptoms, access to care and compliance[1]. Roma people are one of these minorities[2], that distinguish themselves by way of dress or by crowding around the hospital when a relative is sick. They may be reluctant to the dominant culture and values or may choose to remain distinct in their ethnic identity rather than assimilating to ”mainstream” norms. Because of the complex range of beliefs, values and attitudes shared and perpetuated by members of this ethnic group, Roma cultural heritage provides an interpretative framework for perceptions of illness and hospitalization and the organization of health-care modalities.

This paper contends that a focus on the distinct culture which characterizes Roma people can enhance our understanding of their hospital-related behaviour. It argues that a perspective on the Roma culture is crucial in understanding their behaviour linked to hospitalization. Using a qualitative research, the paper also explores the ways in which the beliefs of this ethnic group shape the professional relations between the medical care

[1] E. Pellegrino, P. Mazzarella, P. Corsi, 1992.
[2] A. Bancroft, 2005.

team and their Kalderash patients or next of kin, and how awareness of stigmatization serves as a potent weapon in maintaining the weak position of Roma in the Romanian medical system.

1.1. Theoretical framework

Some of the different theoretical frameworks that have been used in explaining the specificities of the Roma groups have focused attention on issues of race and ethnicity[3] that determine cultural constructs. This has traditionally been one of the key analytical dilemmas in anthropology[4]. Although anthropologists have tended to emphasize the transformative power of culture, the idea that cultural particularities can create barriers in health-care and generate ethical conflicts has remained a basic premise in the specialty literature[5].

The theoretical concept of purification was put forward by the social anthropologist Mary Douglas, whose work *Purity and Danger*[6] argues that people need to classify other people and objects in order to make sense of the world. Consequently, that which cannot be classified is viewed adversely. "The unclassified is a residual category", so anything or anyone that falls outwith these frames of classification "is dirt, polluted, a threat to the integrity of the collectivity"[7]. This notion has been further developed by Sibley in his work on the purification of space which involves the rejection of difference and the securing of boundaries to maintain homogeneity and to purify social space. Interestingly, citing the example of Gypsies, he also outlines how purification can work as a two-way process with the weaker group using purification for their own ends: "We might see purification rules as survival mechanisms which maintain an economically and politically weak group within a larger society"[8]. This dynamic could also be seen as a direct response to exclusion and the lack of access to power on the part of Roma population.

1.2. Literature review

A brief discussion on the literature that draws attention to the topic of Roma attitudes towards hospitalization is necessary. Most theorizations

[3] D. Phillips & T. Rathwell, 1986, pp. 16–18.
[4] M. Herzfeld, 2001, p. 7.
[5] P. Goward, J. Repper, L. Appleton, & T. Hagan, 2006, p. 324; A. Sutherland, 1992a, p. 278.
[6] M. Douglas, 1966.
[7] D. Sibley, 1988, p. 410.
[8] D. Sibley, 1988, p. 411.

on this group have centred upon structural factors: issues of race, ethnicity, and the general incompatibility of nomadism with a sedentary mode of existence[9]. Recently, attention has been given to cultural diversity as an ethical issue surrounding health-care. In general, the ethical issues were related to the conflict between the needs of the Roma patients and the ethical standards of the medical profession. We have identified an interest in exploring the reasons for and patterns of attendance among Roma patients and families in health-care and shedding light on compelling linkages between Roma culture and healthcare – related behaviour[10].

According to the reviewed literature, the most frequently reported ethical challenges refer to:

- Low educational and socio-economic status;
- Poor health expectations;
- Low access to health-care, limited use of health-care provision and unmet needs;
- Lower compliance with the advised treatment;
- Communication barriers;
- Suspicion toward non-Roma people and institutions;
- Health professionals' prejudice and stereotypes about Roma groups and lack of knowledge.

Nevertheless, studies that examine the influence of culture on problems in health-care are meager and insufficient in addressing the complexity of this issue.

In Romania, very little empirical or qualitative information about Roma exists, from any period, to allow us to have more data about Roma healthcare seeking behaviour. Due to their marginal position in Romanian society and the fact that a lot of them are illiterate, we lack information about attitudes and practices from a Roma perspective[11]. In sum, the ethical issues among Roma are not fully understood due to a lack of studies on this topic. Our study reports some findings about cultural specificities of a Kalderash community related to hospitals providing inpatient care, trying to

[9] S. Hajioff & M. McKee, 2000, pp. 865–867. C.L. Zeman, D.E. Depken & D.S. Senchina, 2003, pp. 246-247.

[10] D. Honer & P. Hoppie, 2004, p. 35. A. Lehti & B. Mattsona, 2001, pp. 446-447. A. Sutherland, 1992a, p. 278; P. vanCleemput, G. Parry, K. Thomas, J. Peters & C. Cooper, 2007, p, 208. J. Thomas, 1985, p. 844.

[11] S. Cace & C. Vladescu, 2004; D. Singh, 2011, pp. 127-140. E. Zamfir. & C. Zamfir, 1993, p. 16.

improve health-care workers' knowledge, in order to master situations in which ethical ideals of the medical profession oppose to Kalderash culture and beliefs.

2. Methodology of the research

2.1. Data source

We used grounded theory (GT) as an interpretive research approach[12]. A qualitative method, the semi-structured interview, helped us to gather data, which have been analysed afterwards using the techniques of constant comparison and dimensional analysis[13]. The goal of a GT analysis is to derive conceptual categories, and linkages between categories, from the data concepts. GT seeks to show how the social process makes meaning and how contextual conditions structure the social process. These characteristics make it an excellent methodology to use when investigating the Roma perceptions towards hospital that are simultaneously abstract and strongly rooted in tangible aspects of social life. In addition, "*a constructivist GT offers another alternative: a systematic approach to social justice inquiry that fosters integrating subjective experience with social conditions*."[14]

2.2. Participants

The semi-structured interview was used for 23 Kalderash Roma ethnics – chronic patients and caregivers, from Zanea village community, Ciurea commune, county of Iasi (north-eastern part of Romania). The data collection period was August and September 2011. The members of the research team were postdoctoral fellows within the Faculty of Medicine "Gr. T. Popa", Iasi. Researchers contacted the participants by the President of the Roma Party (Iasi county), the family doctor in the village Ciurea and the leader of the Roma community (bulibash).

We located interviewees with various educational, income levels and age ranges (average age was 58; range = 21-78) and gender (15 women and 8 men) diversity. Levels of education ranged from "no education whatsoever" to vocational school. The percentage of Roma over the age of 18 who are totally illiterate is very high. Lack of experiences related to chronic illness or care for such patients or caregivers was a study exclusion criterion. The research ethics board at the Faculty of Medicine and Pharmacy "Gr.T.

[12] B.G. Glaser & A.L. Strauss, 1967, pp. 21-35.
[13] L. Schatzman, 1991, p. 308.
[14] K. Charmaz, 2005, p. 510.

Popa", Iasi, approved the interview protocol. Participants, who were promised anonymity, provided signed informed consent.

2.3. Interview procedure

The guide for the semi-structured interview included a series of open-ended questions whose topics were: (1) Background (experiences with illness prior to this study) (2) The medical care practice (relation with the medical staff and the family), (3) Communication of diagnosis and decision-making (4) Attitudes facing illness and death (5) Conclusion. In this paper we focus on responses to questions in medical care domain and attitudes facing illness, to elicit individuals' detailed accounts of their own experiences of hospitalization, impact, and consequences of those experiences. Questions in this domain refer to participants' attitudes, preferences, experiences and concerns related to hospitalization, care practice, family ties, communication with the medical team, etc**.**

The semi-structured interviews were conducted in two contexts (couple and individual interviews) and lasted from 30 to 45 minutes. The interviewers were the first two authors of this study. All interviews were audio-recorded and transcribed verbatim. Transcripts were reviewed for accuracy in transcription. Socio-demographic information was collected through a form that contains aspects such as age, gender, marital status and education level. The interviewers used the notes to add information about non-verbal language of the respondents. At the end of the interviews, transcripts of the interviews were compiled and then were applied specific methods of qualitative analysis aiming to identify common views of the respondents, but also specific features.

2.4. Coding and analysis of the interviews

The interviews` data analysis process enabled us to use both inductive and deductive methods of qualitative analysis[15]. The research team from the Center for Ethics and Health Policies was involved in the coding process, and used the NVivo software program to support the analyses. First, a preliminary codebook was developed based on the interviews guides, and used to facilitate the coding process. Through discussions, we agreed on the most prominent codes and then used them as analytical categories. Finally, a network of codes arranged around one key-category emerged (selective coding). The entire analytic process was accompanied by feedback processes among the members of the research team.

[15] A. Baban, 2002, p. 136.

Data were coded and recoded with comparisons of new and old data; codes were grouped and categorized. Hypotheses about the observed patterns were developed and discussed. Further analyses of the data by theme involving additional review and discussions among investigators enabled us to identify emergent sub-themes within the major themes we found[16]. There was a good match between the data and the categories that make up the findings of the current study. The results we report are related to the themes and subthemes around anxieties and attitudes towards hospitalization. They are presented partly as condensed descriptions of data, partly as quotations that are considered illustrative.

3. Results

3.1. The hospital – an ethnically-mismatched place

The Kalderash participants in this study claim family and cultural roots in Zanea village. As a result, they feel at ease and at home, culturally and linguistically guarded in their village environs which increase their quality of life and contribute to positive health perceptions. For Roma Kalderash from Zanea, living in the community is synonymous with well-being. Or, to use an expression of Stoichiţă[17], "The Paradise and the City are symmetrical images" that interfere. Zanea village is the heavenly space, a desirable environment, a perfectly safe one, determinant of the quality of life.

Although interacting with non-Roma, called *gadje*, is commonplace, Roma would prefer to avoid contact with them. In fact, separation from the *gadje* is one of the most enduring Romani cultural values[18], a fact which we have deduced from the interview with a Kalderash community leader:

"*For all my brethren I'll make a kindergarten, a church, a hospital for maternity, a children's hospital, more like these*" (# 1).

Non-Roma are considered polluted because they are ignorant of the Romani rule of cleanliness, that states to keep separate the upper and lower halves of the body[19]. This Kalderash concept of impurity (lower-upper body) serve to separate them from the *Gadje* and to sustain ethnic border[20]. Everything associated with non-Roma is potentially defiling. This particular

[16] A.L. Strauss, 1987.
[17] V.I. Stoichită, 1995, p. 15.
[18] C. Miller, 1975, p. 48.
[19] W.O. Weyrauch, 2001, p. 240.
[20] J. Okely, 1975, p. 42.

view of the world has profound implications for Kalderash people`s lives, including the perceptions about the hospital, where it is difficult to keep the ***cleanliness.*** Prolonged occupation of a place in the hospital means certain impurity. In this case, the Kalderash patient is helped by his family to minimize the pollution risk by using disposable plastic cups, plates, and towels that were not used before by non-Roma:

"*We bring bed sheets from us, there's no problem, a pillow or a bathrobe ... We bring from home a bowl, a spoon, a cup, a towel …*" (# 21)

The delineation clean/ unclean and taboos related to impurity have also been identified during our research in Zanea community, but slightly blurred, perhaps due to constant contact with Romanians (Gadje). The rule regarding separate clothes washing[21] – wife`s clothes must be washed separately from man`s and from children`s – was definitely affirmed:

"*Never mix them. Is this possible? It's not right. Well, I give her my shirt, to wash it, is she mixing mine with her worn-out ones she's wearing? How could I indulge this? She's first washing hers and after that she's taking it out and she's going on with my shirt. I throw the clothes into her face so that she couldn't even take a breathe after. [He is getting nervous] I said:* « *You aren't gonna wash your stale clothes, the children's separately, they shouldn't mix with your dirt, it's not good* »" (# 12).

Within the community of Zanea, self-identification with Roma ethnicity involves an increased awareness of belonging to this group. In this context, the social perception on the hospitalization will be influenced by ethnic consciousness.

3.2. Pollutants in the hospital area

For some Kalderash patients, the hospital elicited considerable anxiety and acculturative stress, also poor perceptions of well-being. The hospitalization gives rise to fears of pollution and to *moral panic* in connection with illness, that is perceived as a deviance from the normal status. In the interviews, we have also identified some of the most serious pollution beliefs:

"I: *Many who come to the hospital will not be hospitalized. Some leave at night... Patient: That's right, they cannot stay here in the hospital. I tell you something: Do not eat from the hospitals, mainly*.

I: *Why? P: You have not seen a Gypsy eating from the hospital. Not all Roma groups have the same notions. A part of Gypsies do not eat from the*

[21] A. Sutherland, 1977, p. 386.

hospital, for there`s dying a corpse, there's blood, there are nails, do you understand me? ... When just thinking food is not prepared on clean premises... To us, the food, the dishes ... this is not possible" (# 5).

The above quote shows that the fear of hospitalization is often accompanied by the view that bodily fluids are polluting. These bodily fluids – feces, urine, pus, vomit, mucus, blood – are defined as unclean in Roma culture.

Food is often seen as polluting, too. Not all food, of course, but food that is not taken from a certain source. To avoid impurity, the Kalderash may refuse the food cooked in the kitchen of the hospital. It is not unusual for family members to prepare meals at home and bring them to the hospital. For many Roma, bringing food to hospitalized relatives is a sign of love and support. To eat together acquires special significance. Sharing a meal shows respect, friendship and loyalty.

Death is an especially prominent source of pollution beliefs. Corpses are often regarded as polluting those who touch them or even those who are too close to them. The taboos against touching seem to play a major role[22]. The pollution beliefs concerning death have also been underlined by the Romanian family doctor of the Kalderash community:

"*If we prior had a case and the pacient died, they will not be coming to you because you have touched the dead*.

I: *Is it contagious*? Doctor*: Not necessarily contagious, not in that way. Something that brings bad luck*".

This suspicion was confirmed by a Kalderash participant in the study:

"*He grabbed the dead that`s why s/he shouldn`t touch the living ones, especially that Gypsy*" (# 21)

The broad range of pollutants identified by us shows how easy it is for Roma people to move to descriptions of hospital environment as polluted, a place that is generaly unwanted. The hospital is considered a hostile area, unclean, where they cannot observe certain rules of cleanliness. Nevertheless, despite their anxiety, Kalderash are in general knowledgeable of hospital procedure. But the pollution claims more often suggest that a lot of ethical dilemmas may arise within the hospital.

[22] N. D. Prakash, 1988, p. 244.

3.3. Family`s crowding around the patient

Roma`s assembly in the vicinity of a hospitalized patient is a social command, but also an expression of concern for his closest relatives. Illness is not only a medical crisis, but a social one as well. This mobilization may include the Kalderash community leaders or other ethnic group members.

The psychology of Kalderash Roma people is very particular because they are characterized by the feeling of belonging and solidarity. When something happens between them, they are all united against the aggressor (in this case, the disease), information goes around the community very fast and there is an immediate reaction. Disease is perceived as a common perpetrator. Participating in a large number, the community members guarantee protection against evil, so one person`s illness engages the entire group:

"*Us, if you want to know, we are very united. Even those not directly related to us should help. If a stranger comes not, means that man hates our guts. But we are together, there, lots, side by side, so! ... We join each other, you know? ... It's a belief: you should be close to that man*" (#12).

Fulfilling family role obligations is very important. The strong identification with, attachment to, and dependence on the family, is part of Roma customary law. Our participants emphasised that the first and foremost Kalderash patients` wish is to have their close relatives nearby. In general, families of the Kalderash patients who have participated in our research successfully maintained filial piety and respect for elders, which was manifested in instrumental (financial support, transportation assistance, help with identifying health-care services) and emotional (showing care, concern, offering reassurance) family support. This reduced patients' stress and improved health-care:

"*If we communicate with each other, know that all this public coming, for example, they come very many, so they cool him and he stay very calm. They have nothing to do with doctors. We are tied together, you know why? Look, for example, if I am not going now for a problem with a relative of my sister ... Oh, she did not come, you saw that she hadn't come! So ... so, at their time, they do not come. And when we are in trouble, then they say:"When we were at the hospital or when we were in the court or I don't know where, you did not come. Us, why should we ...?" So some stuff like this is taken into account*" (# 7)

The gathering together of families when someone is hospitalized is one of the strongest values in Roma culture. By transgressing the customary law, a person is blameworthy from the point of view of the whole community and the fact

is considered as a serious offense. But mostly because of their throng in the hospital perimeter, conflicts arise with the medical staff.

3.4. The relationship between Kalderash Roma and the medical staff

Effective communication with people of different cultures is especially challenging[23]. Roma patients may have trouble communicating about their symptoms. Pain and discomfort are complicated experiences that may be difficult to describe. Health-care staff may not know how best to ask about pain in a way that maximizes understanding. Most of the Kalderash lack the ability to present symptoms as objectively as possible to the doctor, and to assess their health status, because the level of education is an indisputable factor contributing to how people take care of themselves:

"I: *What do you know about your disease? Patient: I feel bad, do not eat, I am on a diet, I'm feeling kinda weak and think I faint*" (# 18).

The Romanian family doctor from Zanea community explained us:

"*When I see a gypsy ... I have to behave as if I see a child who does not speak, because he is not able to explain. The only thing they tell me is that « I can`t no more » and « It starts here and it goes to the head and from the head it goes down to my toes » and so on, but they cannot tell you absolutely anything because they have no idea about what is going on with them. I told you, for so many years, they should have made an education program for them, so that's what the state should have done...* ".

Low educational level may lead to misunderstandings in discussing content and in framing the relational aspects of communication. A Roma female participant in our research explained her perspective on the situation:

"*Some of the Roma who come to the hospital do not know how to explain to the doctor what it hurts. They cannot communicate ... the most are not educated, to understand ... Let`s say «neucoplast », what do the Gypsies understand by « neucoplast »*, I am asking you.

I: *Neoplasm*? *Do you mean cancer*? Participant: *The cancer*. *Do they understand*? *They do not understand*. *It`s impossible*" (# 8).

The answer describes the impact of cultural misunderstandings in terms of incomplete assessments, diagnoses and treatments for Roma population. An obvious hindrance to intercultural communication is the frequent lack of linguistic understanding between doctors and patients belonging to the Kalderash ethnic group. Linguistic barriers may lead to a

[23] B. C. Schouten & L. Meeuwesen, 2006, p. 31.

number of negative consequences, such as feelings of fear and increased chances of noncompliance:

"*There are many things that we do not understand, because we do not have a special technique of communication with them… Because they – this is one of the explanations that I can provide – firstly lack education and it is this aspect that provokes their fear, their permanent doubt. They do not understand; not understanding creates fear. And I was thinking about what they feel when they come to me ...*" (interview with the family doctor of Zanea community).

The quality of the information obtained by the doctor during consultations is closely related to his ability to ask the patients the right questions and to create a relationship with them. Most of the information needed for establishing the primary diagnosis is obtained during the interview with the patient, as a physician currently working with Roma patients told us:

"*I have always thought that they, being ignorant, not knowing anything, what's in their soul when addressing a medical professional, in a hospital or even here, with us, because they are stressed all the time and they permanently have this feeling of fear. They probably think*: *Well, perhaps this can hurt me, instead of making me better ...*"

According to the participants in our research, the hospital raises the Roma patients` fears because most of them do not have knowledge about the effects of some drugs or medical procedures. Reluctance to visit a physician is therefore common and accounts for lack of prevention:

"I: *Why did you refuse insulin injections*? Patient (P): *I was afraid*.

I: *Why were you afraid*? P*: I feared something would happen. And then somethin' even worse happened*.

I: *Haven`t you had confidence that insulin treatment was the best*? P: *You are right*, *yes, right*. *I thought it rises to the eye...*

I: *But haven't they explained to you*? P: *Yes of course*, *madam*, *I kiss your hand*, *lady*.

Patient`s wife: *They told us*: [If you] *Do not take treatment*, *you get into more troubles*!

P: *But we didn`t believe*. *We said* « *Never mind*, *never mind*, *then I left* » (# 22).

If symptoms disappear under treatment, all other therapeutic guidelines could be ignored because they think the disease has vanished, so they tend to abandon treatment prematurely. In these cases, the diagnosis may be perceived as a manifestation of a disease that previously did not exist. Therefore, in many cases, Kalderash wait until they need urgent care and go to the hospital especially when the disease is very advanced or they foresee a crisis. Although the notion of prevention is fairly foreign to the Roma population,

it has yet begun to gain importance in this community with a low level of education.

3.5. Stereotyping the Roma patients and caregivers

When they come to the hospital, some of the Kalderash stand out because of their demanding attitude. Those coming from a different cultural background would characterize these persons as violent in gestures and words. Seeking medical care, they often come into conflict with medical personnel who find their behaviour very confusing and demanding[24]. They may also use violence in gesture and in language, as an expression of the sadness they feel or of increased anger, as a Kalderash participant in the study told us:

"*If something happens, they start to pick on doctors, to curse, talk dirty and because of one or two, all suffer*" (# 5).

The participant above recognizes that some Roma are indeed involved in arguments with doctors, but not all of them. Most of Roma people are acutely aware of the stereotypes attributed to them. Indeed, Kalderash may go beyond the limits of conformity. This freedom in behavior is specific in such situations. The definition of normal behavior or attitudes (language, tone of voice, facial expressions that could be considered appropriate in this context) is cultural, acquired and transmitted traditionally. "*Culture defines the way we could sometimes get out the norms and the contexts where we could do this*"[25]. Deviance is never an absolute rule within this ethnic group, but exaggeration of symptoms, which emphasizes the abnormal intrusion of illness in everyday life, is constitutive of the Kalderash Roma culture.

The distancing between Roma people and the Romanian medical system is not a particularly new finding[26]. Roma people are on the wrong side of an unequal power balance and their behaviour, tactics and strategies bear this out[27].

The categorization – a way to impute predictability – prepares the ground for the imputation of stereotypes. The Roma individual is recognized as part of a community and specific kinds of behaviors are expected from him. Through the processes of categorization, projection and exaggeration,

[24] A. Sutherland, 1992a, p. 278.
[25] C. Helman, 1985, p. 13.
[26] D. Costin-Sima, 2003, p. 101.
[27] J. Okely, 1983.

all Roma are associated with deviance and this leads to the legitimation of exclusion in the collective mindset of the Romanians[28].

This entrenched stereotype that can also be found amongst the doctors derives from the perceived behaviour of some Kalderash people, which is incompatible with the norms of the dominant society. Unfortuntely, this is applied to the whole of the weaker group. The following quote encapsulates a typical attitude amongst doctors and seems to suggest a way to avoid someone's aggressiveness:

"*When we arrived at the hospital, we went with the girl, the doctor on call approached us, the best doctor there, I can feel him. And on our arrival there, at the hospital, he told us*:

"*Out*, *gypsies*!"

"*Doctor*, *whom can we ask*?"

"*I cried, I prayed to God, he even touched the girl. As neither me, nor you are feeling pain now, so it did not hurt the girl. He offended us, he kicked us put, but he did his job, though he mocked at us... he focused on his hands, did not focus on talking*" (# 16).

Indeed, where the process of stigmatization is experienced emotionally, it may serve to further accentuate the power differences. This, in turn, disarms Kalderash, making them to appear helpless in the face of this situation and unable to retaliate.

4. Discussion

Approximately one thousand years ago, Roma left their native India and spread in countries throughout the world. Along time, they represented one of the communities less accepted by history. Despite the fact they have been travelling communities, Roma preserved their own customs and traditions. Their distinct culture is still intact in spite of the intense persecution they have endured.

Some scholars as Sutherland[29], Okely[30] and Grigore[31] claim that Roma thinking is a fundamentally dualistic one. According to this philosophy, the society is divided into Roma and non-Roma (Gadji). This idea deals mostly with the often cited concept of purity, which distinguishes

[28] M. Voicu, 2007.
[29] A. Sutherland, 1977, p. 38; A. Sutherland, 1986.
[30] J. Okely, 1996.
[31] D. Grigore, 2001a, p. 125; D. Grigore, 2001b, p. 13.

the Roma culture from other types of culture. The division ”pure” vs. ”polluted” determines the classification of persons within human society. In a chapter entitled ”Pollution, boundaries, and beliefs” from her research on Roma of California, Sutherland[32] sees this division as a widespread metaphor that traces separations between Roma and non-Roma to maintain the border with *Gadji*.

The same features have been found in the Kalderash community from the north-eastern part of Romania. As our study has proved, the unfavorable attitude towards hospitalization is derived from Roma attitudes in general toward illness and uncleanliness.

The findings of this paper, deduced from the Kalderash point of view, underline major ethical challenges that can arise when the particularities of this ethnic group are not understood and observed. Results indicate that Roma behavior in medical setting is strictly regulated by ***purity laws***. For the Kalderash of Zanea community, the hospital is a harmful and a polluted environment.

The Roma style of seeking care is often frustrating and confusing to medical staff. A serious illness always elicits deep concern from a wide circle of his family members. Moreover, they have a large support network of relatives who come to the hospital in alarmingly large numbers, sometimes camp on hospital grounds, disregard visiting rules, and generally create disorder in the hospital. Hospital restrictions are cumbersome for them.

The Roma patient becomes very anxious when he is hospitalized and has a strong desire to have relatives nearby, that can reduce the disruption coming from being in an unclean place. Moreover, he is aware of his outsider status and is accustomed to discrimination and stereotyping by those who often care for him.

These hospital-related beliefs are reflected in the day-to-day social relations between Roma patients or families and the medical care professionals. Certainly, the ethnic and cultural differences and a lack of understanding and knowledge of the medical care team play a key role in perpetuating stereotypes and reinforcing and maintaining stigma, but there is a need to link Roma beliefs and their characteristics to the process of healthcare.

[32] A. Sutherland, 1992b, p. 32.

A knowledge of certain basic Roma beliefs and behaviours is essential to effectively interact with this ethnic group. For a successful resolution of the above ethical dilemmas, the medical staff should have an understanding of the patient`s cultural background, and the ability to identify the culturally relevant value conflict. Interculturalism requires an inherent openness and willingness to discuss on ethical dilemma until a compromise is reached or an otherwise satisfactory resolution of the problem is achieved. Once a person seeks to understand a different culture and embraces it willingly, a dialogue should ensue[33].

5. Conclusions

This paper has argued that culture, ethnicity and hospital health-care are intertwined in a complex way. The analysis and discussion of data obtained in this study allow us to point out that there are some conflicts concerning the adaptation to the hospital environment.

The Kalderash live in a charmed circle of unchanging taboos, laws and customs, strictly governing and dominating all aspects of life. Their community is a static one, resistant to change, attached to magical beliefs and forms, closed to influences of an open society. Any person born and raised in such a society will take and pass the customs, taboos and beliefs of his community. For Roma, observing the tradition has a sacred and inalienable character, equal to the value of a dogma. In their closed society, nothing can (and should) change, since everything is carefully developed by an intrinsic reason. Therefore, any outside influence is disturbing and would break the *status quo*.

Sometimes, these features of the Roma cultural background create problems in accommodating to hospital rules. The building up of a good relationship between doctors and ethnic minority patients or next of kin is essential. In spite of encounters, it is important for the medical staff to consider the validity of their belief, because a respectful approach to Roma oriented patient care and paying attention to ethnic diversity matter.

Practice implications

Our findings highlight important factors associated with culturally-appropriate care for Kalderash Roma patients. Their cultural norms influencing the behaviour in the hospital perimeter deserve special consideration. Health-care services should be culturally-tailored to the

[33] M. Bennett, 1998, pp. 48-49.

Roma population, in order to meet their medical needs while recognising and respecting their cultural identity.

When doctors provide medical assistance for Roma patients, whose culture they are not familiar with, they could feel justified to force them to do things in a certain way, under the guise of knowing what's best for their well-being. But the imposition of the dominant culture might turn against medical staff. Doctors` claims of moral superiority on the basis of membership in the dominant culture are inadequate for an ethical response to a medical dilemma. Therefore initiatives to maintain and promote their health should consider the way in which lack of respect of Roma cultural specificities accentuates their stress. By knowing these patients' beliefs and accommodating to their practices as much as possible, the doctors will make progress towards promoting a relationship of trust that can lead to a better healthcare.

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