



# Healthy Diversity

## IO2 – Medical Anthropology Reader

This handbook has the ambition to introduce the non-initiated reader into the universe of medical anthropology, showing different ways in which this discipline engages with, challenges and supports various therapeutic practices. Despite of this goal, the book should not be read as an introduction to medical anthropology, rather as a guide for health professionals to the many ways cultural factors may interfere with their work. The book is structured in a way that it can be read independently, but it also connects to another product of the project Healthy Diversity, especially to the book: “Manual of Critical Incidents” - a collective enterprise bringing together the perspectives of 6 European countries on health sector, interculturality and medical anthropology.

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# I) A short introduction to medical anthropology, or: Why would culture be relevant for medicine?

## A. The aim of the book

This handbook has the ambition to introduce the non-initiated reader into the universe of medical anthropology, showing different ways in which this discipline engages with, challenges and supports various therapeutic practices. Despite of this goal, the book should not be read as an introduction to medical anthropology, rather as a guide for health professionals to the many ways cultural factors may interfere with their work.

The book is structured in a way that it can be read independently, but it also connects to another product of the project Healthy Diversity - a collective enterprise bringing together the perspectives of 6 European countries on the health sector, interculturality and medical anthropology. The Catalogue of Critical Incidents is a collection of mini case studies showing how cultural difference may trigger conflicts in the medical work. We classified these cases according to the main cultural dimensions they involve and we found that medical professionals hurt themselves with bigger probability to some dimensions than to others. These recurring dimensions include universal human themes, such as gender, the family, the body, conceptions of life, death, sickness and wellbeing, relation to the individual and to the group– to name only a few. We call these dimensions “sensitive zones”. The problem with these universals is that not in two cultural systems they are interpreted in the same way and different interpretations tend to clash all the more because people usually take their own interpretation as the only valid one. To prove the contrary we invite the reader on a journey in space and time. Selecting some of the dimensions in question we present their cultural variability visiting different regions of the world and looking back to our own European

heritage. These thematic s mini-chapters bring more insights to the critical incidents and encourage the reader to relativize their own position.

In line with its aims, the book is composed of three parts. The introduction – besides giving instructions on how to use it – offers an explanation of the concept of culture that we propose. Part I. contains detailed reviews on some medical anthropological texts produced in the six partner countries: the UK, France, Austria, Italy, Denmark and Hungary. Although these texts necessarily reflect the social reality of their authors' countries of origin, they transcend local issues and their themes nicely respond to each other. We hope that readers will not only find this presentation instructive but also a good read.

## **B. Culture in healing, healing in cultures**

Anthropology studies a vague philosophical entity: culture, while medicine is concerned with the very material manifestations of wellbeing of people. How such different disciplines can enter into conversation and what benefits this dialogue can bring to humankind?

In order to answer this question, culture itself should be defined. Anthropology however does not offer a one-size fits all definition , it is not an exaggeration to state that there are as many conceptions of culture as there are anthropologists out there in the field. Most anthropologists would still agree that culture is more or less like a lens through which humans look at the universe that surrounds them. While individuals receive this lens more or less ready made from their group (or groups) of reference, the lens itself does not precede humans. It is the product of the same human groups which it orients. Geertz' web metaphor expresses this paradox. The famous American anthropologist compares humans to “an animal suspended in webs of significance he himself has spun”. Like for the spider, their universe makes sense to humans only from their point of suspension.

But culture is not only in the heads of people, it is translated in acts. It is made visible by forms of behaviours that we as humans learn from each other. It might sound counterintuitive to state that there is no form of human behaviour that is not learned. If humans are part of the natural world, and surely they are, then at least some of our behaviours must be inborn. In

fact, this is the specificity of the human race: even our most natural acts - eating, drinking, procreating, giving birth, falling sick and dying - are coloured by cultural norms that we learn during socialization.

Does it mean that all individual behaviour is necessarily cultural? This is a very relevant question in the medical field because the answer given to it will draw the thin dividing line between normality, deviance, pathology or idiosyncrasy. Some behaviours do not follow group patterns. The story of Maugli might be a tale, but there are indeed a few documented cases of savage children, unfortunate creatures who grew up locked in a cave or in the wilderness deprived of human company. Gaspar Hauser is one of those. He and others like him lacked any cultural model to follow, so in their cases we cannot talk about socialization. Gaspar never became a man like the others, but after he was discovered and joined the human community he soon learned to speak and interact in a sensitive manner with his fellows. Culture is similar to language. It is an inborn capacity to learn and interiorize cultural norms, but it remains inoperational as long as we do not learn a particular cultural grammar. And understandably we rely on others for that.

Other exceptions exist, drawing individuals away from the realm of culture. Autist children are hampered in their cultural learning by their difficulty to relate to their environment. Mental illness transforms behaviour in ways that are culturally not accepted. Individual combination of preferences creates individualized idiosyncratic patterns that remain exceptional as they are not characteristic to any group. These exceptions however only reinforce the norm. Culture in fact draws the contours of normality in a given group. Anything outside of this realm is considered extraordinary, uncommon, irregular or abnormal. In the last instance is the group that sanctions a form of behaviour or belief as acceptable or non-acceptable, normal or abnormal.

This is where culture becomes highly important for medicine. Because a medical system has the vocation to maintain or enhance wellbeing, and wellbeing in all society is understood in terms of group norms. What obesity is for us was the beauty ideal in the times of the Venus of Milo. What looks like a pathology for me, might be normality for some other people. In a multicultural society telling the difference between pathology, cultural norm and idiosyncrasy

is a constant challenge for anybody. For health professionals such a dilemma has got an additional stake: literally life and death might depend on the good answer.

Anne Fadiman's book on the case of a Laotian child treated in the USA for epilepsy is a good example of the utmost relevance of culture in the medical system. This is a true story which describes what cultural misunderstandings between the family and the medical professionals led to the child's death due to mistreatment. Fortunately, not all cultural clashes have such dramatic outcomes. In most cases cultural misunderstandings stop at a point where they leave the patient or the medical staff (or both) annoyed and frustrated. But it is important to recognise that cooperation and trust between the two sides form always the basic condition for effective healing.

For this reason it is in the elementary interest of the medical professionals to be able to recognise cultural patterns and differentiate these from deviance, pathology or individual characteristics. Deviance might be fought against with various means, pathology might be cured, but cultural behaviour or cultural expectations cannot be changed easily. When cultural differences create tensions the best way to avoid escalation is understanding, tolerance, adaptation or negotiation.

We call the capacity to mobilise these potentials intercultural competence. Intercultural competence is not only important for health professionals because it can help them avoid unnecessary tensions during their work but because it can protect them from making erroneous diagnosis and choosing ineffective intervention.

One of the stories in our collection comes from a physiotherapist. She recalls having had an elderly female Roma patient. When the time came for rehabilitation she asked the woman's husband to bring a pair of panties and sweatpants to the hospital because it is impossible to do physiotherapy with a patient in a nightgown. The man came back with a long skirt. The same request was made again with the same result. In the meantime the physiotherapist refused to work with the patient. The story could have continued like this if the professional had not had the good idea to consult with the patient's daughter who explained that her father would never touch his wife's panties and her mother certainly had no trousers at home. In traditional Roma culture everything that belongs to the lower part of the body is considered

to be polluting, especially any object for a man that has got connection with the lower part of the female body. On the top of that, traditional Roma women simply do not wear trousers. The solution was quickly found by the intermediary of the daughter and the therapy could start.

This is an example which shows how cultural knowledge may facilitate professional work. At the same time it is also important to remember that culture is not a closed box which we would be born into and we would remain in it until the end of our lives. It is more like a backpack which we carry along and which we fill with new stuff continuously while we may lose some of its content during a life time. It may also be imagined as a frame: like all frames at any point of time it is fixed, but during the life it might change; it may broaden or shrink. For this reason, for a person we prefer to speak of a cultural frame of reference, rather than of culture.

A frame of reference does not constitute a closed system with no way out. It is not homogenous and it allows contradictions. A frame of reference - just like the lens - helps us to understand the world. What prevents the physiotherapist from understanding her Roma patient is precisely her own frame of reference in which it is normal for a woman to wear sweatpants or for a husband to touch her wife's underwear. The story is not about a cultural system clashing with normality, rather about the conflict between two different normalities. Substituting the word "culture" for "frame of reference" prevents closing the other in a cultural box.

Another story in our collection of critical incident highlights this danger. A nurse in Austria faces a shocking behaviour from a patient that she identifies as East European. When the patient is told to give a urine sample he attempts to urinate in front of her. The only way the nurse can make sense of the situation is by culturalizing it. For her the strangeness of the patient's behaviour comes from the fact that he is Hungarian. This way of evoking culture does not really help to understand the other, culture in this case might become a code covering prejudices and feeding stereotypes. Essentializing culture might be as harmful for the relation as culture blindness.

The health professional is indeed between a rock and a hard place. What is the right attitude in such a complicated situation? Well, we believe that the first step towards understanding the other leads through understanding oneself. Accepting that our frame of reference is as conjectural as anybody else's is the necessary passage to accept difference. The attempt to reconstruct the frame of reference of the other demands patience and the capacity of putting it into perspective. Mobilising ethnographic knowledge may be as a useful tool on this path as asking questions or engaging a cultural mediator. But empathy, mindful attention, observation and the ability to connect to others are also important capacities.

Having a close look at it, these skills are not only useful for treating patients from exotic cultures. Understanding from where the patient talks and discovering possible causes of ruptures in the communication line, because of diverging attitudes, expectations, mutual identity threats (to mention only a few possible causes of seemingly incomprehensible conflicts) probably facilitate professional work with any patient. In our approach the emphasis is not on cultured-centred nursing, rather on anthropocentric healing. Repositioning the human with all their complexities in the centre of the medical system demands further moves, including relativizing the veridical discourses of the biomedical system. Relativising does not mean invalidating it, to the contrary. It allows realising its advantages on other medical systems, wherever these advantages are scientifically proven, while allowing it to enter in dialogue with other systems wherever such dialogue can improve its results.

Anthropocentric healing also demands a genuine social engagement from all professional working on health issues. The concept of culture should not blind the medical staff to social disparities. The concept of culture we promote includes all diversities, not only the most taken for granted ethnic or religious variations. Again, changing the notion of culture for that of frame of reference might serve as a valuable safeguard, allowing to consider all factors and conditions determining a person's position, including its social status. Wherever these factors engender or deepen health inequality, the intercultural conscious medical staff is asked to take a stand against it.

## C. Samples of medical anthropology

The above considerations are not only ours. The issues raised in this introduction are very much those of medical anthropology. The reader can have empirical evidence. In the six partner countries of Healthy Diversity we scanned the production of medical anthropology over the past 10 years. We were looking for ethnographically grounded case studies and therefore excluded purely theoretical works or handbooks. We established that most papers, books and articles we found in this domain may be grouped in one or several of the following categories:

- understanding and explaining the structural causes of health inequalities
- understanding how different identities and especially the combination of various undervalued identity traits contribute to health inequalities
- understanding cultural and social variations in experiencing health and sickness
- understanding the differences between particular medical systems and their interactions
- understanding the difficulties of health workers in multicultural societies where they feel that they have to meet contradictory requirements

The chapters in Part I. follow this order of themes. In the section **Health inequalities: barriers to access** we find a Hungarian and an Austrian text. Hungary is not an immigration country. Its bigger minority is the Roma community. The disparity in health between Roma and non Roma Hungarians have worried health professionals for many decades and a multitude of explanatory theses have been proposed. The article presented here offers explanation to a general question by investigating a particular disease (arteriosclerosis). Not surprisingly the Austrian article turns toward Austria's own most important minority population, examining the health situation of immigrants.

The section **Health and intersectionality** explores intersectionality in different ways in three articles. The UK example brings together considerations of race, gender and sexual

preference. The Danish case study looks at the combination of the migrant status and old age. The Italian article examines the health situation of migrant mothers, showing how the combination of the factors migration, gender and motherhood enhances vulnerability.

The section **Cultural and social variations in experiencing health and sickness** deals with cultural variations in the experience of disease and pain. Chagas disease is a non-endemic illness in Italy, still it has high occurrence amongst Latin-American immigrants. Besides being seen as an “ethnic” disease it is also a mark of poverty. These markers have an influence on how people experience it. Kohnen’s paper on the perception of pain equally supports the idea that somatic perceptions are to some extent culturally bound. The article comes to the conclusion that experience of pain depends - amongst other things - on learned patterns of how to make sense of it.

The expression **Medical pluralism** refers to situations where different medical regimes co-exist within one cultural system. In these instances patients make strategic choices between available treatments, not infrequently combining these in different ways. The Hungarian example is the ethnography of a Chinese clinic in Budapest frequented by Hungarians. The French text deals with the case of antiretroviral therapy in Africa, looking for an answer to the question why the same medicine seems more efficient in Northern countries than in the South. The article presents interesting examples for the combination of different healing practices in Africa. The third article equally illustrates Northern health interventions in Africa, in the field of HIV/AIDS prevention, bringing a case study from Mozambique.

In the focus of the last section, **Health professionals facing cultural difference**, we zoom on the perspective of health workers. Danish and British professionals seem to struggle alike as much with the experience of difference as with their own fear of appearing insensitive or incompetent when dealing with the perceived cultural other.

### *Part II. Sensitive zones*

This part contains six small chapters. Each of them gives very concrete ethnographic examples for sensitive zones that our team have found most common in intercultural conflicts within the health sectors. The cross-cultural themes visited are:

- gender;
- body;
- death and dying.

## **II) Key questions of medical anthropology – reviews**

The following 12 reviews – clustered in five groups and selected from six countries – are offered as a representation of the recent scientific discussions in medical anthropology in relation to our central domain, health and healthcare delivery. Initially a thorough literature review was conducted in all partner countries in the national languages, resulted in 10-12 items per countries with brief annotations. Afterwards, a careful selection has been made with regard to our focal points grounded in the critical incidents analysis. The selected articles were reviewed and summarized in English by our partners. This collection can be read here, in this part of our reader.

## A. HEALTH INEQUALITIES: BARRIERS TO ACCESS

### 1. *Self-selective mechanisms: the institutional patient paths in the treatment of arterial diseases (arteriosclerosis obliterans) - the case of the Roma (HU)*

Written by Attila Dobos

*Text reference:* László Antal Z. (2004) A „kisebbségi” és a „többségi” betegutak sajátos vonásai. (Antal Z. *Specific features of “minority” and “majority” patient paths*) in: Társadalomkutatás 22 (2–3) p.335–366

#### *Introduction*

This study deals with the characteristics of the relationship between **Roma patients** (here referred to as the “minority”) and the service providers coming from the “majority” population in the institutions of health care in Hungary. The emphasis has been put on the **cultural elements** of these characteristics. This study is based on a study realised originally in 1984 by the same author. For the study he and his colleagues developed a special “**patient path analysing inquiry**” with his colleagues in the Centre for Social Sciences of the Hungarian Academy of Sciences.<sup>1</sup> Since then, this method has become widely accepted for better understanding healthcare service delivery. One of the key components of this method is to study the path of patients with identical diseases from the first contact made between the patient and the doctor by means of in-**depth interviews**. The research included aortic stenosis (arteriosclerosis obliterans), a typical arterial disease in the population that could be lethal. This present study would have liked to, but could not follow the same method as the former one in 1984 for numerous reasons explained in the paper. However, during the preparatory

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<sup>1</sup> László Antal Z. (1988): Beteg-utak [Patient-paths]. In: *Medvetánc*. Magyar gazdaság és szociológia a 80-as években. Budapest, Minerva, 265–291

phase of the research, the author could gather relevant information through interviews in hospitals, visits in wards treating arterial diseases, and fieldwork in Szabolcs-Szatmár-Bereg County, one of the most underprivileged areas in eastern Hungary, to proceed further with the analysis.

### *The Starting Point*

The original intention of this research was to repeat the first investigation after more than 20 years to see where the first results evolved to and to gain a new picture of the situation. The initial questions were: **how can the patients find their way** to recovery in the maze of the principally free and equal healthcare system run by the state? Are there any other **possibilities from the side of the healthcare system to improve the health** status of the population apart from promoting changes in lifestyle? Based on the “patient path analysing” method requirements, **aortic stenosis** was chosen, as 1) it could be identified unequivocally; 2) there are different treatment opportunities; 3) most patients go through all three levels of healthcare: family doctor, outpatient care, hospital. Hence, the research hoped to get an insight into the factors that have an impact on patient paths apart from the disease itself. The most important **results** of this study were: there were very **limited opportunities for high-standard treatments** and only those patients managed to get them in time who successfully recognised the hidden “traffic rules” and understood how to navigate the system. These rules were built out of **social and monetary capital**. Here we had very strong selective mechanisms under the veil of “free and fair” service, so the focus of this recent study was set on these **selective mechanisms** among the minority group, i.e. Roma communities.

### *Changes in the last twenty years*

What has **changed in the last two decades** that has made the iteration of the study impossible? The reasons can be identified in two segments: related to the field of health care and to the question of ethnicity. Firstly, within the domain of health – in relation to aortic

stenosis – the possible patient paths have changed radically: both doctors and patients can **recognise this disease much faster** now, so long lasting detours will not occur frequently. Secondly, due to technological advancements in medicine there are **more tools, treatments and possibilities available** to cure patients even within state-run hospitals. Additionally, with the massive appearance of **private service providers**, these possibilities have increased drastically, including the reappearance of formerly prohibited procedures of **complementary / alternative medicine**. Thirdly, the **financial structure** has changed radically with the **implementation of the DRG (Diagnoses Related Groups) approach**, which link the funding of a hospital to its performance. In the literature of medical sociology and health economics, the impact of such a system on the hospitals and its doctors is well-known now. Accordingly, it urges hospitals to treat more people, possibly with severe diseases, within their institution to get more funds. As a consequence of this impact, it increases the overall health expenditure in the country and more importantly it does not always serve the interests of the patients: while 20 years ago it was evidently the success of a patient to reach the vascular surgery ward, it is not as clear now. With the appearance of this open selection mechanism, **even the accuracy and rightness of a given therapy (and patient path) is not clean-cut anymore**. Drawing from these, the **net of patient paths and its traffic rules have become much more complex** and difficult to explore both for patients and for researchers.

Even more serious **difficulties have emerged in the domain of ethnicity**. The detailed analysis of ethnic differences was not in the focus of interest at all at the time of the first study. The iteration of the first research was motivated mostly by the increased attention dedicated to the ethnic aspects of healthcare service provision. Paradoxically, as ethnic issues have come to the fore, it has become more and more **difficult to make inquiries into and grasp ethnic differences**. Principally, the vast amount of literature and research in the field of Roma studies makes it hard to find a general framework. Moreover, due to the heavy and often emotional debates between different schools and approaches of this field, political considerations have come to complicate the picture. Practically, **this question has become quite sensitive** as different scandals have received publicity in public hospitals, e.g. segregated maternity wards.

All in all, these changes in the last 20 years made it impossible for the author to conduct the same research in the very same way. However, the historical comparison was of great use to analyse further the selective mechanisms.

#### *On the changing patient paths of arterial disease*

As mentioned above, medical advancements and changes in the financial support system are the two main sources of change in patient paths as well. The latter one resulted in the altered system of interests and stakes of doctors and their relation to their patients, while the former one involves the enlargement of possibilities of curing this disease.

#### *Extended possibilities*

One of the most important developments in state-run healthcare (along with five other institutionalised ones) was the widespread implementation of the so-called “Dotter technique” in vascular radiology, which can be used as a one-day surgery in outpatient service to clean out the arteries, instead of having serious and much more demanding inpatient surgeries. But this is only a small thing, compared to the achievements available in private and complementary / alternative medicine: **approximately twenty ‘new’ treatments are accessible for aortic stenosis.**

One of the most important consequences of this change is to find the answer to the question: “**who** gets **what kind** of treatment”, while previously the question was restricted to “who succeeded in getting the appropriate treatment”. Obviously, there are **considerable differences among** the available procedures in terms of 1) how demanding is it for the patient? 2) what side-effects are predicted? 3) how much does it cost? and finally 4) how effective is the treatment? According to the author, these extended opportunities make it possible to see more clearly the new selective mechanisms. There are **no ready-made maps** for the patients to make their way easier, and additionally it is **difficult to get reliable information** about the effectiveness of the given treatment. This is what can be regarded as

intensified **social embeddedness of healing**. All the massive changes that took place in the whole society have a great impact on the patient paths of this single disease. Just to mention a few: more opportunities to travel and seek a solution outside the borders of Hungary; more knowledge available for the public about health literacy, improving the usage of alternative procedures as well; the medical worldview has also opened up towards treatments other than surgery, i.e. complementary / alternative medicine.

### *DRG financial system*

The financial system has significant impact on how wide those patient paths could be, defining the traffic on them<sup>2</sup>. One of the most important results of this DRG-based change is the possibility of having **competing and conflicting interests within public healthcare**, which often hurts the patients' interests. After reviewing the new therapies and giving some basic epidemiological data on this disease, the author reveals two instances of the above mentioned phenomena. **Fibrinolysis** is a preventive technique of breaking down blood clots, but could gain much less 'reward' and funding for the hospital than amputation, driving the system toward amputations. Moreover, although there is significant clinical evidence that shin (lower limb) amputations have a much lower mortality rate than thigh amputations (upper limb), due to the longer after care period it has less funding than the "competing" procedure, driving hospitals towards the less rewarding therapy for the patients. So to speak: they may **sacrifice the interest of the patient for the sake of the hospital**. Because of the financial difficulties of the state-run public healthcare system, it loses more and more patients whose level of demand exceeds what it can offer, hence strengthening its fall-back.

### *The case of the Roma*

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<sup>2</sup> Traffic on patient paths = how many patients get treatment on a particular way

Unfortunately, there are only a handful of studies that have dedicated attention to the **sensitive situations in healthcare institutions** regarding the treatment of Roma patients. Right after conducting some interviews with patients from this group, it became clear to the author that there are **remarkable differences in the culture** of the majority and minority populations, quite often leading to tension. This segment of the research focused on the questions 1) **why this tension takes shape** so often, and 2) **what solutions have been developed** by the different parties to dissolve this tension.

After studying the literature on Roma culture, the author summarises the most important characteristics he found in relation to the problems occurring in the world of healthcare institutions. In the very first instance he makes his point in the well-known debate: is there any Roma culture or is it the culture of poverty and very low socio-economic standards we are talking about? He stresses along with many famous scholars in the field that yes, **without any doubt, there is such a thing as “Roma culture”**, which helped this population to survive through centuries. The most important findings are:

Perhaps the most essential feature of a “minority culture” comes exactly from being in a minority position: **very strong group cohesion** had to be developed in order to fight for survival against the majority claims. Every piece of knowledge, experience that makes the living of the offspring easier had to be equipped by the force of a law. **These inner “laws” often contradicted** the majority population’s law, therefore the group could only survive by evading those laws, further strengthening in-group social ties.

Another important element could be identified within **the ruling values of life** resulting in a different mentality: less aspirations for goods like tools and symbols of comfort, such as better cars, nicer houses, etc. and more **inspiration to live their lives simply with full impulses** of joy and sadness following traditions of their own. This attitude of “just live simply” often contradicts with the healthcare professionals’ way of living.

However, in this regard the central feature of the Roma culture is certainly the **continuous feeling of being threatened by the majority population**. There are clean-cut traces of this feeling of threat in their folklore, just as it has been quite widely identified by cultural anthropologists during their fieldwork in Roma communities. Most likely coming from the

travellers' lifestyles, yet the fear has remained after settlement. As a well-known Belgian anthropologist, Luc de Heusch, put it: it is as if they **were under a “state of siege” continuously** and would develop an approach toward the outer world accordingly.<sup>3</sup> In the institutional situations of healthcare, one key element of success is the trust between the service provider and the patient. Therefore, this particular aspect represents a clear difficulty during the therapy of the Roma people.

#### *Roma patients in healthcare*

Following on from the above mentioned arguments, it is understandable why the Roma **believe that healthcare institutions are “dangerous places”**. The healing procedure is in itself a precarious action due to the dependency of a suffering patient in need on the doctor who has the possibility of offering solutions. Additionally, it is all going to happen **in an institution of the dreadful majority**, where their rules are dominant. Moreover, there is simple a **lack of control over the things they are in touch with**, so no-one can be sure what is polluted by the “Gadjo” and what is safe to touch. Hospitals are especially risky places where dying and birth take place – two dangerous, contaminating actions, according to their worldviews.

The research revealed an interesting fact: **the prevalence of aortic stenosis is quite rare and those that end in limb amputation are even less** among the Roma population (despite the high ratio of smoking), compared to that of the majority population. There are several explanatory attempts for this fact: the “always on the move” and “walking lifestyle” has preventive effects; poverty could be related to a lower cholesterol level; co-morbidity of lung and throat cancer has a distorting effect on this data. Another explanation seeks the answer for ‘why they ignore amputation as a treatment’ in the roots of Roma culture itself. It may also be related to the general late attendance at the doctor.

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<sup>3</sup> de Heusch, *A la découverte des Tsiganes: une expedition de reconnaissance*. Bruxelles: Ed. de L'Institut de Sociologie. de L'Université Libre (1966: 34-49)

### *Selective mechanisms*

Social differences are clearly present in the “equal” healthcare system. Those who are better **off can make their way in recovery much faster** and in a much better quality. The question here relates to those who are on a fairly similar socioeconomic level: the poor from the majority and those from the Roma population. Former studies claimed that there is no characteristic difference in their health status even if the situation of the Roma people is special. For instance, **the delay in visiting the doctor clearly relates to the extent of pain in both groups**: only huge suffering can overcome the social distance. Or, it may come from the lack of knowledge about the consequences of late treatments. However, there is a clear disadvantage for the minority group, which works as a selective mechanism here: **family doctors often refuse to visit Roma people in their homes**. Nevertheless, those who have good personal relations and contacts at the hospital level will find their way to better institutions and treatments, mostly in large centres.

**The weakness of the minority position can be slightly compensated for by the family and community cohesion**, in forms of information sharing and emotional backing. People with the same socioeconomic level from the majority population cannot enjoy this support, so in this regard they might be in the worst situation.

### *Summary*

The biggest difficulty in institutional interaction between the Roma patient and the service providers is the **mutual fear** of each other. It comes from the minority position and affects the behaviour of health professionals. Especially family doctors, nurses and paramedics reported angst in these situations. This partially leads to the decay of the prestige of these professions, which again narrows the path for the patients of low socioeconomic status. Other factors, such as out-of-pocket payments, health literacy – although these were not a direct subject of this study – also represent strong selective mechanisms in their care.

## 2. *Complex entanglements: migration and health in Austria (AT)*

Written by Agnes Raschauer

*Text reference:* Kutalek, Ruth (2009): Migration und Gesundheit: Strukturelle, soziale und kulturelle Faktoren. (translation: Migration and health: structural, social and cultural elements.) In: Maria Six-Hohenbalken / Jelena Tošić, eds. Anthropologie der Migration. Theoretische Grundlagen und interdisziplinäre Aspekte, p302-321. Vienna: facultas wuv.

### *Introduction: Migration experience and questions of health care*

How might an experience of migration prove relevant for health related issues? Migration and health are connected in various complex ways. Drawing on a multitude of studies (her own research as well as secondary data), Ruth Kutalek tries to specify how cultural barriers may affect medical care. She demonstrates the importance of being attentive to cultural factors in administering health care, yet also puts forth an argument for interrogating structural constellations. Challenges associated with migrants accessing healthcare institutions are often attributed to cultural differences, while they actually stem from general problems on a structural level. For example, difficulties in physician-patient-communication are regularly ascribed to poor language competences on the side of the migrants. Yet, lack of communication due to time constraints is a reality in hospitals. It is not only testament to “migrant-specific” issues, but a general problem, which might be made more visible in cases where language differences come into play. Departing from a perspective of migrants as a special interest group, the author claims there are changes needed on a structural level, which the general public would benefit from and not only migrant patients.

Even though public debate often suggests otherwise, migration does not constitute a recent development in Europe. Rather, migration is a constitutive element of European history,

leading to what the author calls a “**multi-ethnic reality**” (p. 302, transl. AR).<sup>4</sup> In the text, Kutalek problematises the common preconception of “migrants” as a homogenous entity. She explains that the label “migrant”, whatever system of classification is used – according to national, social or ethnic background, according to time of migration etc. – always denotes a diverse set of people, many of whom the only thing they have in common is that they are considered a minority. Furthermore, experience of migration often interacts with other social dimensions, such as gender or age, thereby differentiating what is commonly perceived as problems related to migration.

#### *Access to health care institutions*

According to Bollini and Siem (1995), the approach to migrants by the Austrian health care system can be described as “passive”.<sup>5</sup> That is to say that migrants are expected to make use of services and access healthcare institutions, but this process is not thought to change the services and institutions themselves. Thus, there are no systemic answers to “multi-ethnic reality”, such as services tailored to migrants’ needs or efforts trying to reduce barriers migrants face. Kutalek proposes that insurance carriers as well as migrant communities and their representatives engage in common dialogue in order to find solutions for structural issues. To date migrant communities are seldom invited to such debates.

In Austria, people with experience of migration, who are trying to access health care institutions, are confronted with **social, economic, communicative and cultural barriers**. First of all, migrants are seldom specifically targeted by health care initiatives, preventive actions, rehabilitation measures or psychiatric-psychotherapeutic services. Many migrants experience a **higher bar when accessing health care institutions**. One reason is that they may lack information on how the institutions work and where to turn to with a specific ailment. Secondly, the general deprecation of migrants, which in many European countries is a social

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<sup>4</sup> Nevertheless, migration is also subject to time-specific dynamics, i.e. the fostering of the European Union, giving way to specific patterns of migration at a specific point in time, leading also to distinct ways in which migration and health interact.

<sup>5</sup> Cf. Bollini, Paola and Harald Siem (1995): No Real Progress Towards Equity: Health of Migrants and Ethnic Minorities on the Eve of the Year 2000. In: *Social Science and Medicine* 41/6, 825f.

fact, translates to the healthcare system, leading to both direct and indirect forms of discrimination.

*Knowledge about migration and health: lacking data – complex explanations*

Many European countries, Austria amongst them, produce very little data assessing migrants' health status, their access to health care institutions and health related behaviour. The same is true for many ethnic minorities living in Austria. What complicates the situation further is that individuals' health and state of well-being is dependent on **a multitude of factors, interacting in complex ways**. For example, poverty is a crucial factor influencing a person's health status. Risk of poverty is higher for migrants than for the Austrian population at large. Yet even when migrants and Austrian nationals from the same socioeconomic background are compared, migrants' health condition is found to be poorer.

Analysing diverse studies on migrants from different national backgrounds now living in Austria and Germany, the author reports inconsistent findings, making it difficult to extrapolate general statements regarding "migrants' health condition". In order to resolve these contradictions she pleads for specifically addressing migrants in health surveys and breaking down statistical results according to migrant status, which is not a common practice in all European countries.

Not relying on statistical data but on interactive accounts, Kutalek highlights the potential of anthropology for uncovering areas of conflict among different actors in the healthcare sector. Anthropological material lends itself to analysing the specific barriers migrants face in the healthcare system, but also helps with assessing whether challenges can be attributed to cultural, social or structural issues.

*Notions of the body: Norms of physical contact, expression of pain*

On the basis of research the author conducted on Turkish migrants' access to healthcare services in Vienna,<sup>6</sup> Kutalek states that cultural and religious ideas are commonly omitted

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<sup>6</sup> Kutalek, Ruth (2009): Türkische MigrantInnen und ihr Zugang zum Gesundheitssystem in Wien. Unpublished project report. Österreichische Hochschuljubiläumsstiftung.

from clinician-patient interactions and from the management of healthcare institutions. Yet, these ideas are highly relevant for medical practice. One need only think about **norms regulating physical contact**, which impact how the touching of a stranger – which is usually part of medical examination – is experienced. For example, shaking hands is a common way of greeting a strangers in Austria. While medical staff might try to reduce barriers by shaking the hands of their patients, this greeting ritual could increase discomfort among some patients. Devout female Muslims might feel uncomfortable touching a male stranger. Norms of physical contact bear on concepts of prudency and images of the body. Medical practice touches these norms and images in various ways: having an examination, being touched by a physician in the course of treatment (during anaesthesia, during surgery, during wound care), undressing etc. Moreover, **ideas of the body and its inner workings influence how we describe and express pain and suffering.**

During the study on access of Turkish migrants to healthcare services, Kutalek and her team observed the following encounter in a Viennese hospital:

*“A female patient who migrated to Vienna from Turkey goes to the hospital’s drop-in clinic. She points to her heart and explains to the physician: ‘There is fire.’ The physician misunderstands at first and thinks she is having heart trouble. When it becomes obvious that the patient feels misunderstood and she suddenly starts to cry, the physician proves to be very astonished and asks the project interpreter to translate. It turns out, the patient wanted to express she had a ‘broken heart’, which she is suffering from quite badly.” (p. 309, transl. AR)*

Kutalek explains that the expression of pain differs from person to person, yet at the same time it is subject to culturally specific ways of expressing oneself. Communicating pain and suffering epitomises cultural values and ways of interpreting the world. Viennese healthcare professionals are trained from a Western medicine point of view, thinking of pain as a local phenomenon. Other cultural traditions approach pain from a more holistic perspective, viewing pain as something that affects the entire body. Expressing and communicating pain hinges on fundamental cultural ideas, but also on things like language competence and opportunities a patient has to convey what is going on.

This is exemplified by a different account Kutalek portrays. She talks of a woman suffering from rheumatism, who is confronted with a different doctor each time she comes in for treatment. She experiences great difficulty in communicating her specific form of pain, starting from scratch each time, never being able to build on previous encounters and personal knowledge of her case by the doctor.

In a different qualitative study conducted in Vienna focusing on female Turkish migrants and their access to healthcare institutions, lack of verbal communication possibilities, what Kutalek calls “speechlessness” (transl. AR), between patients and staff has been identified as a major concern.<sup>7</sup> Not feeling able to adequately communicate is perceived as problematic not only by patients, but also by staff administering care. Differences in concepts of pain, norms of physical contact or indecency prove to be especially problematic, when patients and professionals find no appropriate way of communicating them. This **lack of mutual understanding** causes frustration on both sides.

*Conclusion: Disentangling social, cultural and structural barriers*

Kutalek contends that within the complexity of migration, health issues are often perceived to be based in cultural differences, while actually they are primarily caused by **structural problems**, for example a lack of an interpreter. In line with this argument, the author states that things like an experience of discrimination, time constraints or hierarchical hospital structures are much more powerful in shaping interactions in the healthcare context than cultural barriers could ever be. Thus, she suggests to be wary of explanations that enforce cultural difference while neglecting the heterogeneity of migrant patients.

Furthermore, the author proposes facilitating the recruitment of second generation migrants living in Austria to work in health care institutions as a measure of **mainstreaming diversity** in these institutions. Also, institutions should tap into the existing competences of their increasingly transcultural staff. Moreover, healthcare professionals as well as their educators at universities and medical schools should be trained in cultural sensitivity.

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<sup>7</sup> Cakan, Nursen (2007): Türkische Migrantinnen und ihr Zugang zum Gesundheitssystem. Master Thesis. Medical University of Vienna.

On a system level, Kutalek pleads for a change to an active approach towards migrants. This may include service providers issuing multilingual information brochures, development and expansion of interpreting services and services with a low-threshold. Yet, it also entails improving the social conditions migrants living in Austria find themselves in.

## **B. HEALTH AND INTERSECTIONALITY**

### *3. Using intersection theory to explore the multi dimensions of inequality and difference (UK)*

Written by Suki Rai

*Text reference:* Julie Fish (2008), “Navigating queer street: Researching the intersections of lesbian, gay, bisexual and trans (LGBT) identities in health research”. Sociological research online, 13(1), p.12.

#### *Introduction*

Health researchers have a tendency to emphasise the differences in health and health care from a heterosexual perspective and suppose similarities among lesbian, gay, bisexual and trans (LGBT). This approach does not take into account the experiences of disabled, black and minority ethnic (BME) and other marginalised groups. This paper looks at intersection theory and how diverse identities and systems of oppression can interconnect. **Intersectionality is simply looking at multi-dimensions of inequality and difference.**

The author uses **three concepts of intersectionality: methodological, structural and political** to explore how being lesbian may be permeated by class and gender and how racism and heterosexism intersect in the lives of BME men and women.

In early feminist analyses and theory, gender was considered as a general category in analysing oppression. Very little or no consideration was given to BME women, disabled women or

women from working class backgrounds. Intersection theory was developed to address the exclusion of black women from feminist theorising and research. This theory maintains that **gender and race are not to be analysed independently and cannot be just “added together”**.

The term intersectionality belongs to the work of Kimberlé Crenshaw. Crenshaw developed a metaphor from the notion of intersections in the US Road system:

‘Intersectionality is what occurs when a woman from a minority group... tries to navigate the main crossing in the city... The main highway is ‘Racism Road’. One cross street can be colonialism, then Patriarchy Street... She has to deal not only with one form of oppression but with all forms...’ (Crenshaw, K. (2001)).

Feminists have used the intersection theory **to look at the relationships between race, gender and class** in terms of (amongst other things) health.

This paper looks at the relevance of intersectionality as a tool to enable LGBT research and knowledge. The paper first examines the notion of assumed similarities and the ways that this has ‘homogenised’ LGBT communities and then explores how this differs with the intersectionality theory.

#### *Disrupting heteronormative discourses of the homogenous homosexual*

Early feminist research sought to identify women as a class and depicted differences only between men and women. In a similar way, early research has sought to look at how the health needs of the LGBT community differ from the health needs of the heterosexual community. It can be said that whilst similarities have been emphasised, differences have been obscured.

It can be said that, although there has been some success in identifying the LGBT group as a social category, inter-group differences such as race, disability and age, have been ignored.

#### *How does intersection theory differ from other approaches in LGBT sociological theorising?*

Queer theorists seek to deconstruct identity categories. They argue that experiences do not fit neatly into a single category. This can be illustrated by the natural attitude towards gender

supposing it unchanging, hence you will always be one or the other. Trans people will place themselves outside of this category and challenge the fixed gender categories. Queer theory aims to deconstruct identity categories and by doing so aims to challenge inequalities.

The author considers three categories of intersectionality: **methodological, structural and political**. These categories will be discussed in more detail below.

#### *Methodological intersectionality*

The author argues that most of the research on gay men or lesbians is still conducted with mostly white, middle class, young and able bodied participants. This can be attributed to homogeneity of the samples collected.

In the most commonly used **frames for sampling** the general population in the UK do not identify households whose occupants are lesbian, gay, bisexual or trans (in the electoral register or in the postcode file, for example).

As LGBT researchers do not have access to the random sampling method, they have adopted innovative ways in which to facilitate diverse groups within LGBT research. Martin and Dean (1993) showed that the population of gay men recruited through a public health campaign were different to that obtained through other sources. This sample was younger, had lower incomes and were predominantly African-American or Hispanic. These men were less likely to be part of or members of gay groups or organisations.<sup>8</sup>

In Hickson et al (2004) the recruitment method demonstrated the significance of targeting particular demographic groups.<sup>9</sup> This study used three sampling methods, Pride events, booklets and online. Men who were less educated were more likely to use the booklet – this method attracted Black and Asian men. White ‘other’ (i.e. non British) men were more likely to use the Pride events and British men were more likely to use the internet.

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<sup>8</sup> Martin, J. L., & Dean, L. (1993). Developing a Community Sample of Gay Men for an Epidemiological Study of AIDS. In C. Renzetti & R. Lee (Eds.), *Researching Sensitive Topics* (pp. 82-99). Newbury Park, CA: Sage Publications.

<sup>9</sup> Hickson, F., Reid, D., Weatherburn, P., Stephens, M., Nutland, W., & Boakye, P. (2004) HIV, sexual risk, and ethnicity among men in England who have sex with men. *Sexually Transmitted Infections*, 80 (6), 443-450.

Similarly, lesbian health research has relied on self-identification. However, many BME LGBT people may not use the term lesbian or gay to describe themselves, and consequently are not included in research. To get around this, health researchers have devised multiple definitions of sexual identity including **desire, behaviour and identity**. These inclusive definitions are believed to encourage the participation of underrepresented groups.

### *Structural intersectionality*

Crenshaw describes structural intersectionality as the ways in which ‘the location of women of colour at the intersection of race and gender makes our experiences... qualitatively different from that of white women’ (1993:1245). Structural intersectionality considers **patterns of social inequality**.

In this section the author seeks to consider how racism and heterosexism work together to reinforce inequalities. The author uses three examples to illustrate this

1. How the experience of coming out may differ for a black gay man
2. How a lesbian’s class position may affect her experience of being lesbian
3. Inequalities in mental health and how they may differ within LGBT communities.

### *Identity formation and coming out in black and white LGB communities*

Coming out refers to two exceptional experiences, acknowledging one’s identity to oneself and telling others that one is lesbian, gay or bisexual. Public acceptance indicates psychological health and self-esteem. Literature on identity formation and coming out is extensive, however again, it relies on a white, western conceptualisation.

Someone who is BME and LBG will be less likely than their white counterpart to be open about their sexuality. Literature around identity formation and coming out do not consider the ways in which BME experiences can differ. Coming out may have different implications and the decision to adopt an overtly gay identity may be viewed as a repudiation of one’s ethnicity (Green, 2003).

### *Lesbians’ classed positions: white working class and middle class lesbians*

Heteronormative discourses constitute LGBT people as middle class and insulated from health inequalities experienced by other social groups. These assumptions have contributed to the erasure of white working class lesbians from research.

#### *Experience of mental health in LGBT communities*

There is growing concern about mental health issues in LGBT communities. **Very little is known about how health needs differ within LGBT communities.** An intersectional approach would be concerned with how and why LGBT people from BME communities have different experiences of mental health. More research is needed to look at the impact of racism and homophobia on BME LGBT mental health in the UK. In Diaz et al.'s (2001) study of the health of gay and bisexual Latino men, many men reported the experience of racism within the gay community.<sup>10</sup>

#### *Political intersectionality*

The author conceives political intersectionality as **political organising** (within social movements) and **political processes** (adopted by governmental and other organisations). Therefore, questions for consideration include:

How can knowledge produced about multiple inequalities contribute to tackling discrimination?

What are the political costs and barriers to producing such knowledge?

The author's discussion focuses on the extent to which politically relevant and recognised institutions are in place to address LGBT inequalities; the absence of statistics for sexual identity; and the degree to which LGBT concerns are represented within political processes.

Among LGBT communities in the UK we do not know how many LGBT people live with children, what kinds of jobs they do, or where they live. There are only estimates about the size of the LGBT population in the UK.

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<sup>10</sup> Diaz, R. M., Ayala, G., Bein, D. E., Henne, J., & Marin, B. V. (2001). The Impact of Homophobia, Poverty, and Racism on the Mental Health of Gay and Bisexual Latino Men: Findings from 3 US Cities. *American Journal of Public Health*, 91 (6), 927-932.

The degree to which LGBT concerns can be represented within political processes is constrained by the lack of infrastructure support for the LGBT voluntary and community sector.

### *Conclusion*

This article looks at the intersection theory and how diverse identities and systems of oppression can inter-connect.

The focus of the article is on health research and looks at whether **multi dimensions of inequality and difference are considered when researching LGBT health inequalities.**

It looks at previous attempts by early feminists to address inequalities between men and women. These early feminists identified women as a class and failed to recognise dimensions such as race, age, class and disabilities.

Similarly, with LGBT research, researchers have failed to consider a multi-dimensional approach by merely comparing heterosexual and LGBT experiences.

The article encourages you to look at the methods by which you collect data when conducting research. For example, the author argues that most of the research on gay men and lesbians is still conducted with mostly white, middle class, young and able-bodied participants. We should look at how we collect data and use different methods to encourage participation from diverse groups.

It also looks at definitions of sexuality. BME LGBT participants may not self-identify as LGBT. **We should use multiple definitions including desire, behaviour and identity to encourage participation and be more inclusive in our approach.**

**Structural intersectionality needs to be considered when looking at LGBT health inequalities.** This particularly relates to the relationship between heterosexism and racism. Consideration needs to be given to how BME LGBT experiences differ from that of their white counterparts. Consideration needs to be given to the following:

- 'Coming out' is different in BME communities. Someone who is BME and LGBT will be less likely than their white counterparts to be open about their sexuality.
- Research assumes a middle-class position for LGBT communities, this fails to recognise other social groups and this excludes their experiences.
- There is very little research on BME LGBT and the impact of racism and homophobia.

Political Intersectionality describes how political structures can be a barrier to research methods. It looks at the collection of data at a national level. In the UK for example, there is very little data that is collected for the LGBT community. There are only estimates for the size of the LGBT population in the UK.

It is important to be mindful of intersectionality when considering health inequalities. This paper encourages the reader to look at the multi dimensions of inequalities and difference.

When we look at health inequalities and health needs, we need to consider that within each social category, such as LGBT, we must take time to consider the inter group differences such as race, disability and age. These differences cannot be ignored as it is essential to consider racism, ageism and varying abilities within the context of homophobia for example. Only then will we begin to have **a better understanding of health inequalities and barriers to accessing healthcare.**

*Further reading:*

- Greene, B. (2003) Beyond heterosexism and across the cultural divide - developing an inclusive lesbian, gay and bisexual psychology: A look to the future. In L. Garnets & D. C.
- Kimmel (Eds.), Psychological perspectives on lesbian, gay, and bisexual experiences. New York, NY: Columbia University Press.

- Crenshaw, K. (2001) Mapping the margins: Intersectionality, identity, politics and violence against women of color. Paper presented at the World Conference Against Racism. Available at [www.hsph.harvard.edu/grhf/WoC/feminisms/crenshaw.html](http://www.hsph.harvard.edu/grhf/WoC/feminisms/crenshaw.html)

#### 4. *Elderly ethnic Danes' and immigrants' use of public care services (DK)*

Written by Margit Helle Thomsen

*Text reference:* "Ældre danskeres og indvandreres brug af pleje- og omsorgsydelser ("Elderly ethnic Danes and Immigrants' use of public care services") by Hansen, Eigil Boll and Siganos, Gallatios, KORA, The Danish Institute for Local and Regional Government Research (at the time of publication: The Research Institute for Counties and Municipalities), Working Paper, 2009, pp 1-35

##### *Introduction*

Elderly people who emigrated from non-Western countries, account for an increasing number of the old population in Denmark. They will increase in number and also constitute a growing proportion of the elderly population, equivalent to a quadrupling by 2030.

These demographic and sociocultural changes raise the question about the consequences for the public sector and the demand and distribution of welfare state benefits. One of the key issues is whether elderly immigrants' lifestyles and living conditions imply that elderly immigrants either make less or more use of social and healthcare services, compared to elderly ethnic Danes. This working paper describes the key findings and conclusions from a comprehensive Danish research on this issue.

##### *Purpose*

The purpose of this research was to examine and analyse whether older migrants are using public services to a greater or lesser extent than elderly ethnic Danes. The study primarily focused on elderly immigrants of non-Western origin, but also involved data on immigrants from Western countries. The total population included people aged 65 or over, residing at that time in the City of Copenhagen on January 1<sup>st</sup> 2007.

The study included three main areas of public and municipal healthcare and social services for elderly citizens:

- Personal care services
- Practical assistance
- Care homes

**Personal care services** include in the Danish context support for personal care needs at any time of day, for example help to get out of bed, personal wash and body care, help to get to bed, medicine etc. From a cost perspective, this implies that care in the evening and night hours are more expensive than care in the daytime.

**Practical assistance** includes support for cleaning, laundry and shopping etc. From a cost perspective, the price related to these benefits would be calculated at a price per allocated number of hours. The category **care homes** covers a range of different types of housing for elderly citizens. This applies for instance to sheltered housing & care homes for people with special needs in relation to diseases, for example special housing for people with dementia etc.

In this research, the three categories were examined separately, but they were also assessed as an overall expression of elderly people's use of healthcare and social care services.

#### *Theoretical-methodical approach and data sources*

With a departure point in these specific healthcare and social services, the research and analysis was based on a specific model framework, called "behavioural model of health service use". By using this model, the researchers gained insight into factors *other* than ethnicity that may explain a particular pattern of use in relation to healthcare services. Thus, the model focused on a number of explanatory variables on the individual level:

- Predisposing variables such as gender, age, education and ethnicity
- Variables that may either increase or decrease the use of public service, such as income, alternative care options instead of public services
- Needs-oriented variables such as individual health indicators

These individual variables were transformed into a number of variables in regression analysis in order to illustrate the extent to which ethnicity and immigrant background actually affected the consumption of public healthcare services. The researchers hereby operated with both

dependent and independent variables. The categories for municipal healthcare and social service would be the dependent variables and the independent variables would refer to factors dealing with ethnicity.

Thus, the elderly citizens in the population were divided into 1) ethnic Danes, 2) immigrants from a Western country with less than 10 years of residence in Denmark, 3) immigrants from a Western country with more than 10 years of residence in Denmark, 4) immigrants from a non-Western country with less than 10 years of residence in Denmark and finally 5) immigrants from a non-Western country with more than 10 years of residence in Denmark.

Furthermore, the researchers controlled a wide range of variables that may influence the need and use of public healthcare services. These variables would include the demographic, socio-economical and educational data, marital status, family, the fact of living alone or cohabiting, hospitalization of different lengths etc. In total, the data sources combined institutional data extractions from municipal registers and national statistics, including:

- Data on the individual use of personal care services, practical assistance and care homes within the total population. This data was provided for the research from registrations and data registers on care and institutions in The City of Copenhagen.
- Data on demographic information as well as data on education and occupation from Statistics Denmark
- Data on use of health insurance and number of days of hospitalisation from the National Health Insurance Service
- Through a series of regression analyses, the explanatory factors were investigated for their significance and insignificant factors were gradually excluded. The final estimates only consisted of explanatory factors with strong significant correlation with the dependent variables, i.e. the investigated healthcare services.

In summary, the analysis of the combined variables and data sources were carried out either as simple logistic regressions or linear regressions. This methodical approach made it possible to determine the significance in terms of use of services and background. Furthermore, the

methodology provided the possibility to correct differences and other factors which may affect the comparison and results, thereby leading to erroneous hypotheses and conclusions.

### *Key findings*

The analysis revealed a long list of differences in the use of healthcare services among immigrants, as compared with ethnic Danes. Some examples:

- Background and long-term residence as an explanatory factor

The general use of the investigated healthcare services would differ quite significantly between the population groups at the time of research. Thus, 40% of the ethnic Danes were using one of services in the investigated year compared to 14 respectively i.e. 18% of non-Western immigrants with more than 10 years of residence.

It is worth noticing that the Western immigrants with more than 10 years of residence would be much closer to the Danish pattern. This may indicate that the combination of Western background and long-term residence may influence the use of public healthcare for elderly people. However, the same trend was seen to a lesser extend among non-Western immigrants of more than 10 years of residence.

- Knowledge about healthcare services as an explanatory factor

As shown, the lowest frequency of use was seen among non-Western immigrants with less than 10 years of residence. This could indicate a reduced need and demand despite the fact that all the population groups belonged to the same age groups. Another explanation may be the lack of knowledge about the Danish welfare system and public benefits. The shorter the residence is, the less the knowledge immigrants may have of the system and its benefits. This may also include the lack of knowledge on accessibility and procedures etc. Furthermore, cultural-institutional differences between the Danish system and the health systems in the countries of origin may be quite significant in terms of the nature, extent and access in relation to public services for elderly citizens. Finally, linguistic and communication issues may probably play an important role in the use of services.

- Family-based care as an explanatory factor

Apart from knowledge, the analyses suggested that elderly non-Western immigrants would rely more on the family's support, especially in the first years of immigration. The results may also indicate that patterns of use over time are adapted more and more to a Danish pattern. It may reflect the fact that awareness of public healthcare services has increased. But it can also show that immigrants increasingly adapt to a Danish lifestyle where generations live apart, and where especially women's fulltime employment makes it difficult to pursue more traditional family-based lifestyles.

- Age as an explanatory factor

Immigrants of non-Western origin with more than 10 years of residence in Denmark are the largest group after the ethnic Danes in the population, but this group of non-Western immigrants would also in average be younger than the ethnic Danes. Their proportion of under 70 year olds was higher and their proportion of over 80 year olds considerably less, compared to ethnic Danes.

- Household as an explanatory factor

The proportion of citizens living alone was significantly lower among non-Western immigrant with more than 10 years of residence than among all the other groups. This may be surprising considering the fact that the non-Western immigrants generally were younger than the other groups, but it may also indicate less need for public care.

#### *Summary of research results*

In summary, the research gave rise to the following results:

- At the time of the research, elderly immigrants received the investigated services less frequently than ethnic Danes within the age group from 65 and over. This applied both generally to all services in total and specifically for each of the investigated types of services.
- In terms of domiciliary care, the **practical assistance component of care** and assistant services used tended to be less for elderly immigrants than for elderly ethnic Danes. This indicates that a greater proportion of the practical assistance were met from other sources among elderly compared to ethnic Danes.

- In terms of **personal component of care services**, it turned out that elderly immigrants would not be using these services significantly less than elderly ethnic Danes. Furthermore, elderly from non-Western countries with a long-term residence in Denmark would actually receive a greater volume of personal care services than elderly ethnic Danes.
- Finally, **the time factor related to duration of residence** obviously played an important role for the use of healthcare and social service. Thus, immigrants who lived in Denmark for more than 10 years, would more frequently receive public care and assistance services than immigrants with a shorter residence time in Denmark.

### *Conclusion*

The research results do not provide a full explanation of the differences observed between elderly immigrants and elderly ethnic Danes in terms of the use of municipal healthcare and social services. However, some of the key findings would certainly indicate that 2 factors are particularly influential in relation to the use of these services:

Firstly, the mere **knowledge of the availability of these services** seems to be of major importance for the patterns of use. Thus, the longer the residence in Denmark, the more closely the elderly resembled the elderly ethnic Danes in their pattern use.

Secondly, **the tradition to undertake care of elderly family members** within the family frame also seems to be very important for the use – or rather non-use - of public healthcare and social services for elderly citizens.

By linking these trends, it can be concluded that in terms of the usage of public healthcare and social services among elderly people, the long term residence may in several respects affect the usage and thereby also the lifestyles. Knowledge and overview of available services is built over time for newcomers. However, at the same time, general socio-cultural and socio-economic conditions have a great impact on the pattern usage, while traditional family patterns are difficult to maintain. This especially includes the socio-cultural and socio-economic tradition where female family members stay at home in order to take care of the

family in general, and in particular the elderly family members. In the Danish context, immigrant families need an earned income from both male and female family members. This condition increases the need for using public care services for elderly family members, thus speeding up the process of change in lifestyles and adapting to a Danish usage pattern in relation to public services.

One may conclude that there is a strong need to disseminate knowledge about the Danish welfare system – and of the specific benefits for elderly citizens – among immigrant families. At the same time, it would be important to enhance the intercultural understanding among healthcare and social professionals concerning the lifestyles, needs and expectations found among immigrant families in general, and among elderly immigrants in particular.

## 5. *Women and mothers: Meaning of their vulnerability in migration flows” (IT)*

Written by Alessandra Cannizzo

*Text reference:* “Donne e madri nella migrazione” (Women and mothers in migration) by Viapiana, S., *Antrocom Online Journal of Anthropology*, 2011; 7:1+, pp. 83-91.

### *Abstract*

In recent years, the role of women in migration flows has also become crucial in terms of structural changes in the migrant communities. The new setting leads them to rethink their traditional values and norms when confronted with the different concepts, ideas and organizational structures of the host country, in terms of an understanding of the body and organization of the social and health systems, etc. Migrant women are particularly affected by such re-signification and negotiation processes, especially as far as motherhood, marital relationships and bodily rituals (e.g. infibulation) are concerned.

### *Introduction*

The paper by anthropologist Stefania Viapiana presents an interesting analysis offering practical examples on how some corporal practices and lifestyles vary according to the country and culture of the origin of the people. Firstly, the author introduces the concept of “double transit”, understood as the challenging situation experienced by the migrant woman who finds the values and norms of the host country different from hers, but also has to deal with the values of her culture of origin. Secondly, the author analyses the new challenge for migrant women fighting for autonomy from the authority of the husband in the new social context. References to eminent experts are offered in the text in an attempt to clarify some aspects of gender identity and to shed light on the meaning of practices of “female genital modifications”, taking up some cases for reflection. In the case of gender identity, some facts presented by the experts underline how in certain cultures the superiority of the man is

perceived as a natural and biological matter, an idea which is greatly shared and actively contributed to by women themselves. The topic of female genital modifications is analysed through several examples indicating such practices as rituals that are preserved by women as part of the local tradition. Finally, a set of studies is presented, which highlights how some traditional practices become challenging for those women who are living as migrants in contact with Western populations.

*Double transit of migrant women and aspects of ethno-psychiatry*

The author offers an overview of research, including recent anthropological contributions, focusing on individual identity crisis experienced by migrants, and on the risk of overlooking gender identity issues in such contexts.

A study by Levinson and Beneduce (2004) has shown that societies with lower incidences of violence against women are those where there is an efficient division of power between genders. Based on these results, the author states that conflicts arising after migration events are the outcome of changes experienced by the couple, which is modified by new life conditions. Therefore, the original idea proposed by Viapiana is that the migrant woman is fighting a new enemy that is the authority of her husband for the conquest of her autonomy in the new social context.

Detailing the novelties introduced by the new setting where the migrant woman is living, the text further clarifies that the cultural identity of the woman becomes even more difficult with no support from family or from the parental group. Part of these difficulties is the fact that she is not able to resort to some of the rituals of the origin country, a circumstance that often causes psychological disorders. Many examples are related to childbirth, for instance as to the protection of the baby from demons (e.g. djinn in the Maghreb region) or special food and hygiene habits for both the baby and the future/new mother. According to Ba, it is possible to define such ceremonies as real “transition rituals” (Ba, 1994, pp. 59-72) aimed at appeasing the fears and anxieties of the woman who has just given birth and decreeing the arrival of the baby in the group.

Viapiana offers her point of view on a “double transit” phenomenon, occurring when migrant women are “confronted by the novelty of the values and norms of the host country, whilst also being painfully removed from the values and practices of their culture of origin” (Viapiana, 2011, p.86, translated).

### *Gender identity and gender conflicts*

In the second part of the publication the author expands on the theories of gender identity and gender conflicts elaborated by a range of experts and researchers, with the aim of providing a theoretical background to the explanation of cultural practices involving the body of migrant women in Western society. The anthropological theories and studies presented offer an overview of the social and cultural construction of the identity of the woman as inferior to men, symbolically and practically. The unequal relationship between men and women is also represented in the different concepts and practices around the body of the woman and her characteristics perceived as inherent “natural” handicaps, such as fragility, less weight, less stature, pregnancy and breastfeeding (Nahoum-Grappe, 1996; Héritier, 2002). In these regards, Héritier argues that the concept of otherness started from something seen as interrupting the world’s harmony, maybe a transgression (she recalls the notion of lost paradise). For instance, Western African mythology holds that women and men used to live in separate and independent groups and were able to reproduce autonomously. Afterward, the discovery by men of women’s body as a source of pleasure and not related to reproduction, offended the creator divinity, which therefore forced men and women to live together. This tradition is not an isolated case as many cultures worldwide have myths where women give birth without any male contribution and are rather fecundated by natural elements (wind, sea) or by parthenogenesis.

Moisseff (1997) proposes another interesting example by stressing how the relationship between settlers and colonised populations, and in general between dominators and dominated people, has an impact and relevance especially in the spheres of sexuality, body, reproduction and gender roles. The author links the conflicts related to gender to the

resistance that the developing economies oppose to the increasing cultural hegemony of more economically developed countries.

*Infibulation, abscission, identity: the marks on the body*

This section of the paper examines the reality of the corporal practices exercised on women's bodies, supported by some examples from different cultural traditions. Systems of signs, mythic and ritual customs focusing on the body of the woman and her sexuality are widely present in several societies. Viapiana stresses the prevalence of such processes controlling the reproductive sphere of the woman, and carrying a wide range of meanings and purposes, for instance purification, marking the passage from childhood to womanhood, or reinstating harmony and social order in contrast with the disorderly female body.

Female genital modifications are practices that could be found since before the emergence of the major world religions (Islamic, Jewish and Christian) and are a persisting ritual for the maintenance of power relations among dominant and subordinate cultures. Different rituals related to such modifications exist in different societies (Ethiopia, Saudi Arabia, Somalia, Egypt and Sudan), where infibulation prevails in order to control the sexuality and virginity of women. Sometimes, it also has the meaning of purification or is intended as the removal of a remotely-masculine body part (the clitoris) to force the female child into the "correct" sexual category (e.g. the Dogon tribe in Mali, studied by Griaule in the 1930s). Through such examples and studies, Viapiana underlines how the integrity of the body, can be listed among one of the most challenging values when it comes to the encounter of different cultures. Different rationales exist for marking the body (e.g. the regulation of power dynamics, as stated by Augé, 2002), which convey different meanings and certainly influence the psyche of the "marked" woman. The experience of infibulation is hardly revealed by migrant women; however, as the author stresses, they refer to it as a fundamental experience in their life, necessary to comply with aesthetic standards of beauty of the female body in their culture of origin (Fusaschi, 2003).

Viapiana emphasises the deeply conflicting values of Western and other societies surrounding female genital modifications, a conflict that migrant women from infibulation-practising countries are bound to experience in the host country.

Van der Kwaak, (1992, pp. 777-787) remarks that for instance in Somalia chastity and the control of female sexuality are deeply linked to the definition of female identity itself. In this context, infibulation has an initiation value that is expressed by both the ritual and the language used, in fact, before the surgery a girl is called gabar (“small girl”), whereas after she becomes qabar dhoocil (“infibulated girl”) and therefore “a marriageable girl” for whom the future husband will have to pay “the bride’s price”. In addition to that, the fact that girl’s hair gets shaved makes even more explicit the initiation meaning of the ritual.

### *Conclusion*

The current immigration system introduces some challenges in the everyday life of those who flee their countries, as well as in the life of the population in the receiving countries. Undoubtedly, women are the most vulnerable in these processes, first and foremost because they are mothers and because of the different meanings attached to their bodies. As supported by Viapiana through several references to a number of studies, migrant women are called to face a “double transit”, as they must confront both the values and norms of the host country, while having to deal with the values of their culture of origin.

On the one hand, the author offers in the text a critical understanding of different practices surrounding the female body in cultures other than the Western. On the other hand, she shows a great distance between the values of the migrant communities and those of the host countries (although with some commonalities, such as the binary conception of female and male), underlining an even greater difficulty for migrant women to negotiate between dominant values in their culture of origin and of those in the receiving society. To conclude the author provides food for thought allowing the clarification of the role of women in societies affected by migration. Given the variety of examples and the diversity of the authors

cited, the text is an accessible introduction to the challenging aspects of cultural diversity related to health.

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## C. CULTURAL AND SOCIAL VARIATIONS IN EXPERIENCING HEALTH AND SICKNESS

### *6. Stabbing pain? A burning heart? Cultural variations in the experience of pain (AT)*

Written by Agnes Raschauer

*Text reference:* Kohnen, Norbert (2009): Feeling and coping with pain in different cultures. In: Ruth Kutalek / Armin Prinz, eds. Essays in Medical Anthropology. The Austrian Ethnomedical Society after Thirty Years, p.321-328. LIT Verlag GmbH: Vienna.

#### *Introduction*

Generally, the experience of pain is either thought of as something purely individual or connected to biological processes that affect all human beings in a certain way. Thus, some people seem to have a high threshold for pain, while some people seem to have a lower one and might be considered oversensitive to pain. However, how humans experience pain and make sense of it, is not only subject to their individual tolerance level or simply given on the basis of biochemical reactions. Rather, experience of pain hinges on social ways of making sense of the world, which affect how bodily sensations are interpreted. In his paper, Norbert Kohnen delineates **cultural variations in** the concepts that underlie **the experience of pain**. Reviewing anthropological research, he gives a vast number of examples of how pain is experienced and processed in a culturally specific way.

Being unaware of variations in how pain might be felt and expressed in different cultures can have negative effects for a medical practice, for example when a doctor thinks that a patient is not in pain when actually what happens is that the patient's experience does not fit with the doctor's preconceived ideas about how pain is felt.

*Anthropologies demonstrating cultural variations in the experience of pain*

Kohnen explains that while there are few cultural variations in the “*sensation threshold* [...] the lowest stimulus that results in tingling or warmth” (p. 321), the ***pain threshold*** is found to be highly variable. A very illustrative example is by Hardy et al. (1952), who reports that heat levels considered painful are experienced quite differently by people living in the Mediterranean and people living in Northern Europe. Heat levels the former define as “warm” are considered painful by the latter.<sup>11</sup>

The author further refers on the ground-breaking work of Mark Zborowski (1951, 1969)<sup>12</sup>, who established that not only experience and expression of pain are highly variable and subject to culturally specific interpretations of the world, but also how communities deal with suffering members. He carried out anthropological research (interviewing, handing out surveys and doing observations on-site) in a veteran's hospital ward, focusing on four patient groups: Irish Americans, Italian Americans, Jewish Americans and Old Americans. Zborowski concluded that while Irish American patients hardly talked about their pain and withdrew in isolation, Italian Americans tended to be quite outspoken about their suffering and in need of social contact. He also reported different approaches to pain in terms of how much weight a patient put on the fact that he was in pain and how much he trusted his own experiences.

#### *“Cultural coping strategies”*

Within anthropology the ways of handling pain that cultural communities develop are called “**cultural coping strategies**” (p. 323). These strategies build upon knowledge and traditions that have been passed down from previous generations and have long informed social practices of dealing with disease, pain and healing. They entail culturally accepted scenarios showing individuals how to act in the advent of pain and how to make sense of it. The “**control beliefs**” a cultural group holds on to be especially relevant for developing specific coping strategies. While the British, the Irish or people from Northern Europe are characterised as

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<sup>11</sup> Hardy, James Daniel, Harold George Wolff and Helen Goodell (1952): *Pain sensations and Reactions*. Baltimore: Williams & Wilkins.

<sup>12</sup> Zborowski, Mark (1952): Cultural components in responses to pain. *Journal of Social Issues* 8: p. 16-30. Zborowski, Mark (1969): *People in pain*. San Francisco: Jossey-Bass.

individual-oriented, with a tendency for an internal control belief, the Italian or the Turkish society are described as family-oriented with a tendency for an external control belief. This means that the former tend to focus on the individual when dealing with pain, keeping feelings inside and opting for social retreat. The latter, on the other hand, prefer the company of family members when suffering and also devise communal strategies for handling pain.

Kohnen describes five distinct coping strategies and attributes each to an “ethnic and religious group” that it is characteristic for, while stressing that “all named strategies will be found proportionately within every culture” (p. 323). Among others, Kohnen names ***fatal strategies of coping with pain*** which entail attributing the ending of pain to a higher entity. As a consequence, the suffering individual has little obligation to act, i.e. to seek a doctor and to do “the right thing” in order to alleviate suffering. Sometimes magical practices are carried out which may have an impact on how the pain is experienced. ***Religious treatment of pain***, customary e.g. among Christians or Buddhists, on the other hand conceptualises pain as a trial an individual has to endure in order to demonstrate his/her faith. A third concept is a ***rational treatment of pain*** in which pain is examined, attributed to a specific body part, monitored and subjected to professional medical treatment. An emotional approach towards pain seems out of place.

*Conclusion: Attention toward cultural variations in experiencing pain needed in medical practice*

Kohnen argues that treating pain as a universal, single phenomenon is detrimental to quality care. Patients might express their experience of pain in various ways: by retreating, by rationalising, by crying and demonstrating emotional distress. No one expression of pain is more valid or more indicative of a true suffering than the other. Holding on to the idea that the experience of pain and even the pain itself, as communicated by the patients, has to manifest a certain way, leads to misunderstandings, frustration and maybe even maltreatment of the patients' conditions. “Every patient is an informant, but not every informant is a good one. Whether or not a patient is a good informant really depends on the

examining doctor and how well they understand their patient and how well they are able to broaden the horizons and experiences of the informant.” (p. 326)

7. Perception of and reaction to the “Chagas” disease in a non-endemic Country: A Multidisciplinary Research, Bologna, Italy (IT)

Written by Alessandra Cannizzo

Review of “La malattia di Chagas in un paese non endemico: il contesto bolognese. Analisi multidisciplinare della malattia e del fenomeno migratorio” (Chagas Disease in a Non-endemic Country: A Multidisciplinary Research, Bologna, Italy.) by Di Girolamo, C., Marta, B.L., Ciannameo, A., Cacciatore, F., Balestra, G.L., Bodini, C., Taroni, F., *Annali di Igiene*, 2010; 22:1

Available in English at *Journal of Immigrant and Minority Health*, 2016. 18(3), pp. 616-623.

*Abstract*

After the substantial change in the epidemiological landscape of Chagas disease, Italy appears to become the second non-endemic area in Europe in terms of Latin American migrants and expected infection rate. The Bologna University Teaching Hospital has undertaken a cross-sectional study in association with an ethnographic research. Comparing the results of the study with previous studies in non-endemic contexts, the researchers were able to identify subjective perceptions of Chagas disease and other significant ill-health experiences in a sample of Latin American migrants in the Emilia Romagna area. Perceptions are important because they impact on possibilities of prevention and cure.

*Introduction*

Through the information collected in the introductory phase, the research aimed to frame the Chagas disease by analysing its origin and dissemination in non-endemic countries. The parts of the population most affected by this disorder are commonly found in rural areas and some authors emphasise the social distance, describing it as “forgotten populations”. Chagas disease is strongly related to poverty and rurality, and the consequences of this stigmatization

is the discrimination in the labour market and moreover the spreading of the disease in non-endemic countries linked to the migration of disadvantaged people looking for better life conditions. Studies conducted by distinguished organisations show that the Chagas disease affects seven to eight million people worldwide. The authors state that, considering the global processes of migration of disadvantaged people in the last decades, Chagas has affected non-endemic areas such as North America, Europe and the Western Pacific Region. The research paper highlights the lack of information on the subjective perception of the disease, which is due to the uncertainty of migrants related to their challenging life conditions, in fact, they often experience more urgent health needs and encounter multiple barriers in accessing healthcare services. The following study conducted by a pool of medical experts, for the first time in the Emilia-Romagna region, aims to provide preliminary data on the Chagas disease and goes into the subjective perceptions of the malady in the context of the new migration flows. In order to analyse the presence, and the subjective perception related to such disease, the project uses a social epidemiology approach, which allows the elaboration of prevention strategies and cure of the affected individuals.

### *Methodology*

In the second section of the paper, the authors explain the methodology they have applied in the study. The cross-sectional study run within the Bologna University Teaching Hospital has included a diversified group of physicians, microbiologists, public health doctors and medical anthropologists. In a broader sense, the project aimed at contributing and promoting the right to health amongst the Latin American population, which - due to the migration experience - is more exposed to socio-economic factors negatively affecting their health condition. As a result, an illustrated multilingual leaflet was co-created with a group of Latin American migrants in order to disseminate the information about the disease and the diagnosis and management service offered by the hospital.

### *Participant selection and data collection*

The authors guide the reader through the full process of data collection carried out through questionnaires and interviews with a group of at-risk people, identified as Latin American

migrants present in the region. All the information collected was reported in a research diary and the results presented for the period (November 2010 - May 2013) were taken through Chagas-disease testing which was free of charge for at-risk people who attended the service for any clinical reasons and for those who asked for it after being reached by the information campaign. From an anthropological perspective the study also dug into the specific historical and socio-cultural features of the migration flows from Latin America in the Bologna area and put these in connection with the subjective perception of the disease.

#### *Data Analysis*

The ethno-anthropological research started first with a mapping of the various gathering forms and places frequented by the Latin American population. The authors specify that one of the main advantages in this phase, but also in the entire research, was the multidisciplinary approach applied. A descriptive analysis of the quantitative variables and the qualitative data investigation were conducted throughout the study. The analysis was refined at the end of the fieldwork when meaningful contents were examined and interpreted.

#### *Research results in the Bologna area*

The results obtained pertain to the quantitative analysis, which shed light on the social background of the disease. 151 individuals were screened of which 94.7% adult Latin American migrants arriving from endemic areas, 3.97% adopted children and 1.32% Italian travellers. The research results show that migrants originating from Argentina, Bolivia and Brazil were more aware of the disease; while Peruvian and Ecuadorians, who represent 40% of the sample along with people coming from Central America, Colombia and Venezuela, had no or limited knowledge about the disease. The ethnographic research conducted revealed how a better social position facilitated the integration with the Italian healthcare system and also proved that tough work and challenging life conditions highly affect the perception and the knowledge of the disease. The ethnographic research also revealed a rather complex situation in terms of the influence of migration patterns on ill-health experiences. For example, a small group of migrants (mainly women) from Brazil, Argentina, Colombia and Chile who had moved to Italy for political reasons and had married Italians showed better health conditions linked

to better integration in the social context, higher social status, and easier access to healthcare and other resources. The various stakeholders interviewed pointed out how participation in the research project could be beneficial in developing new tools for social inclusion through the creation of a network to discuss important issues for migrants, such as jobs, bureaucracy and legality. Indeed, the mapping activity has had the awaited effect of promoting the creation of a dynamic local network of actors directly or indirectly linked to Latin America.

#### *Comparison with previous research and insights*

Through a series of comparative research, the authors provide a more complete analysis, from both the medical and social point of view. In the subgroup of adult Latin American migrants, the overall prevalence of Chagas disease was 8.39%. The percentage is similar to that reported in Switzerland and elsewhere in Italy, but lower than that found in Barcelona. Another comparable data with previous reports is that Bolivians appear to be the most affected group, especially because of the challenging life and work conditions they experience. The authors state that it is widely recognised that older Latin American migrants are exposed to a higher risk of infection than younger people, mainly due to the progressive implementation of control programmes in endemic countries. In non-endemic countries such as Italy, the study confirms in the findings of the previous research risk factors and behaviours associated with the affliction. Chagas disease is confirmed as an issue in the local context where the research was carried out. One of the outcomes was the recommendation to work on rights broadly speaking, and in particular on the right to health, paying attention to all socio-economic and political factors not strictly related to the health sector.

#### *Conclusion*

The data collected from the presented study allowed the authors to evaluate the social aspects of Chagas disease in Italy, as well as to identify potential ways forward to improve the approach to the disease. The paper shows that the awareness around the disease was rather mixed among Latin American migrants who participated in the study. Most of the Chagas-affected individuals knew about the affliction, through family or direct experience and through media campaigns carried out in their country of origin, but the entire sample agreed that an

information campaign on the disease and the related risks would be very relevant in order to enhance the awareness among the at-risk population. The study had the additional effect of creating such an awareness. It also contributed to better assessing the risk factors attached to various socio-cultural features. It is recognised that older Latin American migrants are exposed to a higher risk of infection than younger people, mainly due to the progressive implementation of control programmes in endemic countries. Similarly, having a relative diagnosed with Chagas disease was more common among those who tested positive possibly due to the sharing of the risky environment or the vertical transmission. Moreover, a history of dwelling in rural areas - generally the poorest and the most isolated areas in the Latin American continent - was another shared risk factor among infected individuals, as argued by other authors in some comparative research. The research is particularly relevant because of its setting in Emilia Romagna, a region not yet studied and strongly affected by foreign presence, but also because it was carried out with a multidisciplinary approach. The conclusions and recommendations are directed towards a practical improvement of the healthcare system in order to better manage the Chagas disease. Furthermore, the interdisciplinary nature of the research led to further reflection on the social and cultural implications related to Chagas disease, underlining the importance of integration between medical and anthropological approaches for research purposes.

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## D. MEDICAL PLURALISM

### *8. Why alternative medicine is so popular and what do we learn about the European medical system in a Chinese clinic? (HU)*

Written by Diana Szántó

*Text reference: “A komplementer és alternatív medicina felé orientálódó terápiaválasztást meghatározó tényezők” (Factors explaining the choice of complementary and alternative medicine) by Zörgő Szilvia, Purebl György, Zana Ágnes. Orvosi Hetilap, 2016 . 157. évfolyam, 15. szám . 584–592.*

#### *Introduction*

This paper treats a very broad question: why do people living in a 21st century European society turn away from biomedicine to seek remedy for their health problems in alternative curing systems? The authors search for an answer based on long term fieldwork starting from 2014, conducted in a Chinese clinic in Budapest. Their research sheds light on the fact that any given medical system – including biomedicine - is always a cultural system. The patients frequenting the Chinese clinic combine different cultural systems and navigate freely between these.

#### *About CAM in a comparative perspective*

The use of complementary and alternative medicine (CAM) is gaining in popularity everywhere in Western societies. In a study dated from 2002, 36-42% of the population of the USA was found to use such treatments. In Europe 56% of the population preferred such treatments, while in Hungary only 23.1% chose alternative medicine. It is true that the difference in time

(the Hungarian statistics are from 1989) makes comparisons difficult. National statistics are seldom comparable but large differences usually point at different social contexts and cultural systems. For example, in Ghana 73.5% of cancer patients turn to traditional healing methods, understandable in a situation where most of the people cannot afford Western medicine. It is more surprising that 83% of European cancer patients use alternative medicine, too, according to another study. The adepts of CAM resemble each other in some of their socio-demographic traits: they tend to be well educated, middle-aged women, with long lasting sickness.

The popularity of CAM contributes to the proliferation of services. At the same time the availability of these services affect popular concepts of sickness, health and cure and make people more open to CAM. However, this circular relationship alone would not be enough to explain why individual users turn increasingly towards alternative medical treatments. In order to better understand these choices the authors examine further factors.

#### *Factors influencing choice of CAM*

These factors can be grouped in three large categories: market competition, information flow and cultural “creolization”. The three domains overlap.

Cultural creolization is a spontaneous process, but politics, regulations and the institutional system have a great influence on it. Policies influence what services are available, recognised and endowed with prestige. In Hungary, traditional Chinese medicine (TCM) enjoys high popularity and relatively high prestige, as shown by the project to create a TCM centre in Budapest. Market competition – aided or hindered by the State - affects the availability and choice of different services and also the availability of different world views. In the new global world order, individuals are in contact with a variety of worldviews and are not only free to choose, but also obliged to. They must compose their own hybrid cultural system out of different elements.

Information technology makes a great number of ideas, conceptions, and world views available. In principle, internet has made the access to information almost limitless, but in

practice people tend to filter the information even before they access it according to their world view. Because cultural institutions tend to lose their credibility in late modernity, authenticity has to be found elsewhere: in personal experiences and in primary relations. When it comes to choices of therapies, people listen to their peers more than to the authorities. The combination of different world views lead to mosaic-like personalised, syncretic cultural systems. The self itself has become “divided, hybrid, often incoherent, inconsistent” (p. 586)

Complementary and alternative Medicine (CAM) is not only about alternative services, but also about alternative world views. Those believing and practicing CAM tend to support “ecological sustainability, cultural diversity, social optimism and spirituality”. An American author invented the term “cultural creatives” to describe the cultural system of this community. Zörgő et al. borrow the term and seem to suggest that it is applicable for CAM users in Hungary. Cultural creolisation in medicine affects two very important domains: the definition of health and aetiology (ideas dealing with the causes or origin of a disease).

CAM finds its place in the gaps that the biomedical model fails to address: pain and suffering, and the ability to give a meaning to these experiences.

### *The field*

The paper is based on information from 150 patients from the Chinese clinic, which constituted towards the field for this study. The results, beyond answering the original research question, also shed light on the patients’ expectations towards medicine and therapy in general. In other words, beyond the theoretical question “why people turn to Chinese medicine for cure”, the paper also answers a more practical question that might orient possible ways of adapting the biomedical medicine to the non-satisfied needs of the patients. The most widespread of these needs relate to the doctor-patient relationship. Patients appreciate the time the doctor is willing to spend with them, the expression of attention they receive, and they are also aware of the non-verbal signs of care and sympathy of the medical

staff. Medical communication is also experienced as violent in many circumstances, especially at the moment of revealing a diagnosis and offering a (negative) prognosis.

Another factor that makes CAM attractive is the fact that biomedicine does not have a therapy for all diseases at all stages, or the therapy it offers has too many negative side effects. It is not unusual in either case that CAM is used in a complementary manner beside a traditional biomedical treatment.

Another reason for the choice of CAM is related more generally to the identity of the person and to the world view he or she identifies with. Zörgő et al. call this factor “philosophical congruity”. People practicing some form of Oriental physical exercise or diet are more open to CAM. A holistic world view, attributing equal importance to the corporal and spiritual identity of the person can also be a good indicator of sensitivity to CAM.

CAM has got strength where biomedicine has its weakness: the individual has a deep need to construct order out of the chaos that constitutes his or her world. A recurrent complaint of patients encountering biomedical treatment is the lack of explanation of their illness or the refusal of the doctor to hear their own explanation. In case biomedicine does not offer an acceptable explanation or does not convincingly promise a cure, people might feel disempowered and impotent facing their disease. Turning to CAM might be interpreted in this case as an active move to take their curing “into their hands”. Losing confidence in biomedicine threatens with submerging into chaos unless one does not find a credible alternative. Such a loss in confidence might be caused because of late or bad diagnosis, unbearable side effects of a biomedical treatment, fatal prognosis or simply because the style of communication is experienced as alienating.

CAM helps to find a new order in the chaos by proposing a new cosmos in the somatic, moral and cognitive sense. It is important that the cure proposed should be consistent with the aetiology the person can identify with. The authors show the example of a patient who believes that cancer is not an independent sickness but a sign of a weak immune system. He would not concede to chemotherapy for fear of further weakening his immune defence. Traditional biomedical treatments, with a special importance given to drugs, are often

associated with a way of life alien from nature and spirituality. CAM in this case helps to find a way back to a mythological closeness to nature and might be interpreted as a form of critique of the capitalist way of life where treatment is largely in the hands of the pharmacological industry.

One popular form of aetiology attributes all kinds of somatic diseases to psychological states. This explanatory mechanism is also a means to fight the feeling of impotence caused by the chaos, as it gives almost unlimited power to the patient to influence his disease through acting on his psychological state.

Finally, one potential cause of the popularity of CAM can be explained by what the authors call “the need to extend the cosmos”. Many people say they come to the clinic just out of curiosity or because they are open to any solutions that serves health. At the same time, the attraction CAM is able to exercise on the person depends greatly on his or her cultural values. As mentioned before, affinity with other health-centred behaviour, Eastern philosophy and sport might facilitate openness towards CAM. It is interesting in this respect that a strong Hungarian ethnic identity, putting emphasis on “traditional roots” might also push somebody towards Chinese medicine.

### *Conclusion*

The article puts the seemingly individual choice of turning to CAM in an interesting cultural context. Its main virtue is that by investigating a particular practice, that of CAM-users, it sheds light also on the fragmented nature of the late modern self, forced to assume an increased responsibility for individual choices between competing cosmologies and aetiologies. It also shows that any medical system (including biomedicine) is not only about finding the right treatment, but equally importantly about helping to find some sort of coherence in an otherwise incoherent world. By identifying patients’ motives for turning to alternative treatments, the paper also shows a mirror to biomedicine, helping to identify and capture needs that remain most commonly unsatisfied in a biomedical health system.

9. *Indigenous and biomedical concepts of disease: A complementary approach to HIV/AIDS prevention in Mozambique (AT)*

Written by Agnes Raschauer

*Text reference:* Kotanyi, Sophie (2005): Zur Relevanz indigener Konzepte von Krankheit und Ansteckung für eine wirksamere HIV/Aids-Prävention im soziokulturellen Kontext von Mosambik. (translation: Relevance of Indigenous Concepts of Disease and Contamination in the Socio-cultural Context for an Effective HIV/AIDS Prevention in Mozambique.) Curare Zeitschrift für Ethnomedizin und transkulturelle Psychiatrie, 28:2+3: p247-264.

*Introduction: HIV/AIDS prevention's limited success*

In this article focusing on HIV/AIDS prevention in Mozambique and Sub-Saharan Africa, Sophie Kotanyi argues that the limited success of prevention efforts can be attributed to the fact that they rest heavily on a biomedical approach while neglecting indigenous concepts of disease and contamination. In her view, HIV/AIDS needs to be conceived as a sociocultural matter with prevention practices taking into account local ways of viewing the world and forging social relationships. Building on research the author conducted in different regions of Mozambique, she investigates how indigenous concepts and practices might be integrated into HIV/AIDS prevention in order to strengthen its impact.

It is not a new idea that the design of medical practices and social intervention need to embrace a local population's values, ideas and way of living in order to be accepted by that population. For the practices to resonate, they in some way have to fit with or at least engage with existing beliefs. Yet, HIV/AIDS prevention in Mozambique and Sub-Saharan Africa seldom incorporates local concepts and belief systems into their practices. Starting from this observation Kotanyi sets out to analyse how indigenous concepts of disease may inform HIV/AIDS prevention. She interrogates not only how prevention efforts are being undermined by indigenous concepts, but also how these concepts might facilitate prevention practices.

### *Biomedical notions of prevention vs. traditional healing concepts?*

To date, prevention rests heavily on a biomedical notion of infectious diseases and how they are being transmitted. Biomedicine refers to a vision of medicine prevalent in the Western hemisphere, where health care systems are commonly based on this approach. According to a biomedical model, knowledge of health and disease is gained through natural sciences and scientific practices, stressing the importance of biological processes treating bodily conditions understood as diseases. It is linked to specific assumptions about what constitutes health / a healthy body and which factors are deemed relevant for diagnosis and cure. While physical and biochemical processes are given priority, social context and individual experiences are largely neglected.

Traditional healing concepts on the other hand are based on the specifics of local culture. They emerge from beliefs, historical practices and modes of social organisation. Commonly, they follow a holistic approach – fundamentally different from the practice of categorising within biomedicine. “Traditional” means that ideas and concepts have been passed down from previous generations, mostly in an oral fashion. Thus, traditional healing concepts are not fixed, but change over time, in the course of being passed down from one generation to another, but also in the course of on-going social practice. In this way, they are not old, obsolete practices, but ideas that have descended and are moulded to current life.

Kotanyi argues that there is a general lack of cooperation between biomedical experts and experts of indigenous medicine in Mozambique and many countries in Sub-Saharan Africa. Traditional medicine had been criminalised in Mozambique in the past, which is no longer the case now. Yet state authorities remain hesitant to accept traditional healing as a medical practice. According to the author, it is generally not the traditional healers who resist cooperation, but representatives of the state, who expect the healers to dissent rather than engage with them. Concepts of health, disease and healing are tied to questions of power.

### *Complementarity*

In some African countries efforts have been made to include traditional healers in prevention measures. Yet the attempts produced little success, since members of the biomedical system

or state actors tried to incorporate indigenous methods of healing by trying to fit them into the biomedical model. Thereby, they were secondary to the rationale of biomedical prevention and their specific character was lost.

Kotanyi proposed a complementary approach to HIV/AIDS prevention instead. Based on George Devereux' concept of complementarity (1972) indigenous and biomedical explanations are viewed as two different dimensions of the phenomenon of health / disease, each following a distinct rationality. Notwithstanding the fact that patients can hold on to biomedical ideas, they can hold on to indigenous ideas at the same time. Approaching these two models in a complementary way means assessing each according to its own logic and not from the standpoint of the respective other. Held to the standards of biomedicine, indigenous concepts will always seem deficient and vice versa. According to the concept of complementarity, both approaches shall be explored in keeping with their own rationale. Since biomedicine and indigenous concepts aim at different things, they are not to be fused, but can supplement each other.

In this way, both approaches shall be paralleled, since each is able to shed light on specific elements of HIV/AIDS prevention. Paralleling biomedicine and indigenous concepts help to arrive at a fuller, more nuanced picture. As a consequence, prevention strategies that are developed based on a complementary approach might prove better suited for the local contexts they are targeting.

For example, using healing plants is an element of indigenous healing practices. Being treated with healing plants can aid a patient with many HIV/AIDS related symptoms, such as herpes, loss of appetite or diarrhoea. Moreover, ritual procedures which are associated with healing practices might produce further beneficial effects. These treatments can happen complementary to biomedical procedures. In the best case, traditional healers and biomedical experts communicate and agree on a course of action so as to maximise beneficial effects and avoid negative interactions.

### *Indigenous concepts*

Disease and healing in Mozambique and Sub-Saharan Africa are largely infused by indigenous medical concepts. Only a small proportion of the peoples in Sub-Saharan Africa adhere to the notion that disease is caused by biological processes. Most aetiologies prioritise social reasons. These aetiologies play a vital part in how locals deal with HIV/AIDS prevention measures.

Within indigenous healing the meaning of a disease is key. In order to uncover this meaning, one has to assess when, where and why an ailment came about. Disease is usually interpreted as a disorder in the sick person's social relations – either between the living and the dead or among the living. The analysis of disease aims at reconstructing the sick person's social relationships to find the reason for sickness within these relationships. Among the indigenous concepts Kotanyi researched, there are four main causes for disease: 1) ancestors (deceased), 2) ghosts, 3) witchcraft and 4) disease that was sent from God or happened “just so”. According to the author, each explanation can be relevant for HIV/AIDS prevention. In the following remarks we will focus first on the example of ancestors (deceased) and then on the example of witchcraft to discuss how these concepts might be paralleled with biomedical prevention practices.

Disease befalls when one's relationship with dead ancestors is disrupted; harmony between the living and the dead being key for happiness and health. The relationship can be disrupted, if the bereaved do not adequately perform the important burial and bereaving rituals. Disease might also be attributed to ancestors when the breaking of a taboo is suspected. For example, after losing a spouse, a widow/widower is expected to conduct traditional purification rituals, since each death brings about a form of social contamination to the bereaved. In order to transform this contaminated state of being, the bereaved need to conduct purification rituals. Not conducting these rituals means breaking a taboo, which is thought to cause disease. Ancestors are also said to react to the breaking of sexual taboos. Since ancestors are considered moral authorities and may influence behaviour, HIV/AIDS prevention should focus on how beliefs surrounding ancestors could serve to benefit prevention strategies.

Another reason why it is important to engage with indigenous concepts of ancestors is that symptoms associated with an HIV/AIDS infection are often times not interpreted as such, but as consequences stemming from breaking a taboo. Combining biomedical expertise with expertise of traditional healers might lead to an earlier identification of HIV infection: symptoms pointing to the breaking of a taboo might also be pointing to HIV/AIDS.

Moreover, some indigenous purification rituals that are to be performed after the passing of a spouse involve a ritual sexual act in order to cleanse the widowed person of social contamination caused by death. From a biomedical standpoint these rituals carry a high risk of spreading HIV/AIDS. In some regions, these rituals are being transformed to minimise the potential of infection, i.e. by abstaining from coitus. If there is no dialogue between experts of indigenous medicine and biomedical experts, people might be faced with having to decide between remaining in a socially contaminated position or engaging in high-risk sexual behaviour.

A second concept that could prove relevant for communicating and devising prevention measures is witchcraft. Witchcraft refers to relations among the living that have taken a negative turn. In Mozambique it encompasses all types of evil thoughts and intentions people have, but also unintentional harmful behaviour, for example caused by envy. Since humans pass on the deadly disease HIV/AIDS to other humans, it can be perceived as result of witchcraft. Kotanyi cites one example of a nurse in Paris, who is originally from Congo, living with HIV. Even though the nurse subscribed to biomedical explanations of HIV/AIDS, it was most important to her to uncover, if there were workings of witchcraft in her family. She did not want to die being considered a witch. Following indigenous concepts, a dead witch is not able to pass from dead person to ancestor, which in turn means not being about to safeguard the living family members. This example not only shows that people may hold on to different types of aetiologies at the same time, which may seem conflicting, but are meaningful to them. It also points to the potential of engaging with concepts of witchcraft for HIV/AIDS prevention. Sick persons will receive much more community support, if they are thought to be a victims of witchcraft and not witches themselves.

Kotanyi argues that it is largely the inconsistency between socially held ideas and beliefs and the rationale of HIV/AIDS prevention that hinders its impact. Especially, since the differences are not being addressed. While HIV/AIDS prevention follows biomedical notions of infection, contamination as it is understood by many people living in Mozambique and Sub-Saharan Africa is a highly social concept.

*Conclusion: How HIV/AIDS prevention can benefit from paralleling biomedical and indigenous strategies*

In order to arrive at more successful prevention strategies, Kotanyi engaged with indigenous concepts of disease prevalent in Mozambique and Sub-Saharan Africa. Her findings point to the fact that contamination, disease and healing are dimensions of social life, which are not dealt with individually, but by engaging with one's community and its core beliefs. Thus, prevention needs to systematically involve local communities, communicate in local languages and employ common forms of disseminating information. Brochures, for example, are no adequate way of communicating in highly oral cultures, which put a prime on metaphors, story-telling, song and dance.

Additionally, Kotanyi explains that it makes a lot more sense to address social notions of contamination instead of solely taking into account biological causes for HIV/AIDS infection. Whenever indigenous concepts serve to facilitate infection, they should be discussed with traditional healers, experts on indigenous medicine, and local authorities, in order to adapt them accordingly. Whenever concepts lend themselves to fostering prevention, they should be incorporated into prevention strategies. Thereby, it is important not to subordinate these concepts to biomedical rationale, but to parallel them with existing biomedical prevention strategies.

Thus, people involved in prevention efforts need to engage with indigenous concepts in order to make prevention more effective. By respecting differing aetiologies, HIV/AIDS prevention could increase its impact.

*10. How come the antiretroviral therapy is failing in a continent like Africa where the importance of these treatments is crucial? (FR)*

Written by Aurélie Benoit

*Text reference:* “Les antirétroviraux en Afrique : de la culture dans une économie mondialisée (Antiretroviral treatments in Africa : when culture meets globalized economy)” by Alice Desclaux in *Anthropologie et Sociétés*, “Volume 27, numéro 2, 2003, pp. 41-58

<http://id.erudit.org/iderudit/007445ar>

*Introduction*

The article « Les antirétroviraux en Afrique : de la culture dans une économie mondialisée » (« Antiretroviral therapy in Africa : Culture in a globalised economy ») deals with the case of antiretroviral therapy in Africa, which is not quite as effective as in the North, in spite of its crucial importance in fighting sexually transmittable diseases in that continent. That ineffectiveness seems to be the result of “local drug use not meeting the international recommendations”. It has therefore to be asked for what reasons drugs are used in an “improper” way.

*Why the treatment is not taken? The misleading cultural reasons*

First of all, Alice Desclaux recalls that this failure is commonly explained by “culturalist” views: STDs and the medication linked to them are subject to cultural constructions that have been largely studied by the anthropologist of medication . But here, the author immediately stands against the suggestion of a cultural cause, especially when it comes to compliance with medication, in other words: “a patient’s behaviour that matches the recommended therapy”, “compliance with the follow-up, with hygiene and dietary rules as well as the medication”. Antiretroviral drugs can be considered as effective by medical professionals only if their

observance exceeds 90%. In addition to the causes also found in the North, the reasons for a possible observance failure are principally economic or caused by health system malfunctions in those countries, for instance by the physician's absence at the monthly appointment. In another article she wrote in 2001, «L'observance en Afrique: question de culture ou «vieux problème» de santé publique?» (“Compliance in Africa: a cultural issue or an old public health problem?”), the author declares that cultural-related issues actually exist (a statement which does not necessarily contradict this article, in which she treats the subject in a more evasive way) but, in this particular case, she considers these explanations to obscure other possible reasons.

*Explanations are more likely to be found in physical or economic reasons*

The causes she mentions are more physical; indeed, antiretroviral therapies lead the patients' symptoms disappearing. Therefore, the patients are seen as cured and their entourage expects a form of counter-gift, due to the concessions it had to do while supporting their care. This is an interesting point, because it highlights a different vision of solidarity, based on a “give and take” principle.

Alice Desclaux then insists on the economic aspect, that is the want of free access to antiretroviral therapies. “Children, health professionals and patients formerly involved in clinical trials” actually have free access. Similarly, in almost every African country, “members of associations for people living with HIV received subsidies that partially or totally covered the therapy costs, so did widows with dependent children”. There is a categorisation, therefore, which involves a hierarchy between patients (as well as more specific categories exceptions depending on the countries). The author raises the question of the value ascribed to a human life. For the rest, indeed, the prices exceed 100 dollars a month, in a region where over one in three people earn less than one dollar a day.

*An alternative to foreign medication: the neo-traditional drug*

Consequently, in an effort to increase the access, “neo-traditional” therapies are developing. But these alternative drugs eventually cost quite as much as the classical antiretroviral drugs they are supposed to substitute for. The emergence of this new market is due to African health professionals taking advantage of “a space left vacant by biomedicine and recently created by the social construction of antiretroviral drugs”. Here lies, in fact, the point of this article: in the ambivalence of these drugs labelled as “neo-traditional”. They are supposed to originate from traditional medicine; nonetheless, they are legitimated by “business owners” using more scientific, “Northern”, arguments. This was born as a defensive strategy based on alien roots.

#### *Medication as meaningful objects*

The author explains the emergence of this vacant space by the “double lack of access as well as the identity meaning”. A drug isn’t a neutral item: in fact, classical antiretroviral drugs come from the North and are meaningful. Developing “neo-traditional” drug is also a means to reclaim an item laden with meaning.

#### *Conclusion: Neo-traditional treatment as a means to re-appropriate a foreign object*

Moreover, the behaviour towards antiretroviral therapy is to be understood in an economic context which is also subject to power struggles. In response to globalisation and the following inequalities, the use of antiretroviral drugs shows a resistance strategy by making drugs, as a symbolic object, local again. Drugs are in fact full of meaning, economically (because of the categorisation resulting from its accessibility) as well as socially (for business owners using it in their individual strategies).

These antiretroviral drugs also favour the legitimacy of biomedicine as well as new forms called “neo-traditional”, because of several advantages they bring to local people: an increased accessibility to medication; an efficacy similar to that of scientific methods; a means to defend an African identity through the symbolic load of the drugs.

The author does not clearly establish if this specific use of medication is a problem or not, she just highlights the symbolic place of the medication to some people, and how their utilisation influences a new “medical system geography”, but also how they are an illustration of social dynamics.

## **E. HEALTH PROFESSIONALS FACING CULTURAL DIFFERENCE**

### *11. Intercultural Encounters in Danish Hospitals – Lived Experience of Diversity (DK)*

Written by Margit Helle Thomsen

*Text reference:* “Patienter med minoritetsetnisk baggrund i det danske sundhedsvæsen – En fænomenologisk undersøgelse af sygeplejerskers oplevelse af mødet med minoritetsetniske patienter på en dansk hospitalsafdeling” (“Patients with minority-ethnic background in the Danish health services – a phenomenological study of nurses' experience of the encounter with minority-ethnic patients in a Danish hospital ward”) by Nielsen, Ben Farid Røjgård, 2007, thesis, pp 93.

#### *Introduction*

This study was conducted in clinical collaboration with nurses in a Danish hospital within the Capital area. The goal was to investigate how nurses communicate with patients of other ethnic origins other than Danish. Based on a phenomenological approach and analysis, the study crystallized three phenomena of particular importance for nurses' perception of and relation to patients with an ethnic minority background: the specific framework for communication, the different attitudes towards illness and the different cultural and social behaviours. Based on these three phenomena, the study focused on the challenges associated with the use of interpreters and the use of the term "ethnic pain". This concept reflected the widespread perception among the nurses that ethnic minority patients exaggerate their pain. Finally, the phenomenological analysis pointed to the impact of phenomena such as food, the involvement of family and friends in healthcare services etc.

#### *Aim and objectives*

The overall aim of the study was to uncover and analyse the intercultural encounters between Danish nurses at Danish hospitals and a growing number of patients and relatives of other ethnic-cultural origins than Danish. Thus, the objective has been to identify the changing competence needs, the changing service requirements arising out of this intercultural encounter between healthcare professionals and new groups of patients in the Danish health system. What new qualification needs should be met for the nurses to maintain the quality of service of nursing and care, as generally offered to patients and relatives of Danish origins? What situations in particular require new and different skills in order to meet the ethnic-cultural diversity among patients, their families and relatives?

In relation to these objectives, the study focused on nurses' own experience from the assumption that the lived experience would be the strongest driving force, if the nurses were to adapt their practice to the patients' diverse needs, their well-being and recovery.

#### *A professional as well as a personal approach*

From this approach, the study first and foremost concerned the nurses' **professional** awareness. At the same time, it revealed the importance of **subjective** and personal experience as well. The questions to which the study sought an answer are the following.

- Which phenomena and challenges do nurses experience in the intercultural encounters?
- How do these phenomena influence the quality of nursing and care offered to these patients?
- How do the nurses respond to the differences as compared to the contact with Danish patients?
- How do the intercultural encounters affect the nurses' professionalism?

#### *Data sources – a field study*

With these objectives, the researcher has chosen a qualitative approach, supplemented by desk studies. Thus, the study was based on **qualitative research interviews** supplemented by observations among the nurses in the study, all of them working in a hospital ward with at least 5 years of practical experience. The researcher used open, semi-structured interviews in

order to ensure that the informants had the opportunity to talk freely and spontaneously from their individual perspectives, following their own ways of thinking, associations and experience patterns. All interviews were transcribed, thematically organised and coded.

The qualitative research interviews were combined with **participant observation** of the nurses' daily working situations in a Danish hospital ward. By using the observation method, the researcher increased and qualified the insight into and the understanding of the daily context that the nurses referred to in the interviews. Furthermore, the observations were a suitable method for observing the verbal as well as the non-verbal and bodily interaction and communication between the nurses and ethnic minority patients and relatives.

The study was located in the Capital area, justified by the fact that the share of ethnic minority citizens was particularly high in this area – and hence the probability that the nurses would experience intercultural encounters on a regular basis is high.

#### *Terminology, concepts and theoretical-methodical approach*

As the overall scientific theoretical approach - in harmony with the phenomenological research tradition – was to capture and describe the lived experience of the informants. Thus, the researcher mainly used the **phenomenological description** method that goes back to the German philosopher Edmund Husserl.

In addition, the researcher relied on considerations from the Norwegian philosopher – and educated nurse – Kari Martinsen. In her research, she argued that good practice in professional care and nursing should unite a **relational, a practical and a moral dimension**.

Furthermore, the researcher involved theoretical considerations by the Danish anthropologist Bodil Selmer to discuss the cultural attitudes underlying the institutional understanding of professional nursing in the Danish health system.

#### *Concepts to describe patients of other ethnic origins*

The researcher reflected on the very concept of ethnic minority background/origins. With reference to the Danish anthropologist Kirsten Hastrup, he claims that the concept of **ethnicity** arises only when it becomes politically and socially relevant in a society to make a clear

distinction between the majority population and minority groups. Thus, the concept of ethnicity is seen as a **relational and situational** concept rather than a concept for certain traits of the individual person. Citizens of different ethnic origins are constituted as different from ethnic Danes, and the difference is given importance and significance solely by virtue of the distinction. Thus, the ethnic minority patients were involuntarily seen as **others and different**.

### *Key findings*

The nurses pointed to **three phenomena** which were generally considered to be characteristic for the intercultural encounters with patients from ethnic minorities:

- Communication
- Different concept of illness
- Different cultural and social behaviour on the ward

### *First phenomenon: the communication*

The nurses emphasised the lack, or inadequacy of the Danish language among ethnic minority patients as a phenomenon that substantially affected the intercultural encounters. Linguistic skills played a fundamental role in communication in general and in particular in the nurses' ability to perform their **professional communication** about the patients' situation and treatment procedures. Communication was considered a basic part of the nursing and care functions:

*"As the first thing, I always think if they can understand me, i.e. the language issue. It's something I initially find out – are they able to understand Danish... and do they understand what I'm saying ... " (Interview, quoted from the study)*

### *Passive versus active communication*

The nurses found the ethnic minority patients to be generally **passive** in communication. For example, the patients rarely indicated that they didn't understand the information given about their disease. They pretended to understand, and then later turned out to be confused about the treatment etc. In addition, several nurses claimed that the ethnic minority patients – unlike many Danish patients – did not themselves look for information about their own

disease, for instance on the Internet. The nurses interpreted this as reluctance to "**take responsibility for their own illness**".

*To use or not to use interpretation – that's the question*

At the time of the study, there were certain official guidelines for interpretation in all hospitals in the Capital area. However, several nurses actually tried to limit the use of interpretation. Sometimes, the nurses used family members to interpret. But generally, the use of interpreters would depend on the nature and severity of the disease in the individual case. Questions related to death, severe illness and also intimate issues would generally require external interpretation and should not be interpreted by family or close relatives. In general, the nurses would prefer using the same interpretation agency in order to build a mutual understanding and a common professional platform for interpretation.

*Overall conclusion*

From the nurses' experience, the greatest challenge in the intercultural encounters would be linguistic barriers and interpretation needs, pulling resources from the basic nursing and care. Basically, language barriers would upset the balance between **pure information and dialogical communication** about patients' well-being, pain, emotional distress, care and nursing needs. The more difficult it was to communicate verbally with ethnic minority patients, the greater the emphasis is on practical and formal information. From the nurses' perspective, this would often impair the basic care and, consequently, delay the recovery process.

However, the emphasis on language challenges would in some cases be coloured by more **private attitudes, when nurses would be critical to** ethnic minorities' lack of ability or interest to learn Danish.

*Second phenomenon: different concept of illness*

**"Ethnic pain"** - many nurses shared the perception that ethnic minority patients generally articulated pain much stronger than Danish patients:

*"I also think that more often than Danish patients, they (ethnic minorities, red.) claim to have more pain. We talk about it from time to time - and call it ethnic pain ... "*  
*(Interview, quoted from the study).*

The nurses generally noticed an ethno-cultural difference in terms of **feeling pain and expressing pain**, when comparing ethnic minority patients and Danish patients. From the nurses' point of view, the Danish patients were much more likely to swallow their pain and be discreet about feeling pain.

#### *Bodily knowledge and awareness*

As another general observation, ethnic minority patients often seemed to be more ignorant about the body's **anatomy and physiology** than Danish patients. A few nurses even interpreted the lack of body awareness as a result of inadequate schooling in the patients' countries of origin.

In addition, the nurses observed that ethnic minority patients would generally prefer to stay in bed for quite some time after a surgery. In contrast, the general practice in Danish hospitals is that the sooner you get on your feet and become mobile again, the faster you will recover. The ethnic minority patients apparently **linked the disease to being bedridden**. This also implied a longer hospitalisation compared to Danish patients with similar disorders and treatment needs. The ethnic minority patients apparently were afraid to be discharged and felt more secure staying in the hospital.

Furthermore, the nurses noticed a difference when ethnic minority patients and their families often **reacted with anger** and even threats by unforeseen changes, for example cancellation of a surgery.

#### *Overall conclusion*

From the nurses' experience, it was difficult to assess from both a professional and personal point of view whether ethnic minority patients expressed "real" pain or whether they exaggerated the pain level. This dilemma was perceived as an obstacle to professional care and nursing. Furthermore, the lack of physical insight was considered to be a difficult matter

in situations, where they were to explain minority patients about the embodiment and bodily expressions of their specific disease.

In some cases, the nurses automatically linked the lack of bodily knowledge to poor schooling. However, by this perception, the nurses seemed to mix the professional assessment with more private and even ethnocentric preconceptions of levels of education and civilisation in so called third-world countries. Likewise, the perception of “ethnic pain” may be seen as a negative preconception.

**In summary**, the nurses experienced that ethnic minority patients behaved contrary to professional standards and procedures in the Danish health system, for instance in relation to recovery.

*Third phenomenon: different cultural and social behaviour in the ward*

*Private food in hospital:* the nurses pointed to various differences in cultural and social behaviour. One significant difference was linked to **food**, as ethnic minority patients would often have meals delivered to the hospital by family and relatives. This would never be the case for Danish patients. However, some nurses expressed a positive position to this phenomenon, while other nurses would consider the private food deliverances as a disturbance for other patients.

*The impact of strong social networks:* ethnic minority patients would often have strong social network and consequently many visits, when hospitalised. Some nurses would emphasise the advantage of a strong social network in terms of patients’ recovery. Other nurses regarded the many visitors as a nuisance for other patients as well as for the professional staff.

*Overall conclusion*

From the nurses’ experience, there would be both positive and negative effects of cultural and social differences. Some nurses were focused on the importance of cultural habits in terms of the patients’ well-being and recovery. Other nurses would be more negatively focused on the impact of cultural habits on the practical and professional procedures in the ward.

### *Summary and perspective*

The study highlighted communication, different attitudes towards illness and different cultural and social behaviour as crucial phenomena in the intercultural encounters.

### *Communication*

The nurses found that language barriers made it difficult to get knowledge of minority patients' background and thus to clarify the patients' individual situation, resources, needs and requirements.

The inability to establish a dialogical communication resulted in a form of **objectification**, as the nurses – despite their professional intentions – felt unable to recognise the individual life history, identity and integrity among ethnic minority patients. The general experience was that the **interactive aspect** of communication was broken and consequently, the nurses lost opportunities to use the socio-cultural and psycho-cultural interpretations and empathetic "readings" they usually used in communicating with patients. This led, in some cases, to situations where nurses instead resorted to stereotypes and even ethnocentric interpretations that would lean towards negative preconceptions and generalisations about ethnic minority patients.

### *Different view of illness*

The nurses spoke of "ethnic pains" as a term for excessive articulation of pain among ethnic minority patients. This was interpreted as a different ethnic-cultural view on illness and pain thresholds. Lack of insight into anatomy and physiology was also seen as a cultural difference. Previous research had focused on cultural differences in terms of pain thresholds, but no clear answers were given. Apparently, the articulation of pain is more about cultural expectations as to **when and how to express pain** - than about the pain itself. The Danish medical anthropologist Beth Elverdam described how reactions to and expressions of pain are cultural and a result of socialisation. Thus, the nurses' experience could also be seen as an expression of a Danish cultural approach and interpretative framework, where "good" patients are swallowing their pain. Beth Elverdam also stated that lack of knowledge of the body's

biological functions are **not synonymous** with lack of body awareness. Similarly, perceptions and interpretations of disease and illness symptoms are culturally conditioned. When ethnic minority patients would rather stay in bed, they probably expressed a feeling of being ill, whereas the nurses from a Danish approach considered them to be almost healthy.

*Different cultural and social behaviour*

The nurses referred to differences connected to food and the large flow of visitors as well as the passive role that generally characterised ethnic minority patients.

This experience reflected that patients' and professionals' roles in the healthcare and hospital context are socially and culturally defined. **The more authoritarian the professional role, the more passive the patient role.** Being educated and socialised in a more dialogical and non-authoritarian system, the nurses had difficulties coping with a passive patient behaviour.

## 12. Health Professionals and how they perceive patients from diverse ethnic groups.

(UK)

Written by Suki Rai

*Text reference:* Kai, J., Beavan, J., Faull, C., Dodson, L., Gill, P. and Beighton, A. (2007).

Professional uncertainty and disempowerment responding to ethnic diversity in health care: a qualitative study. *PLoS Med*, 4(11), p.e323.

### *Introduction*

Communities are becoming increasingly diverse in terms of ethnicity and race. Health professionals and governments are trying to ensure that everyone has equal access to healthcare, however there is increasing evidence of **racial inequalities in relation to health** outcomes.

Some health authorities have introduced “**cultural competence**” training to develop the skills of individuals and organisations allowing them to work better with people from different cultures. These health professionals are taught about ethnic differences in health beliefs and practices, religion, and communication styles, to help them provide the best service.

This article aims to understand how **health professionals experience** and perceive their work with patients from diverse ethnic groups. In particular, it looks at whether their behaviour is influenced by ethnicity in ways in which might contribute to health inequalities. This study uses **cancer care to explore this further and by conducting a qualitative study**, with 18 focus groups comprising of 106 health professionals of differing disciplines, in primary and secondary care settings. The study took place in the Midlands, UK.

### *Methodology*

The study used focus groups instead of one to one interviews so that group interactions could take place. These focus groups or discussions were used to look into attitudes,

opinions, and assumptions as well as to allow participants to discuss each other's perspectives.

Each of these focus groups were either homogenous by discipline, to enable sharing of experiences, or a multi-disciplinary group that encouraged discussions from within a care team.

The characteristics of participants was broken down as follows:

Category	Characteristic	Number (%)
Health Professional background	Physician <sup>i</sup>	22 (21)
	Community-based nurse/nurse specialist	21 (20)
	Hospital based nurse/ nurse specialist	18 (17)
	Allied health professional <sup>ii</sup>	16 (15)
	Link worker or advocate	21 (20)
	Health Service administrator or manager	8 (7)
Reported frequency of working with patients from ethnic minorities	At least daily	52 (49)
	At least weekly	21 (20)
	At least monthly	8 (7)
	Less than monthly / uncommonly	25 (24)
Age Range (y)	24-35	25 (24)
	36-45	34 (32)
	46-55	33 (31)
	56-65	14 (13)
Ethnicity	White & UK born	63 (59)
	South Asian <sup>iii</sup>	31 (29)
	African Caribbean	3 (3)
	White European	7 (7)
	Chinese	2 (2)
Languages spoken other than English	South Asian <sup>iv</sup>	27 (25)
	Cantonese / Mandarin	2 (2)
	Caribbean Patois	2 (2)
	African <sup>v</sup>	2 (2)
	Other European <sup>vi</sup>	14 (13)

<sup>i</sup> Hospital, primary care, or palliative care.

<sup>ii</sup> Physiotherapists, occupational therapists, or radiographers

<sup>iii</sup> Born in or descended from those born in Pakistan, India, Bangladesh or Sri Lanka

<sup>iv</sup> Urdu, Punjabi, Hindi, Mirpuri, Sylheti or Bengali

<sup>v</sup> Shona or Swahili

<sup>vi</sup> French, German, Spanish or Italian

These discussions were started with a broad question, “Could you comment on any experiences you have had when caring for people from an ethnic minority background?” These discussions lasted between one and half to two hours.

### *Results*

Professionals that were interviewed wanted to provide a good standard to care for patients from diverse backgrounds. However, they felt that they were **challenged with communication, language and working with families of the patients.**

### *Professional uncertainty*

Professionals stated that they experiences **uncertainty** when faced with patients they perceived as being culturally different. Faced with this “difference”, professionals felt apprehensive and uncomfortable. The respondents highlighted that they lacked cultural awareness and knowledge and that they were worried about how this would affect their patients. They feared that their lack of knowledge may lead to “mistakes” or getting it wrong.

Some professionals **were worried that their lack of cultural awareness** could be perceived as discriminatory or racist. However, some respondents felt that if they made more of an effort to address the cultural needs of their patients, this could be perceived as preferential treatment, not only by patients but colleagues too.

### *Focus on cultural expertise*

The professionals recognized that their ignorance and the need for more cultural knowledge. They felt that they need training on how to approach patients from different cultural backgrounds.

In situations where professionals were dealing with patients from a different ethnic group to themselves, some suggested that they might ask the patient directly to explore issues. However, this approach did cause some fear and worry that they might say or do the wrong thing which could offend their patient. For example:

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*“Instead of thinking this is a patient, ...treat them exactly as we do any other patient... you get overwhelmed with the fact that it’s an ethnic group instead of a person.”*  
(Palliative Care Team).

Most respondents felt the need to learn more about different cultures and have “set guidelines” on cultural differences. Others, however, thought that given the diversity within ethnic groups, this could lead to stereotyping patients and that patients should be treated as individuals. For example:

*“Of course, we have got mixed up cultures now, haven’t we? We have got second and third generations of children and grandchildren, fairly westernised in many families... quite hard to get your heads round isn’t it? Because we don’t quite know who we’re dealing with ...”* (Palliative Care Team, p.5)

*“Even though you might say this person is Polish, within that there will be all sorts of different likes and dislikes, preferences, cultural differences, everyone is different...”*  
(Palliative Care Team, p.4)

*“It’s not a production line you know. Every person is individual. Miss X’s needs are different from Miss Y, whether they have the same disease. It’s really not, you can’t just say in black and white... It depends, person to person. Every case is different”.*  
(Physician)

There were few instances where professionals felt able to discuss their “uncertainty” with patients, or indeed asking the patient about their perspective, concerns or beliefs. There were the following two exceptions though.

*“To think about how you speak to people and to think about what the family and what the patient themselves most want to know and how they want to know it...It’s listening isn’t it? It’s being aware of, you can’t just say this is a Muslim family therefore this is how I’ll do this as a template... You have to be able to modify how you deal with these situations...”* (Physician, pp.3-5)

*“I think what has helped me, it’s very much built into counsellor training...is a model*

*around working with any kind of difference rather than around checklists... and yet I still struggle to know how to meet people who are very, very different to me.”*  
(Multidisciplinary hospice team)

### *Professional disempowerment*

**This uncertainty that professionals experience had disempowering effects.** They felt disempowered by anxiety and stress when experiencing cross cultural interactions.

Respondents worried about, or did not know how to ask their patients about values and perspectives that were important to them. Those professionals that had experience of diversity, and had some form of cultural awareness training, still worried that they might get it wrong and offend their patient. Respondents also stated that they felt uncomfortable as professionals and worried that their patient care could be compromised.

Others felt that patients from different ethnic backgrounds should be “matched” with professionals from a similar ethnic background.

Others felt that patients from different ethnic backgrounds should be “matched” with professionals from a similar ethnic background.

Others felt that they were less able to use trust and empathy as an approach for fear of doing the wrong thing. Others felt more empowered following cultural awareness training. For example:

*“I attended a workshop... (the message was) we all have basically the same needs... don’t get yourself tied up... because you’re worried... We have to try and find a way of making sure that people can access services. For me, that was quite freeing really... I don’t have to know everything about every religion, every culture... I found that very helpful and I think it could be easy to hide behind well I don’t know and perhaps they need something different and I can’t give it...”* (Palliative care multidisciplinary team)

### *Conclusion*

Professionals in this study wanted to provide a good standard of care for all patients. However, they stated that they experienced uncertainty when they were faced with patients they perceived as being culturally different – this made them feel uncomfortable. They feared that their lack of knowledge may lead to mistakes or to them getting it wrong.

Some professionals were concerned that their lack of cultural awareness could be perceived as racist or discriminatory. By contrast, some professionals felt that if they made more of an effort to address cultural needs then this could be perceived as preferential treatment, by both patients and colleagues.

The approach to ask a patient directly to explore their issues caused some fear and worry that professionals might say or do the wrong thing and offend the patient.

There was some anxiety around experiencing cross cultural interactions. Respondents did not know how to ask their patients about values and perspectives that were important to them. Even when professionals had received training around cultural awareness, they still worried that they might get it wrong or offend their patient.

Worryingly, other professionals felt that patients from different ethnic backgrounds should be “matched” with professionals from a similar background. This would encourage further stereotyping and would not help professionals in being culturally competent.

The openness in which professionals were able to discuss the challenges they face when dealing with diverse patients, was very useful. It allows us to understand the difficulties they face when dealing with patients who are from a different cultural background to them.

**The anxiety and feelings of being uncomfortable that the professionals describe could inadvertently contribute to inequalities in health.**

Health professionals need to be more culturally aware and have an understanding of cultural needs and what shapes culture. Professionals need to build on their **cultural competence** to avoid being culturally blind. This would eliminate the fear that professionals face when dealing with patients who are culturally “different” from them.

Professionals need to be aware of cultural differences and they need to avoid dismissing

culture for fear of offending their patient. Professionals also need to look at **each patient as an individual**. They need to consider their patient's individual needs and empower the patient with choices. There needs to be an opportunity for every patient to be involved in their care.

### III) Sensitive zones – relativizing universals

#### a. The body in a cross-cultural perspective

Written by Éva Nagy

##### **Why is it so complicated? – The diverse interpretations of the body**

Thinking about the human body we head into a tumultuous discourse of many different voices. Numerous scientific fields, political and cultural movements, religions, arts are represented in this multivocal dialogue. Despite the common interest toward the human body, these approaches reflect on the phenomena around the body in divergent ways, however influence and form each other.

According to Shilling (Shilling 2005) the body is ubiquitous and at the same time elusive phenomenon in the modern thought, but not just modernity shows great interest toward this subject. One hardly can find any community in time and space which leaves the human body blank or untouched, and doesn't 'use' it to demonstrate its rules, values, concepts of power, existence and social boundedness.

Maybe one possible explanation of the omnipresence of the human body is coming from its bifold characteristic, namely its individual and universal quality. On the one hand, body is the territory of unconscious and instinctive, and as such it is a source of highly intimate, deeply personal talk and subjective reflections. On the other hand human body is considered as universal category, something which is possessed by all human beings, where the word 'possession' refers to the universal experience of embodiment, as a fundamental part of human existence. To put it to a more simple way, we all live in a body which is at the crossroads of personal and social, common and individual, material and spiritual. Typical conflicts of the modern health care systems, such as doctor-patient relationship, or in more general, the interpretation of definitions of illness, disability and health, even the problem of modern societies' relationship to the human body (for example the ideas about beauty, death, suffering and pain) are somehow connected to this kind of duality.

## **The socially embedded body**

The medical anthropological approach interprets this kind of duality through the lens of social embeddedness of the body. In a more simplistic way it is about the differentiation between the two coexisting dimensions of bodily experiences, namely the physical body and the social body. We all have a physical experience of the body, which is never standing alone, but it is deeply embedded into a social context. Therefore the social body is a collection of socially and culturally defined categories which always modify the knowledge about the physical body. The way we think about different attributes of bodies, like the optimal size and shape of it, or the different conditions, functions and structure of the body, even the gender, the age, the colour of the body are socially constructed, and express a universe of culturally defined meanings. (Synnott 1993). At the same time, the body is a filter through which we get in touch with the world around us. So, the physical and social body permanently influence each other.

Howson illustrates this embeddedness with great plasticity through a short experiment of self-examination: “Just for a moment think of your own body. Where do you start? With your appearance (the spot that has materialized from nowhere, the bad hair day)? With its shape and size (...)? Are you more aware of your body at some times rather than others, such as when you trip over your feet in a crowded room, belch unexpectedly or break wind in company? (...) Now think about the bodies of other people. (...) soon you will find that the bodies of other people become conspicuous in other ways – smell, size and shape, personal habits. (...) [P]eople experience and engage with the social world and with other people from an embodied perspective. Put another way (...) the physical characteristics of our own bodies contribute to shape our perceptions and interactions with others in everyday life.” (Howson 2004:2)

Human body has a great symbolic value. With a reference to Mary Douglas’ thoughts, the physical body can be considered as a natural symbol, that is, body symbolizes naturally “the relation of parts of an organism to a whole”, more concretely, the individual’s relation to his/her society. In primary sense, the physical body serves as an endless resource of analogies

for social and political life (like head of the government, a social body, heart of a country, etc.). Additionally, in the practices of body regulations we can identify the ways of control conducted by the society over its members. Growing social control implies strengthening and widening bodily control: it is expanding to wide spectrum of body related phenomena, just as smells, noises, movements, and communication about its inner processes. For instance, it is not allowed to show certain parts of the body publicly, or it is not acceptable to talk (or sometimes even think) about different functions or organs of the body. With the increase of control, the body seemingly becomes more and more invisible in social interactions. “The more complex the system of classification and the stronger the pressure to maintain it, the more social intercourse pretends to take place between disembodied spirits. Socialization teaches the child to bring organic processes under control.” (Douglas 1996:76) As a summary, body is a symbol of the self, the embodied identity of a person, something what we are. Simultaneously, the body is a symbol of the society: it is something we have, the greatest determinant of the self because of the social meanings manifested through body regulations. (Synnott 1993:1-2)

As a consequence of this relationship between the physical and the social body, the symbolic power of the body serves a perfect territory for medical anthropology to take a look on power relations, social differences, family systems or religious beliefs of different cultures. The body itself through its ever-changing conditions (from birth, anomalies of the body to death) offers special field for anthropological investigation of culturally diverse answers on universal experience of fragility of human life.

The cultural connotations of malfunctioning or disabled body not less inspiring for anthropological research. However, medical anthropology started its carrier after WWII, and the first references to applied anthropological approach in the field of medicine have arisen in the early 1960s (Sobo 2011), the body itself remained out of inquiry within medical anthropology till the 1990s. (Lock 1993, Green 1998) Due to the growing consciousness and interest around the body from the late 1970s, problematization of the body slowly became the part of the medical anthropological horizon. Questions of biopower and governmentality elaborated by Foucault, and the recognized discrepancies between medical taxonomies and

subjective illness experiences of patients, draws anthropology's attention to biomedical categories. (Lock 1993:140-141) Within the realm of medical anthropology a critical view has been emerged as a response to the dominance of the biomedical model over body issues in modern societies. Where this dominance is coming from?

Due to the triumph of modern medicine based on natural scientific traditions, medical understanding become the most legitimate and competent way of speaking about the human body for the 20<sup>th</sup> century. The biomedical model reduces the bodily events to somatic questions, so the social, cultural, psychological or mental aspects are closed from its cosmology about body-related phenomena. It considers body as an anatomically, physiologically defined complex unit, and malfunctions of it can be analysed and treated with the help of universal classification system of medicine. With the rise of the clinical medicine from the middle decades of the 19<sup>th</sup> century, the patient is more or less passive actor of the healing process, who subordinates himself to the directions of the physician. (Jewson 2009)

The modern medicine established the foundations of mass-medical care which handle thousands of cases. According to Weber, the effectiveness of these complex organizations guaranteed by the rationalization of all levels of work, hierarchy of authority, and regulation of actors (Larkin 2011). Rationalization process (Ritzer 1993) is necessarily extended to the patients, too. A category of the 'average patient' is needed to maintain effectiveness, so the culturally, socially coloured, more and more diverse individual needs, special or rare problems and conditions are easily stay invisible. As a consequence the patient who is an individual with individual identity, needs, life story, fears and knowledge, experiences impersonalization, obscurity and may insecurity in the uniformalised system of health care. Moreover, the rationalization of medical delivery systems (Ritzer 1988) and changing lay concepts and knowledge about the body affects the medical profession, as well.

As a response of these challenges anthropology observes the actors in the world of health and illness in their totality, never cuts them away from their social and cultural contexts, and consider body as multidimensional, complex phenomena, which should be examined alongside diverse aspects and methods. (Bánfalvy, Molnár 2000).

## Examples of the body social – the identity and technologies of body alteration

Seeking for examples of intersection of the physical and the social body, alteration of the body could be one of the most referred illustrations. The body is an interface between the self and the society: the two spheres uses it like a message board for continuous communication, so far, that we cannot think of the body in purely physical sense even if it is represented in its most natural conditions. Temporary modes of body alteration, like body painting or permanent technics like tattoos or circumcision can be identified in variable societies. (Sanders-Vail 2008) People use it as an aesthetic practice to be more attractive, or as a tool of self-expression. But body alteration is also a means of performance of social status. Ebin mentions the ritual tattoo of married Ainu women in Japan, who got a blue moustache-like tattoo to distinguish them from the unmarried female members of the community. A smaller version of the tattoo has been prepared during their puberty which gains its final form after the wedding. Beside the face the hands of the married women are tattooed as well, to express their loyalty and allegiance to their husbands. (Ebin 1979) Body alteration, for example cosmetic surgery in modern societies, may interpreted as an inscription of the body, that is, the society through the preferred resizing and reshaping techniques represents its standards of normality, health or beauty, which is a way of discipline and regulation of its members. At the same time in the era of flood of images about bodies, tattooing or piercing of the body could be action of protest against the virtuality of the body, and emphasize the “flesh and blood” reality of it. Schildkrout says “these practices may highly symbolic, but they are not metaphorical. They represent a kind of ‘border skirmishing’ (Fleming 2001, p. 84) between selves and others and between social groups. They inevitably involve subjects who experience pain, pass through various kinds of ritual death and rebirth, and redefine the relationship between self and society through the skin.” (Schildkrout 2004:320)

To put it in a nutshell, the physical and the social body is reflecting on each other through the relations between the natural and artificial alteration of the body. The traits of passing time like wrinkles, changing weight, height or physical capacity evoke social answers in the form of body alteration. Nevertheless, there is a significant difference between the traditional and

modern consumer society. As Featherstone explicates, in traditional societies all relevant milestones of life are signed by body rituals, where activities with physical and biological roots (eating, drinking, decoration, mutilation, purity rituals) symbolizes the changing social status of the naturally changing body. So body alteration draw attention to the lapse of time. In modern societies body alteration techniques occur in an opposite way: the reshaping of the body is happening with the aim of hiding the marks of time, the boundaries between life-cycles disappear or at least become blurred and porous. The symbolic effects of body alteration possibly reach under the skin. The maintenance or conservation of the body is a time-consuming and turn to be a distinguished lifestyle form. The young, capable and thin body is a masterpiece of life, and the social relevance of attractiveness gains increasing significance in the interactions between the members of the society. It is the era of the self-preservationist conception of the body. (Featherstone 1982)

## Summary

The flourishing concepts and binaries around the body mirrors its inner symbolic power, but during the analyses of meanings and interpretations of these symbols, it is important to make analytically difference between having a body, doing a body and being a body. “It reminds us, that self and the body are not separate, and that experience is invariably, whether consciously or not, embodied.” (Nettleton 2010:57) From the point of view of the everyday practice of health care, the recognition of this kind of interconnectedness shows a way to a complex model of health, illness and disability, and in a more general sense, it creates a chance for a more self-reflective understanding of medicine and health care work.

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## **b. The social construction of gender**

Written by Diana Szántó

### **Gender in cross-cultural perspective**

In intercultural studies several attempts have been made to identify a definite number of dimensions along which cultures may differ. One of the leading interculturalists, Hofstede (2001), has proposed 6 dimensions, one of which would be the axis masculine/feminine. In his theory masculine cultures would value competition and strength, while feminine cultures would attribute more value to caring and tenderness. This division corresponds so much to the stereotypical image of men and women in Western cultures that it just appears natural. But do we have any reason to believe that the distribution of these values along the division female/male is universal?

Gender is the social meaning attributed to sexes – male, female and- in societies which allow it - to individuals not conforming to this basic duality. Gender is based on the biological attributes of the sexes, but it is not determined by them. It is not about biology, it is about representations and social expectations. Of course, Hofstede knows that gender roles are socially constructed and consequently they may vary greatly from society to society, but even he maintains an implicit assumption about the universality of gender roles as we think of them in most of our Western societies.

Ethnographic evidence from different parts of the world contradicts this assumption. One of the first anthropologists, who managed to scatter ideas about the universality of gender ideologies, and with that to scatter American ethnocentrism, was Margaret Mead. With her “Coming of Age in Samoa” she showed to the American public that not only different ideals about sexuality and gender relations exist in the world but apparently Samoan girls that are exposed to much more libertarian moeurs than contemporary American girls grow up to healthier and happier young women. Studying different cultures help question our most basic ideas about gender. In Europe for example we tend to take it for granted that „mothers are

caring, fathers are more distant”, „mothers represent safety, fathers’ discipline.” We even often believe that sexual emancipation and equal rights for women is a question of development and hence an advantage that modern societies have over traditional ones. We think it is logical that in „traditional societies the female role is to give birth and nurture the offspring (these two roles being inseparable), the male’s role is to protect the family”. Studying gender from an anthropological perspective allows a better understanding of the subtle interrelatedness between biology and culture, and contributes to the important realisation of the fact that not everything that sounds logical is necessarily true or universally distributed.

Scientific research amongst the primates seem to confirm that male aggression and female tenderness are inscribed in our biological heritage and this fact is explained by the functionality of such separation of social roles. In most (although not all!) non-human primate societies such patterns are indeed demonstrated (Smuts 2001). However researchers observed also that male and female primates behave differently in the presence of the opposite sex. Captive macaque males, when separated from females showed a variety of infant caretaking, inversely in all-female groups, female primates developed behaviours that otherwise characterise males in mixed groups. Interestingly, deeper explorations in the animal world seems to support anthropology’s relativism according to which both female and male individuals carry a wide range of behavioural potentials which are getting activated by social structures or alternatively remain latent if they contradict normalized social patterns. Already in the non-human primate world: gender is both biological and social!

In the human world cultural variations are even more to be expected. But intuitively there must be some universality behind the differences! In all human societies babies as a rule are born as biologically male or female (it does not mean that there are no exceptions to the rule). Structuralist thinkers, such as Lévi-Strauss (1964) and Françoise Héritier (1996) think that the duality of the sexes is indeed the basis not only of the social structure but also of symbolic (and hence also of scientific) thinking. All our cognitive functions are based on the elementary capacity of categorisation, the most fundamental building brick of which is the ability to think in binary oppositions. „The duality of the sexes is good to think” – as structuralists say, by

which they mean that this primary opposition helps us to understand the world as a series of related oppositions between identical and different.

However, the fact that – if structuralists are right - all societies are based on the dual relationship of the sexes does not mean that their thinking is absolutely determined by biology. Amongst the Inuit for example the biological sex and the identity of the person were separated (Heritier 1996). It is not the biological sex of the baby that would determine his/her identity but the sex of the soul-name he/she was supposed to reincarnate. Accordingly, a boy carrying a female soul-name could be brought up as a girl until the puberty – a fact that would not stop him from performing social tasks associated to his sex as an adult man, without ever losing his female part of identity. „With the same symbolic ‘alphabet’ – writes Heritier – which is rooted in a common biological nature, every society works out different cultural ‘phrases’ that are unique to them” (Heritier 1996).

For Héritier, there is more to the difference between the sexes. Male and female are not only universally thought as different, but are also situated on a symbolic scale that is inherently hierarchical of nature. Accordingly, she thinks that male domination is universal, perceptible even in matrilinear societies, although she admits that domination may translate into very different practices and representations, some of them being more subtle than the others. She affirms that the essential reason of this hierarchical order is not the real or supposed biological fragility of the women; rather it is the consequence of human, i.e. mammal procreation. Amongst humans there is an evident biological tie between the mother and the child, while this same tie is logically only hypothetical between the father and his offspring. Consequently males always try to control reproduction by social means – hence the necessity of their domination.

Comparative ethnography tends to support Heretier’s thesis. Indeed, it is difficult to find a society where some kind of inequality does not exist between the sexes, and our modern societies in the West certainly do not constitute any exception. However, ethnographic explorations seem to suggest that there is a direct correlation between the extent and scope of the contribution of women to the domestic economy on the one hand, and their social

position on the other. Equality grows with the recognition of the weight of female work in the household. Also, domination is seldom an absolute relation. Our own cultural expectations (especially our stereotypes of so called „traditional societies“) might blur our vision and can stop us from recognizing elusive mechanisms that work towards an equilibrium in the couple, enhancing the social position of the women.

Even in societies well known for their male supremacy, women might have an important leverage which is not always immediately observable. The Javanese is such a society. An important corpus of anthropological literature describes how in Java social status is associated with mystical power, a quality usually attributed to men, as men only are believed to possess the self-mastery necessary to achieve it. The external signs of mystical power are calm and refined comportment and speech style in public. Women are thought only exceptionally able to attain this ideal. In an interesting study, Suzanne Berner (2001) demonstrates that although this picture is not false, it reveals only half of the truth.

Berner argues that in Java (and probably elsewhere too), there is not one, but at least two gender ideologies: a hegemonic and a counterhegemonic one. The mainstream ideology is usually represented by men (and that is why it is also more accessible to anthropologists who tend to be men too) and it reflects gender relations exactly as described above. There exists however a counterhegemonic ideology according to which gender relations look quite different. First of all, it is a fact that in Java women are quite active economically. They often trade or have other jobs, which non-infrequently makes them de facto the provider for the family, while the men can enjoy leisure at home. The market, where most of the sellers are women (male merchants are Chinese, Arab or European!) symbolically bears the mark of lower social status, because according to the dominant ideology dealing with money is regarded as vulgar and unrefined. In the facts however, women's involvement in commerce enhances their economic independence. Women also keep the domestic economy in their hands: husbands are expected to turn over the totality or most of their salary to their wives, who then decide on the spending in the best interest of the family. Girls can inherit in the

same way as boys and after marriage they keep their own belongings. Thus, from a material point of view, women enjoy an equal or quasi-equal status with men.

From a symbolic point of view, however, women have defiantly less prestige than men, not despite, but precisely because of their involvement in economic activities. Women do argue loudly in the market, slap each other in a joking manner, and use a verbal style which would be incompatible with the composure demanded from men. According to the hegemonic ideology, this very behaviour is the proof of women's incapacity to control themselves, a fact that naturally relegates them to the second place, after men. At the same time, the counterhegemonic discourse (which is not simply only the women's voice) holds that to the contrary, men are less capable than women to control their passion, that is why it is prudent to keep them away from money (which they would probably spend childishly on women). This alternative ideology recognises women's double (economic and symbolic) strength and evaluates their social position accordingly.

At the end, this double distribution of gender roles, and gender styles, remarks Brenner, serves the collective interest of the family. Wealth is necessary for prestige but the process of acquiring it compromises social status. Because women take their social status from their husbands, their economic activity does not disadvantage them socially, while it contributes to the family's wealth. It is not that women „naturally” behave in a less dignified manner than their husbands; they are obviously capable of composure. In fact they are the ones who teach their daughters and sons of good manners at home, but in public they are allowed to be less self-restrained than their husbands. Consequently, they have at their disposal a broader range of styles in public than men. Men however might show less self-control at home where they are not on a public scene. This is an interesting example that proves how discourses and practices regarding gender statuses might be contradictory within the same society and while there is a universal tendency to imagine difference organised on a hierarchical scale, hierarchy might look different when seen from different angles.

The Javanese example sheds light on the important nuances that colour gender relations in most societies, but certainly does not contradict the idea that motherhood and fatherhood

prescribe social roles that are deeply rooted in biology. There are however strong ethnographic evidences that prove that motherhood is not less socially constructed than fatherhood. The Baule (Etienne 2001) represents a particularly interesting case from this point of view. Amongst the Baule men's and women's contribution to economic production are equally recognised, women might achieve high social status in their own right and until colonisation female chiefs were not rare.

As in many African societies wealth and social recognition are related to the number of dependents. A big number of children is thus considered as a source of recognition in the present and that of social security for the future. However, as the descendance is patrilinear amongst the Baule and women live in their husbands' house, their children are considered as dependants of the husband and his close relatives. Adoption and fosterage might be a solution for women to increase their social status as adopted children, as opposed to biological children, remain under the control of the woman who receives them as a „gift” from the biological mothers.

While adoption is a natural part of the kinship system both in rural and urban communities, it has a special role in contributing to the social and economic ascendance of rural women who migrate to the city and devote themselves to petty trade. Rural families are happy to send some of their children to the city to foster mothers in the hope of assuring the schooling of their children in this way. Maternal care in Baule society is not considered as an automatic attribute attached to biological motherhood. To the contrary, some biological mothers are thought not to be gifted to raise children, while some adoptive mothers have the reputation of being a good parent and consequently might receive a big number of children to raise. This case, which does not stand alone in West-Africa, undermines the assumption „that maternity is irrevocably natural” as opposed to fatherhood which is admittedly social.

Paradoxically the recognition that fatherhood is socially constructed entails a supposition that fathers everywhere and at all times „naturally” develop less bond with their infants than mothers. Hewlet (2001) compared the time fathers spend with their infant in the USA and amongst the Aka Pygmies of the Central African Republic and he came to an interesting

conclusion. He found that American fathers hold their babies between 10 and 20 minutes a day, while Aka fathers tend to hold their infants an hour during the daytime and 25% of the time after sunset. Not only Aka fathers spend more time with their children, their parenting style is also different from American fathers. American studies emphasise the importance of fathers' „vigorous play” with babies. Aka fathers seldom engage in such play. Instead, they demonstrate tenderness: they kiss, hug and sooth more than mothers.

Why is father-infant bonding so conspicuous amongst the Aka? Hewlett's answer is that this is because Aka fathers are simply more present in children's lives and this is a consequence of the organisation of Aka life where men and women often engage in food seeking activities together. Aka people practice net hunting, in which men, women and bigger children equally participate. Therefore the sexual division of labour is less strict in Aka society than in most hunting (and non-hunting) societies. Consequently fathers know better their children and they do not have to use strong stimuli in order to trigger an answer when interacting with them. (It is interesting that according to Hewlett not only American fathers but also American working mothers who have less interaction with their babies use strong stimuli with their children.)

The Aka example reveals an interesting correlation between the women's status, parental roles and general ideas about hierarchy and equality. The Aka are notoriously egalitarian, they have several mechanisms to maintain „individual, intergenerational and gender equality” (for which they are notoriously despised by their neighbours, who see in this liberty a lack of order). (Hewlett 47) Although there are specific male and female roles, inverting roles by no means counts as strange or rare and little boys and girls are also socialised in this way. This observation seems to confirm another theory on gender relations according to which the less a society separates gender roles according to a strict division of labour, the more freedom and equality its women enjoy. It also shows a strong relation between shared parental roles and gender equity.

If ethnographic case studies prove that male and female identity are always constituted in culture-specific ways, shedding doubt on a universally shared symbolic dichotomy between men and women, it still seems natural to suppose that everywhere there is a direct relation

between sexual identity and gender identity. In reality, there are also great variations in how sexual identity is constituted in different societies. As opposed to modern Western cultures where it is assumed that sexual identities are more or less fixed, in many parts of the world sexual identities are fluid, multi-faceted and do not necessarily function as basic constituents of gender identity.

Herdt (2001) offers a case in point with his study of coming of age amongst the Sambia. The Sambia is a hunting and horticultural people of New Guinea. They live in small hamlets in the mountains. Society is divided in exogamous clans but marriages might occur within the same hamlet. Nuclear families live together in small huts. The Sambia do not believe that sexuality determine gender: while girls obtain their full sexual female identity progressively and without any major social drama, boys have to be progressively initiated by adult men into adult sexual roles. Girls continue to dwell with their parents until their marriage. However, boys, when they reach about 7 to 10 years of age are abruptly drawn out from the family unit and are transferred to the men's house.

Masculinity, strength and combativity are highly valued in this society and cohabitation with women is considered to „pollute“ the male identity with woman-like elements. Time passed in the man house therefore has the main goal of „cleaning“ the boys from female pollution. While the girls' sexual maturation is considered a natural process, the boys' sexual maturation has to be enhanced socially. Initiation is in the hands of the men's secret society and is repeated several times until the young men reach their full adulthood, sealed by the birth of their first child.

„Maleness, unlike femaleness, is not a biological given“ (165). Girls are believed to possess a menstrual blood organ, the tingo. Boys possess another organ, the kere-ku-kereku, the repository of semen, which is empty in the beginning and has to be filled up progressively until full maturity. Through initiation adult males inseminate the boys orally in order to provide them with the necessary quantity of semen „the very essence of maleness“. For the Sambia initiation entailing homosexual practices does not relativize the masculine sexual identity, to the contrary, it is the royal path to full masculinisation.

Just like the Sambia boys who engage in homosexual practices in their youth before contracting heterosexual marriages, girls in some cultures also have available socially acceptable forms of same sex relations that do not compromise their future chances of married life. Evelyn Blackwood (2001) reports on several such cases. In all these cases women and girls engage in same sex sexual and emotional relations but the examples vary in the extent to which these relations and corresponding practices become an essential and fix attribute of their gender identity. In Lesotho (South Africa) for example, school girls may engage a culturally institutionalised relationship that they call mummy-baby. This type of friendship links an elder, more experienced girl to a younger one. The younger one may have only one „mummy”, while „mummies” may have several „babies” at a time. As the small ones grow older they may turn to be mummies for others. This is an intimate and loving relationship involving exchanging love letters, gifts and initiation to adult sexuality. As girls grow up, they may start to have boyfriends as well. Heterosexual relations tend to replace the strong same-sex mummy-baby bonds, but some women keep these relations throughout their married lives, without provoking resentment on the part of their husbands. Such practices have been reported from South Africa from the 1950s. Aboriginal Australian women constitute another case. According to Roheim, before missionary times, extramarital same sex-and heterosexual relations were accepted both for women and men. For girls, erotic ritual play was part of initiation. Such plays amongst adolescent girls are also part of normalised culture for the !Kung of the Kalahari Desert.

While in these instances adolescent sexual homosexual plays and even institutionalised sexual relations do not have consequences for adult marital life, other cases are recorded where changing sexual identity can transform totally gender identity. In the 19<sup>th</sup> century China marriage (arranged marriage as a rule) was an essentially oppressive institution for women. The development of the silk industry allowed some of the young girls to earn their own wage and postpone marriage infinitely with the approval of the parents who benefited from the financial support of their daughters. With time, resistance to marriage produced intimate sisterhoods. Sisters lived in the same households in which heterosexual relations were

banned. A young woman who chose this life style took a public vow to refuse marriage that established her legal status and secured her a due place in ancestor worship in her natal house (Sankar 1986). In Indonesia too, there is a way for young girls to escape their gender status. Tomboi are a category of girls who act like boys. “Although tombois have female bodies, they are locally understood as female-bodied men who are attracted to (normatively gendered) women” (243). The variety of these examples show that there is no one specific way in which a direct relation could be established between dominant gender ideologies, kinship and political systems and the construction of sexuality.

While anthropologists explore diversity in contemporaneity, historians allow relativize norms held to be universal based on temporal variations. Thomas Laqueur (1990) who investigated the changing representations of biological sexes in the West pushed social constructivism even further. He demonstrates that not only gender is socially constructed but there is also nothing natural in the way how biological sex is understood. In our Western tradition, starting with the ancient Greeks, for many centuries what he calls the “one sex thesis” was upheld. Women were not imagined as essentially different from man; their sexual biologies were rather represented as inversed versions of male sex organs. Their sexuality was also pictured as identical with that of men. Conception was thought to be a condition of female orgasm and women’s sexual pleasure was thought to be equal or even stronger than men’s. This situation changed radically with the advent of capitalism. In the 18<sup>th</sup>-19<sup>th</sup> centuries women were already pictured as radically different from men biologically as well as mentally and spiritually. Female sexuality became a taboo and even the existence of female orgasm was questioned. Laqueur supports his thesis with an ample collection of visual material taken from ancient anatomy books and artistic representations. His aim is not only to prove that biological sex is socially constructed before gender, but also to show that social representations about the sexes just like those of gender roles are always political, responding to ideological demands of the dominant political order. The normalised, gendered and sexed body is the mirror picture of the idealised society, in the West and elsewhere. That is why

ideas about what is male and female is a classical and one of the most sensitive of sensitive zones in intercultural encounters.

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### **c. Dying, mourning and end of life rituals in different cultures**

Written by Attila Dobos

#### **Death and dying**

The problem of death – as being the limitation of our known world – certainly concerns one of the most important and vital questions of all human of all time. The answers given to it tell us much more about the worldview of the community than any statement of this purpose. At the same time the more general claims we would like to make, the more ambiguous we will be. It is because there are many different aspects we can take once we would like to understand our mortal lives, so ourselves, and these differences sometimes contradict each other. For instance through the lenses of science, one cannot catch the essence of spirituality or soul, as these will transcend the possibilities of scientific tools. Vice versa: in a religious context, it makes no sense to argue for or against scientific achievements as belief has another nature and function than that of knowledge. Yet both perspectives seem to be very important for us.

However, few universal characteristics of mortality can be found throughout space (culture) and time. As many historian of religion pointed out from the very beginning of our collective memories, there has always been a belief that by the death of our bodies ‘we will not die’ entirely so that we have a part of us what remains alive, what is independent of our body yet definitely belongs to us. „Belief in a survival after death seems to be demonstrated, from the earliest times, by the use of red ochre as a ritual substitute for blood, hence as a symbol of life.”<sup>15</sup> Skulls and lower mandibles are preserved with religious purposes from 400.000-300.000 BC, and we can speak with certainty of burials from 70.00-50.000 BC. Another important absolute character seems to be the collective consciousness around the image and ritual of death. In each community, there has been numerous and definitive meanings

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<sup>15</sup> Eliade (1981) p. 9

surround the loss of the deceased and expressed in rituals, although in very different forms and purposes. These meanings also help processing feelings about loss, like grief.

Keeping health care in focus, we cannot avoid discussing the biological, medical or simply the scientific understanding of this elementary phenomenon. Moreover, our times, often referred to as 'late modernity' appear to value highly (if not exclusively) the scientific explanation of reality. From this regard, we should take biology – the 'science of the living' – as a widely accepted context in our profession. Naturally, this will not be satisfactory, but necessary starting point.

One common way in understanding death is to start with finding the smallest living unit in human life, which is the single cell. Multicellular creatures – like humans – composed of huge amount of cells, in our case it is over a hundred trillion individual cells ( $10^{14}$ ), each with a life of its own. Therefore, "The death of a human being is a direct, irreducible consequence of the death of his or her component cells."<sup>16</sup> Investigating death in the level of cells revealed many unexpected complexities and adventures, e.g. the suicide of certain cells. However, most of all it seems that the earliest forms of single-cells did not share a cardinal feature of life – what would also define us as alive –, i.e. the programmed, hence obligatory death. They may die – also today – as a result of changing environment, like lack of food or the presence of more powerful hungry cells, or accidents, but there is nothing programmed into them that they must die by ageing. "Death is not inextricably intertwined with the definition of life."<sup>17</sup> And it was the case for at least the first billion years of life on earth. How can it happen? The answer lies in the first fundamental feature of all living creature: capability of the replication of their own DNA and the transmission of it to the offspring. Single-cells have asexual reproduction, which means that they do not need any other peer from a different sex to produce offspring: they reproduce themselves by fission, by self-division. As a result, two (theoretically) identical cells will come into life as offspring with the same DNA and then the process continues. Hence, these organisms never die (due to ageing) as we cannot really imagine death without the dead

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<sup>16</sup> Clark (1996) p.3

<sup>17</sup> Clark (1996) p.54

corps – at least if they die due to another reason, there is always a cadaver and we will understand this clearly as the ultimate end of the cell. Death, in this reading of biology, is not a consequence of life, but that of reproductive sexuality.

Another approach in modern biology that drives us toward philosophical considerations focuses on an additional cardinal feature of life: metabolism. It is known to be a feature that every living creature has and no dead things have. To our knowledge life only exist in the physical form of organisms. If the organism fails to *do* metabolism, it dies. We can say, “organisms are entities whose being is their own doing. That is to say that they exist only in virtue of what they do.”<sup>18</sup> Their existence lays in their operation and they do not exist apart from this doing. However, since this operation depends not only on themselves, but also on the environment in which they are living, the “peril of cessation is with the organism from the beginning. Here we have the basic link of life with death, the ground of mortality in its very constitution.”<sup>19</sup> In this regard, death is the state without metabolism. Speaking philosophically within the European continental tradition, we tend to consider death both as a *potential* (we may die at any time) and a *necessity* (we have to die once) at the same time.

Form these two brief introductory thoughts one may see the complexities of defining death even on the level of biology. However, we should make a distinction in defining death and establishing criteria to which something or someone has to be considered dead. In the case of human beings, it has even greater significance that leads us to cultural and thus to moral considerations. The dominant death criteria used today serves as a good example of this.

The classical approach to death has been linked to our oxygen demand: the most important component in maintaining human life – among others – is oxygen that can make cells working by circulation. Therefore, loosing spontaneous breathing or heart beating meant death. To verify it was relatively easy, but held many possibilities for mistakes (e.g. Romeo and Juliet), still – together with cadaveric rigidity – it has been used till the middle of the 20<sup>th</sup> century. Due to technological advancements, South African surgeon Christiaan Barnard has conducted the

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<sup>18</sup> Jonas (1993) p. 155

<sup>19</sup> Jonas (1993) p. 156

first successful and public heart transplantation in Cape Town in 1967<sup>20</sup>. Obviously, the criteria of being dead needed to be revised afterwards: one may be still alive without her beating heart, but with a heart of someone else. In the following year at Harvard Medical School an ad hoc committee composed of doctors, lawyers, philosophers and theologians set the new criteria, what was basically a special case of irreversible coma, known today simply as brain death. The developed method can guarantee a 100% reliable diagnosis – even with spontaneous heart beating. This definition has begun to be introduced in most of the countries worldwide in the coming years, except few ones, like China, Japan and other Asian countries. Here comes our point: it was simply impossible (and still is) in some cultures to identify life with neurological activities – it is deeply against their traditional perception and collective knowledge on life and death.<sup>21</sup>

To sum up these considerations above, death should be seen more as a continuous process in which a certain point is defined by the given society according to its tradition, morals, beliefs and technological opportunities to divide the living from the non-living. In the following paragraphs, some instances of these differences will be given.<sup>22</sup>

The expression of experiences of lethal illness, death and dying and grief varies heavily throughout the world. Additionally, the function of these expressions and experiences differs profoundly in various cultural contexts on the top of the already mentioned – seemingly – universal characters. Moreover, within one context many different components may play a part in funeral rites and burial: the circumstances of death (e.g. violent behaviour, illness, and suicide), age at death, social status, reputation, gender and naturally the dominant religion / belief of the family. Lastly, the same or very similar rites could have radically different or opposed meanings in diverse cultures: e.g. pouring alcohol into the ground (libation) amongst

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<sup>20</sup> Although we should note that it was not a real success as most of the patients died within few weeks after the transplantation with this method. This resulted in a world-wide moratorium on heart transplantation till the beginning of the 80's when the procedure has developed into a much more reliable level with an acceptable mortality rate.

<sup>21</sup> It took nearly 30 years in Japan to introduce this approach into the legislation by the 104/1997 act on „The Law Concerning Human Organ Transplants“

<sup>22</sup> Most of the examples are taken from the Encyclopaedia of Medical Anthropology I-II, edited by Carol R. Ember & Melvin Ember

Yoruba people means to summon the spirit of the deceased if help is needed, while in many Roma communities numerous things have to be done in order to avoid the return of the spirit, e.g. pouring alcohol to the ground during the wake is for the peace of the departed, to support her way to heaven. Giving drinks to or feeding the newly deceased can be found all over the world but for different reasons: to get closer to, to respect, to purify, to avoid return, etc.

Treating the dead corps has basically two opposed approaches: in one end of the range the cadaver is dangerous, dirty and represents the risk of connecting the realm of the dead with witches, wicked spirits, diseases, curses and nightmares, while in the other pole it is for the sake of communion and maintained connectedness to stay as close as possible to the dead body. In the first case they mostly buries the body as soon as possible, feasibly within a day, try to make death happen in a distant place and apply massive purification strategies with everything attached to the corps, the deceased person or to the place of death (e.g. in certain aspects in the Navajo, Japanese, Greek cultures). In the latter case they apply long rituals, wakes, death-watches, staying close (even sleeping next) to the corps for days (e.g. in certain aspects amongst the Yoruba, Maori, Romani or British people).

The Yoruba buried the corpses under the floor of the house or outside the door often in unmarked sites – if the death was natural and in timely fashion. However, those whose deaths are considered ‘unnatural’ for numerous reasons (e.g. infants, disabled, albinos, suicides, killed by lightning, etc) are treated differently: in some cases no mourning is allowed, the burial takes place outside the town in the bush, or – in the case of suspected witches – there is no burial at all, but their bodies are thrown into bush areas. The Greek buries their passed away relatives within 24 hours in a loosely made wooden coffin to help decomposition of the corps, so they can perform a rite of exhumation after a period of 3.5 or 7 years to see the condition of the exhumed bones: if the bones are clean and white, the sins of the deceased have been forgiven and she managed to get into heaven. If a young girl or boy die among the Roma people, they often cover the body or the coffin with woods in piles in the grave to protect the body from the weight of the ground.

The expressions to be used during terminal stage, funeral rites or in mourning are also showing very different attitudes throughout the world. While under the reign of the biomedical scientific approach it is obligatory to share every available information with the ill person (unless she forbid it) in a very concrete and understandable way, in many parts of the world the domain of usable expressions are strictly ruled. For instance in traditional China the word “cancer” is not allowed to use in front of the patient for the sake of the patient: it is held that they would not be able to tolerate it and it would make them sicker. So they simply do not use to it. Among Romani people, quite often they avoid to use the proper names for illnesses, as it would make them ill; or try to keep the stay in hospital as short as possible as it is not clean, being full of diseases what makes the patient really sick. In Mongolia, when discussing the death of a close individual they use euphemisms instead of talking about death, like: to come of age, to become a spirit.

Fortunately, these instances can be continued through hundreds of pages, but perhaps the few above mentioned example could also serve to make it tangible and clear: death and the social reality around it with following patients of lethal diseases, mourning, expressions of grief and rites of funerals are totally embedded into the cultural realm of the given community and can only be understood through the lenses of it.

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## **IV) Contact us**

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