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Ethnic and Cultural Diversity: Challenges and Opportunities for Health Law

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Abstract

Guaranteeing equal health care of appropriate quality implies taking ethnic and cultural diversity into account, without over- or underestimating the importance of these grounds. Besides awareness of its relevance, it is essential to have disaggregated data to better understand the relationship between ethnicity and culture on the one hand and health and health care on the other hand. From a health law perspective, it is a prerequisite to understand the conceptual and normative meaning of equality and non-discrimination, also in relation to the right to privacy, and to be aware of the need to collaborate with other legal and non-legal disciplines.

Keywords

Health law, human rights law, diversity, discrimination, equality, privacy

1. Introduction: Roma

According to a 2003 report by the then European Monitoring Centre on Racism and Xenophobia, Romani women encounter considerable problems in accessing public health care.² According to this study, based on research conducted in various European countries from Spain to Lithuania and from Ireland to Moldova, Romani women are reported to have been refused assistance by general practitioners and health care institutions; they are being segregated in health care facilities; they allegedly receive inferior and degrading treatment; and come across difficulties in accessing emergency care imposed as a result of their ethnicity.

In addition it is known that ambulances systematically refuse to serve Roma settlements and neighbourhoods, and that Romani women in various European countries were subjected to forced sterilisation.³ In October 2008, the European Court of Human Rights (ECtHR) declared a case admissible concerning the forced sterilisation of Roma women. The case concerns a complaint lodged by eight Slovakian women of Roma origin who, after their stay in Slovakian hospitals, would not get pregnant despite efforts to conceive. They could not prove that their infertility was the result of a sterilisation performed during their stay in the hospital, now that they could not get access to their medical records and were not allowed to make photocopies their files either. In addition, they complained about the denial of access to an independent court. The complaints with respect to the alleged violations of Article 8 and Article 6 paragraph 1 ECHR were considered admissible, whereas the complaint with respect

¹ This contribution is based on a presentation given in Edinburgh on 11 April 2008, at the occasion of the first congress of the European Association of Health Law. The author wishes to thank the organisers of the congress and the support received from 'stichting gezondheidsrecht'.

² EUMC, *Breaking the barriers. Romani women and access to public health care*, Luxemburg: Office for Official Publication of the European Communities 2003.

³ Anon., 'Access denied. Roma's struggle for public health care', *Equal Voices* 2007, Issue 22 (December 2007), p. 25-27.

to the prohibition of discrimination was considered manifestly ill-founded.⁴ A judgment of the Court on these issues is expected to come out in the near future.

Whereas the treatment of Romani women across Europe, within and outside the health care sector, may in many respects be exceptionally – at least that is what we might hope – it illustrates that the health care system is confronted with patients of different ethnic and cultural backgrounds and is not always capable of treating everyone as equals. Promoting equal access to health care of appropriate quality – of maybe even: equal health opportunities – independent of one’s ethnic or cultural background, or any other particular status, is one of the challenges to be addressed by health lawyers in the future, if not as from today.

In this contribution, I will analyse some of the underlying conceptual, legal and practical issues to be addressed by health lawyers, are they to make a contribution to the elimination of health (care) inequalities, paying proportional attention to ethnic and cultural diversity.

2. Legal Standards

Equality with respect to access to health care of appropriate care is not just merely an ethical principle, closely related to the principle of justice.⁵ It is also firmly embedded in law, including European and international human rights law.

2.1. *Biomedicine Convention (1997)*⁶

According to the well known Biomedicine Convention, ‘Parties [to this Convention – AH], taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality (Article 3 – Equitable access to health care).’

2.2. *General Comment no. 14 on the Right to Health (2000)*⁷

General Comment no. 14 of the Committee on Economic, Social and Cultural Rights is probably the most authoritative, if not at least the most elaborated, international standard on the right to health, as laid down in Article 12 of the International Covenant on Economic, Social and Cultural Rights (1966). According to this instrument, ‘... the Covenant prescribes any discrimination in access to health care and underlying determinants of health ... on the grounds of race, colour, ... national or social origin ... (§ 18).’

2.3. *Council Directive 2000/43/EC (2000)*⁸

According to Directive 2000/43/EC of the Council of the European Union, based on Article 13 of the Treaty establishing the European Community, Member States shall prohibit direct and indirect discrimination based on racial or ethnic origin with respect to:

Article 3 paragraph 1 (e): ‘Social protection, including social security and health care’

Article 3 paragraph 1 (h): ‘Access to and supply of goods and services which are available to the public, ...’

⁴ ECtHR 9 October 2007, *K.H. et al. v. Slovakia* (dec.), appl.no.32881/04.

⁵ T.L. Beauchamp & J.C. Childress, *Principles of Biomedical Ethics* (sixth ed.), Oxford: Oxford University Press 2008.

⁶ Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (1997), *ETS* no. 164.

⁷ The right to the highest attainable standard of health, 11 August 2000, UN-Doc. E/C/12/2000/4.

⁸ Council Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin, *OJ* 2000, L 180/22.

2.4. *Interim Conclusion*

An interim conclusion would be that the right to equal access to health care of appropriate quality without discrimination on grounds of race or ethnic origin is protected on an international, European and – at least in many countries – domestic level with a view of guaranteeing equal (health) opportunities and human rights for all.

3. **Legal Concepts**

Now that denying individuals equal access to health care of appropriate care on the basis of their ethnicity or culture is considered to constitute a form of discrimination, or at least raises suspicions of discrimination, it is important to clarify the meaning of the terms equality, non-discrimination, ethnicity and culture.

3.1 *Equality and Non-Discrimination*

Equality is generally understood to mean that equal cases should be treated equally and unequal cases unequally to the extent of their inequality. The principle of non-discrimination is the counter part of the principle of equality. It prohibits the adverse – ‘unequal’ – treatment of persons on grounds that are intimately related to human dignity, such as race and ethnic origin.

Thus seen, equality and discrimination always entail making a comparison. Or, to put it differently, a person can only claim to be a victim of discrimination if he can prove that he is treated less favourable than a comparator. This interpretation of the principles of equality and non-discrimination is to be rejected. This would mean that an employer does not discriminate on the grounds of race if he can prove that he does not only harass black and other minority group people, but harasses everyone. This, as it is known ‘I am a real bastard defence’, was struck down by the House of Lords in the case *Zafar v. Glasgow City Council*.⁹ As a result, the term discrimination also includes cases of unjust or unreasonable treatment without a comparator. It is important to extend the meaning of discrimination to this end now that the problems ethnic and cultural minorities encounter in society, including with respect to access to health care, are often incomparable to the problems of other groups in society.

At the same time we should realise that treating unequal cases equally can also reflect or perpetuate inequality in society, in particular in case of standards or practices that are one-sidedly tailored to cater the needs of one particular – mostly: the dominant – group in society. Treating ethnic and cultural groups according to the same apparently neutral provision, criterion of practice can therefore disproportionately affect members of these groups. In other words, in case ethnicity or culture are relevant, equality requires to take these factors into account. It is therefore important to acknowledge difference to the extent relevant.

3.2 *Ethnicity and Culture*

The term ‘ethnicity’ is closely related to the concept ‘race’. They both refer to the – presumed common – genealogy or ancestry of a group of people, if not their identity. The first efforts to scientifically define – or should we say distinguish – the human race(s) were stimulated by European imperialism and colonialism. The need to differentiate between ‘them’ and ‘us’ was strongly felt. Important in this respect are the work of the François Bernier - *Nouvelle division de la terre par les différents espèces ou races qui l'habitent* (1684) – and the Swedish biologist Carl von Linne (Linnaeus) who in his book *Systema Naturae* (1758) distinguished four types of human beings. Although nowadays often seen as a social construct, it is

⁹ *Zafar v. Glasgow City Council*, House of Lords 13-10-1997, I.C.R. 1998, 120-126.

generally believed that persons shall not be discriminated against on the basis of their race or ethnic origin, which is part of their felt or attributed identity.

Whereas race, in common day language, sometimes confines itself to skin colour and other biological and genetic characteristics, ethnicity often also covers shared cultural, linguistic, behavioural or religious traits of a group. In this respect it is important to recall that the International Convention on the Elimination of all Forms of Racial Discrimination (1965) defines racial discrimination as discrimination on the grounds of race, colour, descent or national *or ethnic origin* (Article 1).

The term ‘culture’ refers to patterns of human activity, or traditions, and the symbolic significance and importance of these for the members of a particular community. These shared traditions are thought to be part a person’s identity and therefore merits respect and protection.

In the United Kingdom ethnicity and culture are considered to be closely related concepts: in 1983 Lord Fraser held that for a group to constitute an “ethnic group” it must at least have a long shared history and a cultural tradition of its own, including family and social customs and manners. Other relevant factors would include a common geographical origin; a common language; a common literature peculiar to the group; and a common religion different from that of neighbouring groups or from the general community surrounding it.¹⁰

Earlier I contended that discrimination is a form of unequal treatment with respect to a particular ground, human characteristic that is intimately related to human dignity. Many conventions and national laws offer protection against discrimination on grounds of race or ethnicity, but few on grounds of culture. In fact, culture is often perceived as part of one’s racial or ethnic background, if not religion or belief. This means that unequal treatment on the basis of culture is less suspicious, less prone to be qualified as discrimination, than unequal treatment on the basis of race or ethnicity, unless it can be seen as part of the latter or another suspicious ground.

4. The (Ir)relevance of Ethnicity and Culture

Ethnic and cultural diversity is a reality, across Europe as well as elsewhere. Whereas most countries have always hosted ethnic and cultural minorities, in many European countries diversity has become more visible over the course of the last few years as a result of the influx of migrants, refugees and asylum seekers as well as through family reunification, the adoption of children from third countries, etc.

4.1 The Relevance

Why should health lawyers be aware of and pay attention to the diverse composition of the population of our countries? The simple answer to this question is: because there is a demonstrable link between ethnic and cultural diversity on the one hand and differences with respect to the type of diseases and the prevalence of diseases, or more generally: morbidity and mortality, access to health care, and effectiveness of diagnosis and treatment on the other hand. Examples of diseases that disproportionately affect people of particular ethnic groups include Tay-Sachs disease, cystic fibrosis, sickle cell disease, thalassemia and other hereditary hemoglobinopathies as well as type 2 diabetes, colorectal cancer and other types of cancer. In other words, ethnicity and culture correlate with health disparities and therewith fall within the realm of law.

¹⁰ *Mandla and another v Dowell Lee and another* [1983] 1 All ER 1062 (HL) at 1066j-1067d.

But what are the root causes of these differences? Besides health disparities that are the result of migration, isolation, selection, culture and genetic variety,¹¹ there are health disparities reflecting inequalities in the health care system or society at large (education, employment, housing, participation of groups in medical research¹² etc.). Here, let me emphasise, that the environment and lifestyle behaviours, often influenced by the social and physical environment and societal opportunities, contribute for 70 percent of an individual's health, whereas health care (10) and genetics (20) only for 30 percent.¹³

With respect to health care, there is ample evidence that ethnic and cultural minorities do not always receive the same quality of health care, do not have the same access to health care and are underrepresented amongst health professions.¹⁴ In this respect, it is important to recall that cultural diversity is reflected in differences of behaviour and less obvious areas of values, beliefs and traditions with an impact on health,¹⁵ including perceptions on health and disease, the role of the family and the futility of treatment.¹⁶ It can therefore be concluded that there is a relationship between the quality of health care and one's health status depending on the cultural group one belongs to according to both objective criteria and subjective perceptions. The fact that in most countries minority patients are treated by physicians pertaining to majority groups and applying professional standards matching the needs of majority groups, may add to the objective and subjective health disparities instead of reducing these.¹⁷

In the United States, a country with a rich history of multiculturalism, these and other problems were reason for then president Bill Clinton to announce the President's Initiative on Race. However, not only in the US, also on this side of the Atlantic Ocean has the health care system and have health care providers sometimes difficulties is attaching adequate weight to ethnic and cultural factors. In fact, it sometimes believed that ethnic and cultural diversity are irrelevant factors with respect to the treatment of patients. At the same time, it is sometimes assumed that ethnic and cultural variety is the main or sole reason for health problems.

4.2 *Acknowledge Difference to the Extent Relevant*

Generally speaking, there is nothing wrong with acknowledging the difference between individuals on the basis of their unique characteristics and circumstances they find themselves in, including their ethnic and cultural background. In fact, such is a requirement for ensuring equal access to and the enjoyment of health care of appropriate quality and non-discrimination.¹⁸ Therefore, it is important to acknowledge difference, including ethnic and cultural difference. At the same time, we should neither under- nor overestimate the importance of ethnic and cultural diversity on health and health care.

While many health care providers in our countries seem to think that ethnic and cultural diversity is irrelevant for the treatment given – “no, I do not discriminate” - there is ample

¹¹ J.S. Alper (ed.), *The double-edged helix: social implications of genetics in a diverse society*, Baltimore: Johns Hopkins University Press 2002.

¹² S. Epstein, *Inclusion: the politics of difference in medical research*, Chicago: University of Chicago Press 2007

¹³ Ch. Grosel et al., *Health and Health Care 2010. The Forecast, The Challenge* (2nd edition), Princeton, NJ: The Institute for the Future 2003, p. 23.

¹⁴ American College of Physicians, 'Racial and Ethnic Disparities in Health Care (Position Paper)', *Annals of Internal Medicine* 200, p. 226-232.

¹⁵ M. Martin, 'Meeting the challenges of cultural diversity in the Irish healthcare sector', presentation given at the conference *Meeting the challenges of cultural diversity in the Irish healthcare sector*, 6 November 2001.

¹⁶ Ch. Obihara et al., 'Tussen twee werelden. De grens van medisch zinvol handelen kan per cultuur verschillen,' *Medisch Contact* 2008, p. 334-337.

¹⁷ R.A. Williams, 'Cultural Diversity, Health Care Disparities, and Cultural Competence in American Medicine', *Journal of the American Academy of Orthopaedic Surgeons* 2007, p. S52-S58.

¹⁸ C. Torres-Parodi & M. Bolis, 'Evolución del concepto etnia/raza y su impacto en la formulación de políticas para la equidad', *Revista Panamericana de Salud Publica* 2007, p. 405-416.

evidence that health care providers do take the patient's ethnic or cultural background into account when making a diagnosis of a patient. Recently, for example, researchers in the United Kingdom demonstrated that psychiatrists – at least in England and Wales – wittingly or unwittingly allowed their clinical judgment to be influenced by the skin colour of their patients.¹⁹ Also, individuals pertaining to black and other minority groups in the United Kingdom were much more likely to be compulsorily admitted to in-patient units to be diagnosed with psychosis than white patients. This, according to some, showed that the British mental health sector was institutionally racist, leading to a heated national debate on the role of race in the mental health sector.²⁰

This suggests that while physicians think of themselves that ethnicity and culture are irrelevant (underestimate), they subconsciously attach considerable weight to these factors (overestimate).

4.3 *Acknowledge the Importance of Communication*

Ethnicity and culture seem to be particularly relevant when it comes to communication, including the provision of information and obtaining the patient's consent for a treatment option. In fact, without good communication, it is virtually impossible to obtain the patient's consent for treatment.²¹ Courts have imposed, sometimes, far reaching obligations on care providers to ensure that the patient can understand the relevant information before giving or withholding consent.²² But also otherwise, we can hardly underestimate the significance of good communication with patients.²³ Good communication can not only be inhibited by a lack of cultural sensitivity on the part of the physician, but also be hindered by insufficient language skills on the part of the patient. The latter can have disastrous results, as was exemplified in the case of *Vo versus France* examined by the European Court of Human Rights. The applicant in this case, Mrs Vo, is a woman of Vietnamese origin who attended Lyon's General Hospital for a medical examination scheduled during the sixth month of her pregnancy. On the day she had an appointment, another woman, Mrs Van Vo, was due to have a contraceptive coil removed at the same hospital. When Dr G., who was to remove the coil, called out the name "Mrs Vo" in the waiting-room, it was the applicant who answered. After a brief interview, the doctor noted that the applicant had difficulty in understanding French. Having consulted the medical file, he sought to remove the coil without examining her beforehand. In so doing, he pierced the amniotic sac causing the loss of a substantial amount of amniotic fluid. Eventually, the pregnancy had to be terminated on health grounds, after it had been diagnosed that it could not continue further.²⁴

More recently, the European Court of Human Rights came out with a judgment concerning a man who was forced to do his military service at the age of 71 year old. The man was a shepherd, who had always worked for local villagers and who spoke only Kurdish. In 2000, at the age of 71, he was taken by gendarmes to the military recruitment office, where he was certified medically fit to perform military service. Subsequently, he underwent military

¹⁹ Commission for Healthcare Audit and Inspection, *Count me in. Results of a national census of inpatients in mental health hospitals and facilities in England and Wales*, London: Commission for Healthcare Audit and Inspection 2005.

²⁰ S.P. Singh & T. Burns, 'Race and mental health: there is more to race than racism', *British Medical Journal* 2006, p. 648-651 and R.M. Murray & P. Fearon, 'Searching for racists under the psychiatric bed: Commentary on... Institutional racism in psychiatry', *Psychiatr. Bull.* 2007, p. 365-366.

²¹ ECtHR 9 March 2004, *Glass v. the United Kingdom*, appl.no. 61827/00.

²² Supreme Court of Canada 9 October 1997, *Eldridge v. British Columbia*, [1997] 3 S.C.R. 624, 1997 S.C.C. 327.

²³ G.L. Kreps & E.N. Kunimoto, *Effective Communication in Multicultural Health Care Settings*, Thousand Oaks: Sage 1994.

²⁴ ECtHR 8 July 2004, *Vo v. France* [GC], appl.no. 53924/00.

training for recruits for one month. He was forced to take part in the same activities and physical exercises as 20-year-old recruits. He was the target of jokes, had problems eating at army barracks since he had no teeth and he suffered from heart and lung problems on account of temperatures dropping to as low as minus 30°C. After one month he was transferred to a hospital where he received a certificate exempting him from military service on grounds of heart failure and old age.

Here the Court found a violation of Article 3 of the European Convention on Human Rights (ECHR) – prohibition of inhuman or degrading treatment or punishment – explicitly taking into account the language barrier the applicant was confronted with. The Court acknowledged that the impossibility of the applicant to speak with his superiors and physicians on his health problems added to the suffering he underwent.²⁵

But, as said, not all problems can be solved by way of communications. Sometimes health disparities are the result of deep rooted traditions, such as food patterns, consanguineous unions (marriages between close biological kin) as well as violence against women. The health risks involved can only be reduced effectively by being fully aware of these traditions, which involves knowledge of particular groups and their traditions.

5. What is needed

The basic question we are facing today as health lawyers – as well as health policy makers and others – is therefore: how do we adequately weigh ethnic and cultural diversity without underestimating or overestimating difference? The basic problem in this respect seems to be a lack of:

- a) Data and
- b) Awareness and Sensitivity.

a) Due to a lack of disaggregated data we do not know to what extent health (care) disparities are related to ethnicity or culture.²⁶ We neither know whether health inequalities are caused by genetic factors or if they are the result of individual choice of social circumstances?²⁷ The latter is rather important in view of the strategies to be developed on an individual or collective level to reduce these inequalities²⁸ and the role the law could play in achieving more health equality and to counter discrimination in the health care sector.

Collecting and other forms of processing medical data immediately raise the question whether such is allowed from a privacy perspective. Here it should be recalled that the right to private and family life, as laid down in – for example – Article 8 of the ECHR.

b) Awareness in general is needed to acknowledge differences and to know how much weight should be attached to ethnic and cultural diversity with respect to the provision of health care. When discussing such items as quality of health care, the professional standard, the participation of various groups in medical research, etc. we need to ask ourselves to what extent the particularities and needs of ethnic and cultural minorities have been taken into account.

²⁵ ECtHR 4 March 2008, *Taştan v. Turkey*, appl.no. 63748/00.

²⁶ P. Braveman & E. Tarimo, 'Social inequalities in health within countries: not only an issue for affluent nations', *Social Science and Medicine* 2002, p. 1621-1635.

²⁷ K. Stronks, *Socio-economic Inequalities in Health: Individual Choice or Social Circumstances?*, Rotterdam: Erasmus Universiteit Rotterdam 1997.

²⁸ K. Stronks, *Maatschappij als medicijn* (inaugural lecture), Amsterdam: Universiteit van Amsterdam 2007.

6. Comprehensive or special health care?

This brings us to maybe the most difficult point: In case these problems – the absence of data and lack of awareness – are solved, we will have to answer the question whether the health (care) disparities related to ethnicity and culture can be addressed – or at least reduced – by a universal / mainstream health care system or by specific / targeted measures, within or outside the health care sector.²⁹ As said before: equality sometimes implies treating people the same, but in case of relevant differences people should be treated differently in proportion to their inequality. But inequality can also be the result of treating everybody the same without acknowledging differences, like in the case of a health care system that is above all geared to cater the needs of the majority, or at least the most dominant groups.

Personally, I am not very much in favour of introducing *segregated* institutions and services, be it alone because of their associations with the ‘separate but equal doctrine’.³⁰ that it but it has to be acknowledged that they can be useful, maybe just for an interim phase, particularly in case the mainstream services fail to take the particularities and needs of minorities into account.

7. Challenges and opportunities for health law

Achieving equal health for all is a challenge that lies beyond the scope and possibilities of health lawyers. Yet, as health lawyers we are committed to promoting equal access to health care of appropriate quality. In this respect, it is important that we acknowledge the detrimental health effects of inequality and discrimination, including forms of discrimination related to ethnicity and culture.

To sum up, and thinking of the Romani women who are being denied equal health care in many European countries, I see the following opportunities and challenges for health lawyers:

- (1) We need to understand the conceptual and normative meaning equality and non-discrimination, also in connection to the right to privacy and other human rights.
- (2) We should acknowledge and know how to assess the impact of ethnic and cultural diversity on human health, health care and health systems, and ways of communication.
- (3) We should neither over- nor underestimate the importance of diversity of health and care.
- (4) We should be aware of the importance of disaggregated data.
- (5) We should be willing to collaborate with other disciplines – legal and non-legal.

²⁹ J. Fuller, ‘Multicultural health care: reconciling universalism versus particularism’, *Nursing Inquiry* 1997, p. 153-159.

³⁰ Struck down by the US Supreme Court in *Brown v. Board of Education*, 347 U.S. 483, 74 S.Ct. 686, 98 L.Ed. 873, 38 ALR.2d 1180 (1954).