Book Review:

Ethics and the non-discrimination of vulnerable groups in the health system

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Book Review

Ethics and the non-discrimination of vulnerable groups in the health system

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The volume Ethics and the non-discrimination of vulnerable groups in the health system is the product of an atypical endeavour, probably the first of its kind in Romania, undertaken at the initiative of a civil society institution, the Association for Social Development and Inclusion, in partnership with and important and prestigious entity from the Romanian academic environment, the “Gr. T. Popa” Medical University in Iasi: the introduction in the graduate curriculum of this medical school of a course concerning the ethics and non-discrimination of vulnerable groups.

The undertaking, supported by the Open Society Foundations/ Roma Health Project, aims to bring to the attention of medical students notions of medical ethics and non-discrimination in medical and health services, with a precise reference to the Roma community.

The work is the result of a collaboration between specialists in the domain, personalities who are known in academic research due to their papers concerning applied ethics in health and the ethical analysis of health systems – Vasile Astărástoae, Cristina Gavrilovici and Mihaela Vicol – together with two experts in Rome issues: Dezideriu Gergely – who brings to this paper an impressive experience in combating discrimination –, and Sandu Ion, who teaches high-school history and specialises in the Roma history and traditions.

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The work provides an approach based on the plurality of perspectives and multidisciplinarity, reuniting arguments from ethics and philosophy, from sociology and law, from history and culture, concerning discrimination and the principle of non-discrimination of patients as a fundamental ethical requirement and as an essential measure of the responsibility of medical profession.

The first section is the paper’s ethical argumentation, being organised in three chapters: the first makes a brief history of the evolution of medical research from an ethical perspective and presents a number of ethical aspects of research applied to vulnerable populations; starting from the detailing of the concept of “vulnerable individual” in biomedical research, and from the explanation of ethics codes and principles in biomedical research, the authors analyse from an ethical point of view the inclusion of specific vulnerable groups in medical research – specifically pregnant women and children. The second chapter underlines the importance of the cultural element both in the way individuals signify their illness or suffering, as well as in medical practices. Thus, the authors analyse the risks that cultural differences could create hostile attitudes in patients in relation to certain medical practices or wrong clinical evaluations concerning the patients’ faculties of judgment: “some practitioners, when faced with certain beliefs (...), less familiar to them, consider them to be insane and therefore assume that anyone thinks this way is most likely mentally incompetent” (p. 28). These findings are followed by a number of useful recommendations for an ethical approach of cultural diversity by medical professionals, taking into account language barriers, religious and spiritual beliefs and values required for “adjusting clinical judgement” (ibidem) and for finding the optimum medical solution for the patients. The third chapter casts the obligatoriness of non-discriminating against patients as an important dimension in the sphere of the medical professional responsibility, identifies its origins and the way it is reflected in medical professional codes and in the Romanian laws. Thus, Law 46/2003 concerning patients’ rights forbids the discrimination of patients based on race, sex, age, ethnicity, social origin, religion, political option or subjective criteria such as likes or dislikes, stating that “in essence, there must be any difference between the various categories of patients, apart in terms of medical classification” (p. 38).

The second section of the paper is structured in seven chapters and focuses on the social and legal approach of discrimination, starting from the analysis of key concepts: prejudice, stereotype, and discrimination. These terms are defined, detailed and operationalised, and the relations, interferences and differences between them are described.

This section also presents the results of opinion polls carried out by specialised institutes in Romania, which underline the population’s perceptions and attitudes concerning minority groups, including the Roma minority. Then the paper presents a number of demographic indicators relevant for the gap in health status between
the Roma and the non-Roma. For instance, in the EU the average life expectancy at birth is 76 years for men and 82 years for women, whereas for the Roma, this life expectancy is estimated at 10 years lower. Whereas the average infant mortality rate in the EU is 4.3 per one thousand live births, in the Roma communities it can be up to six times higher, depending on each country, and the disparities are related to the Roma’s living circumstances, to their limited access to health and medical services, to the lack of adaptation of prevention programmes to the cultural specificities of the Roma minority etc. The authors also analyse health from a social and legal perspective and place it in the realm of human rights, the nature and contents of this right remaining to be operationalised and analysed. The focus of discrimination in the medical services is placed on the backdrop of the context created by the results of several assessments of the perception of discrimination, such as that carried out by TOTEM Communication for the Romanian National Council for Combating Discrimination. This assessment appreciated that the following categories of population had the highest risk of discrimination in Romania in 2010: HIV-positive individuals, sexual minorities and the Roma minority; the discrimination concerns all the areas of social life, from access to education, to jobs and healthcare. Besides, the precariousness of health status amongst the Romanian Roma by comparison to the majority population has been documented by numerous sociological studies, as has been their restricted access to healthcare services (Cace, 2004; Cace & Preoteasa, 2004; Cace & Vladescu, 2004; Rebeleanu, 2006; Popescu, Rat, Rebeleanu, 2009). These studies have found that, despite high degree to which the Roma population has been included in the public healthcare system and in the national health programmes has grown in the past ten years, important factors of latent discrimination linger in the Romanian healthcare system, including in the doctor-patient relationship. This part of the paper also presents in detail the Romanian and European regulations concerning the protection of various vulnerable groups (ethnic minorities, women, children, people with disabilities) in terms of access to healthcare, the legal framework required for the prevention of discrimination in Romania and in the European Union, as well as the institutions in charge of fighting discrimination. The legal analysis also includes the presentation of discrimination forms and is enriched by the presentation of case studies, which particularize the analysis in the domain of Roma discrimination.

The third section of the paper adds the cultural element, recognising that the legal instrument, although essential for regulating behaviours in the sphere of discrimination, and effective due to its coercive and punitive character, is, however, limited. Therefore, it is necessary that this instrument is accompanied by a more in-depth reflection in terms of mentalities, beliefs and stereotypes, which are the true underpinnings of discriminatory behaviours. For example, the results of a public opinion barometer published by the Soros Foundation Romania in 2005 pointed out the fact that the Roma identity is not understood by the wider
public as an ethnic identity but instead as a deviant behaviour category, in other
words, being a Roma meant more often than not being a potential criminal
(Duminica, Lupu & Rughinis, 2009). Knowing and understanding the mentalities,
prejudices and stereotypes related to the Roma minority justifies the third part of
the paper, which presents the cultural argument and in which the reader becomes
familiar with essential aspects concerning the Roma history and traditions; a
number of vital Roma cultural aspects are presented as a synthesis: the role of the
Roma family, its specificity, traditional trades etc.

Whereas most evaluation studies concerning risk and inequality in Romania
underline the modest results of the social policies aimed at the Roma population
(Preda, 2009), as well as the increase exclusion risk this population category
faces, the paper Ethics and the non-discrimination of vulnerable groups in the
health system is an innovative contribution to the medical academic environment,
aiding the familiarisation with and understanding of elementary notions concern-
ing medical ethics and the phenomenon of discrimination, especially of the
Roma minority. This is also an innovative product of a dialogue between the civil
society and the academic environment, as well as a valuable instrument in the
formation of a tolerant and open attitude on the part of the current and future
medical professionals in their relationship with vulnerable groups.

References