

Review Article

Negotiating Rules and Interpretations in the Field of Healthcare Rights

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ABSTRACT

Background and Aim: The article argues for more active participation of ethnocultural minorities in healthcare decisions and highlights the relevance of strategies aimed at creating a bottom-up engagement of people and groups, as well as of measures aimed at broader organizational flexibility, in order to meet migrants' and minorities' needs.

Methods: The current study aimed at casting light on negotiating rules and interpretations in the field of healthcare rights and its scope using primary and authentic sources on law and rights and seeking the related keywords in these sources.

Ethical Considerations: The principles of research ethics have been observed in studies and citing the primary texts and sources.

Results: Finally, the article clarifies that these strategies are not simply the outcome of a welcoming attitude of the Western healthcare system.

Conclusion: but may be interpreted as a specific duty resulting from the notion of 'particularly vulnerable groups', as formulated by the ECtHR in its case law: when vulnerable groups are at stake, every decision about state actions and rules regarding healthcare should start from an aprioristic favor towards the needs of vulnerable minority groups.

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Introduction

When we speak about healthcare rights, we should consider the fact that, according to the WHO, health is a state of complete physical, mental and social wellbeing, rather than the mere absence of disease or infirmity (World Health Organization (1948) "WHO definition of Health" in Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June 1946, entered into force on 7 April 1948). In other words, health is not an objective 'fact', but is a condition of being involved, of being in the world, of being together with one's fellow human beings, of active and rewarding engagement in one's everyday tasks' (1). For that reason, such a right entails more than the right to be treated and cured. It implies – among other things – that individuals and communities must be allowed to have a voice in

decisions concerning the definition and determination of their well-being, and the recognition that their participation is integral to health promotion (World Health Organization (1978) Report of the International Conference on Primary Health Care [Declaration of Alma-Ata], Geneva, Switzerland). In other words, the right to health does encompass the right to make decisions about one's body and wellbeing, the right not to be discriminated against in medical treatments, the right to consent (and to withdraw it) to any medical treatment, but also the right to participate in health decision making processes. That is, it encompasses the need to involve people not only in the benefits of healthcare but in the decisions and actions that collectively shape and rule public health (2). Accordingly, the right to health requires not only the availability of healthcare services, nor only the scientific quality of medical practices, but also that the healthcare system is

accessible and *acceptable* (CESCR - Office of the United Nations High Commissioner for Human Rights (2000), General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12) Adopted at the Twenty-second Session of the Committee on Economic, Social and Cultural Rights, on 11 August 2000).

An accessible healthcare service guarantees the accessibility of any useful and necessary information, in a non-discriminating way: concerning minorities, it means taking into consideration the specific hurdles that they may find in reaching public health providers, and in receiving the specific information they need. While many factors can influence individual health, such as biological factors, social and community influences, living and working conditions, and personal habits, they can all interplay with migration, both in the sense that they may show particular implications for migrant communities, and because migration can exacerbate their impact (3). All these factors should be taken into account to grant an *accessible* healthcare system: and among other factors, social stigma, discrimination, social exclusion, and separation from their socio-cultural norms pose specific challenges to migrants' and minorities' health (3).

Concerning acceptability, 'health facilities, goods, and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples, and communities (UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant), 11 August 2000, E/C.12/2000/4). As the International Bioethics Committee of UNESCO stated in its Report on Traditional Medicine Systems and their Ethical Implications, traditional medicines imply a specific approach to life, death, health, and illness, and entail a different view of the patient, practitioner, patient/practitioner relationship, health services, risk factors, etc.

Accessibility and acceptability are two pivotal issues in improving healthcare policies: only the consideration of the specific needs of minorities, and the disparities between people and within groups, in terms of health literacy, individual and group behaviors, may help to enhance the

appropriateness of health services in different societies.

Consequently, the promotion of sustainable, accessible, and just healthcare systems in various societies is rooted in forms of participation by minorities (4, 5). Such participation should have multiple drivers: the change of some health-related behaviors, better health literacy both for providers and patients, real involvement in the broad macro-level decision-making contexts (6), etc. Without the participation and active involvement of minorities, the focus on personal choices and individual autonomy fails to enable people to contribute to the decision-making process and does not allow adequate policy formation. This is the reason why we should put some effort into a more complex methodology to realize the aim of a sustainable and just healthcare system, through the identification of patient preferences and, at the same time, the solicitation of minorities' voices. This approach should highlight the complex nature of health, that is the equal importance of personal conditions and individual preferences, on the one hand, and of socio-environmental determinants and cultural issues, on the other (5).

However, the idea of greater participation of minorities in the field of healthcare policy-making poses many problems, which are not merely related to practical difficulties, but too theoretical questions and challenges. First, it is not completely clear what the relationship is between health conceptions and ethnic identities. The definition of ethnic minority is in itself problematic (7, 8), but it may even be more arduous when health-related issues are considered. If we consider the relevance of several characteristics (culture, religion, language, traditions) that make minority members different from those of the rest of the population, and which are at the same time the object of a sense of solidarity directed at preserving them (9), health-related issues may appear ambiguous. It is not easy to understand the relevance of some health traditions and conceptions for the preservation of the identity of minorities: this is not because health is less relevant than other practices and traditions (e.g. food or rituals), but because health conceptions, much more than other issues, transcend minorities' limits.

Second, even if we could demonstrate the relevance of a specific health tradition or

conception for the minority's identity, the balance between the protection of such a tradition and the defense of individual freedom and rights is highly problematic. Of course, such a question is of general relevance in questions concerning minorities (10, 11) but about health challenges, it becomes even more difficult. This is because Western health laws are rooted in several principles, such as the patient's autonomy, freedom of treatment, and informed consent, that give a clear priority to the single individual and his/her rights. In other words, in a field where the single individual has a greater priority over the group, the balance between individual autonomy and group autonomy seems to be decisively in favor of the first one.

To deal with such questions, I will argue for a multifaceted legal approach to involve minorities in healthcare policy-making processes. In the first part, I will analyze some specific challenges linked to the access to healthcare systems by minority groups, to show what kind of vulnerability they face both as individuals and as groups. In a second chapter I will discuss some cases related to the use of complementary and alternative medicine (CAM) by some minorities and migrant groups, to show that even if such practices are not exclusive to minorities, they sometimes become relevant for their identity. Third, I will argue for a legal strategy, which takes these aspects of minorities' vulnerability seriously, at the same time balancing them with respect for individual rights. Such an approach is partially based on the idea of empowerment, provided one caveat is stressed: the main problem concerning healthcare issues is not the power imbalance between the majority and minorities, but rather the specific vulnerabilities they face, and the ways to overcome such difficulties by allowing wider margins of participation of both minority members and groups.

One final remark must be stressed: the following analysis takes into consideration the broad European context, even if it focuses on specific cases and examples. Challenges can indeed vary in the national healthcare system we take into consideration, but the differences are mainly quantitative, not qualitative. Different causes can be analyzed concerning the UK or France or Denmark and Italy, and different minorities live in these countries, revealing different problems in accessing healthcare systems and different

medical traditions. Nevertheless, the theoretical questions are for the most part similar, at least from a legal point of view: these questions concern the room we may leave for minorities' traditions, the strategies we may adopt to improve minorities' conditions, and the policies to enforce minorities' right to health, within legal systems that – even if different from each other concerning specific aspects – are rooted in a same medical tradition and a common conception of individual autonomy and freedom.

Methods

The current study aimed at casting light on negotiating rules and interpretations in the field of healthcare rights and its scope using primary and authentic sources on law and rights and seeking the related keywords in these sources.

Findings

1. Access and related challenges.

The first type of vulnerability that migrant minorities face in Western countries is related to the access to healthcare services, and to the barriers generated even in universalistic healthcare systems. Due to such barriers, migrant communities risk being undertreated and unprotected, with significant differences in the prevalence of some pathologies between migrants and native people.

Recent research on diabetes shows that the incidence and mortality rates are much higher in migrants than in native people (12). Both in the Netherlands, the UK, and Italy, for instance, diabetes is more common among the main groups of immigrants, and large differences are to be found in rates of diabetes-related mortality compared to the local native population. Further analyses (13) show similar results also for seven other European countries, showing that the mortality is much higher than in native residents, particularly among the young population.

These differences might be ascribed to genetic factors, at least in part, but they are at the same time linked to failures to achieve treatment goals or to lower screening rates and preventive measures (12). For instance, research data about migrants from the Philippines in Italy (one of the largest migrant minorities in the country) show how migration and genes interplay in diabetes rates. People coming from non-Western countries

often have a genetic predisposition to tackle hunger and starvation: thus, when exposed to the different diet and lifestyle of the country of immigration, they are particularly prone to stock energy reserves and thereby gain weight (12).

Besides this, many social determinants can play a role: not only low socioeconomic status but also separation from family, xenophobic feelings in the larger community, traditional beliefs influencing health-seeking behavior, the lack of policies to protect migrants' labor rights, and welfare, etc. Even if problems may be stronger within insurance-type healthcare systems, several reports show that migrants are undertreated also in systems based on a principle of equality of access (such as many European healthcare systems), due both to personal barriers and socio-cultural conditions: for instance, worse patient-provider interactions, with regard both to verbal interaction and to personal empathy (14, 15). Similar results have been reported also concerning other pathologies, such as breast and colon cancer, despite universal healthcare coverage, or vaccination coverage in some religious minorities (16).

In addition to the above-mentioned factors, research on asthma highlights the fact that poorer health-related outcomes may be related to particular social and cultural backgrounds, and beliefs, attitudes, and behaviors arising concerning health. For instance, a lesser familiarity with the idea of preventive treatments – at least in first-generation and recent migrants –, which can be at odds with protocols and plans for the management of specific illnesses within the population (17), as well as a greater familiarity with curative rather than preventive cares.

At the same time, bias and stereotyping of ethnic minority populations by healthcare providers can play a role in migrants' lower health conditions and can affect the type or quality of care provided. I am not referring to explicit forms of discrimination, but a lack of cultural competence and an inability to comply with language preferences, as well as to more objective difficulties to translate medical concepts into languages in which there are no equivalent terms (17). Such difficulties may hinder the patient-physician interaction, and thus the outcome of the consultation: patients from ethnic minorities may be less confident in healthcare practitioners, and less aware of the recommended treatments.

In a similar perspective, interesting results come from studies on mental health conditions. In Europe, many minorities (among others, Chinese, Indian and Pakistani communities) experience high rates of mental health problems, linked both to social circumstances (e.g. unemployment, living conditions) and to other factors such as family absence, migration trauma, and cultural diversity (18, 19). What is at stake, however, is that such communities frequently receive inadequate healthcare services, in two directions: services can either fail to engage with these communities where there is need, or they may show excesses of compulsory and restrictive treatments (20). These discrepancies are linked not only to prejudices or biases among practitioners (even if they can play a big role) but also to differences in cultural categories about illness. In contrast to Western culture, some communities do not conceptualize distress as an illness and use different explanations and remedies for what psychiatry interprets as illness, so labeling them as common physical problems, which can be less socially disadvantageous (18). The same reasons for social reputation and traditional beliefs lead minorities to see religious leaders as the principal point of contact and support, and traditional treatments are frequently reported as an alternative to seeking medical help (18).

These examples demonstrate that minorities are often more vulnerable than native people concerning access to healthcare services, and find themselves in conditions of under-treatment and insufficient protection. Such a vulnerability stems from different types of barriers: cultural barriers can play a big role, for instance leading to different interpretations of symptoms and different health behavior, but other factors are relevant alike. Bias towards ethnic minority populations by healthcare providers, the lack of cultural competence, as well as specific behavior arising from particular social and cultural backgrounds, may become barriers to accessing healthcare services: and to the extent that the right to health requires not only the availability of healthcare services, and the scientific quality of medical practices, but also the accessibility of healthcare, these barriers are to be seriously considered. Concerning minorities' conditions, we should reshape our healthcare system to overcome – as much as possible – these limits.

2. Acceptability of healthcare services

The acceptability of healthcare practices is a second pivotal factor we shall consider concerning the condition of minorities. As already mentioned, the right to health requires not only that health facilities, goods, and services are accessible, but also that they are acceptable, that are respectful of medical ethics, culturally appropriate, and sensitive to gender and life-cycle requirements (UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 14: The Right to the Highest Attainable Standard of Health *cit.*, par 12 c). From that point of view, healthcare services are acceptable for minorities only to the extent that they take into consideration their cultural sensitiveness and are respectful of their particular approach to life, death, health, and illness, and to a patient-provider relationship.

A first challenge arises from the need for informed consent concerning treatments. In many European countries, consent to treatments is not only necessary for the very lawfulness of the treatment provided, but must be exhaustive, understandable, and personalized (21; see also the Oviedo Convention for the Protection of Human Rights and Dignity of the Human Being concerning the Application of Biology and Medicine, art 5). On the contrary, the use of the Western model of informed consent, which is a model rooted in the concepts of autonomy, individual self-determination, and freedom of conscience, quite often leads to incongruence between the cultural values of those whose consent is at stake (22, 23). Not only do the beliefs about individual autonomy vary across cultures, but the number and the role of people involved may change considerably. This is for instance the reason why people from some cultural minorities neither really ask for complete and autonomous control over medical decisions, nor do they want the same information content in disclosures (22, 24). Accordingly, to provide acceptable treatment, the patient's culture should be taken into account when his or her informed consent is due, carrying out a strategy suited to this particular point of view. Personal culture can influence the quantity of information, the way of giving it, and the persons who shall be involved, to deeply change the meaning of informed

consent and the practices which are consistent with it (22, 25, 26).

A second challenge – and an even more difficult one – arises from the use of complementary and alternative medicine as part of cultural/traditional identity. It is true that the use of CAM goes beyond minorities' limits, and that such a kind of practice is largely used even by non-members: however, there are situations where ethnic minorities place an identity value on the use of traditional medicine, even if alternatives are accessible. I will consider two different minorities (Chinese minority in the UK, and some small Albanian communities in Italy), and their use of traditional CAM, as examples of that issue.

Concerning the first case, some research shows that the British Chinese communities often underuse health care facilities and services (27, 28), in terms both of consulting a general practitioner, and accessing hospitals compared with the members of the majority group (29). Such a difference is partially linked to the use of Traditional Chinese Medicine (TCM) that, at least for the British Chinese, is represented by Chinese herbal medicine. The use of TCM is widespread notwithstanding a concurrent use of Western scientific medicine, and even if it is more prevalent among religious people (Buddhists) and among those who are more involved in the Chinese community's life (27). Once again, factors such as cost, hospitalization duration, availability of medicine, and accessibility of health services, may influence people's choices (for instance, TCM is considered to be more expensive than Western medicine), but evidence suggests that traditional Chinese medicine is largely shared by members of the Chinese minority.

Several works indeed show many problems concerning the complex interplay between different migration histories, subjective and group identities, and health-related behavior. On the one hand, the British "Chinese" identity is formed through a set of numerous migration pathways and shows differences in socio-economic conditions, cultural background, religious beliefs, and languages, thus being anything but a homogenous 'community' (29). On the other hand, the ethnic origin may be one other factor that we may use to explain people's choices regarding healthcare practices and personal behavior (30). We should be aware that

significant variations may occur in the role that a specific community (such as the British Chinese) acknowledges herbal and other traditional remedies for the everyday maintenance of good health and that the line between everyday health practices and more formalized medical treatment is often blurred (29). What is at stake, however, is that people negotiate multiple healthcare systems – public and private, Western and traditional, drawing on remedies and practices from different sources – in order to obtain the desired outcome (29, 31). This is where we should start from, in any further policy planning regarding more *acceptable* healthcare practices.

We may observe a similar phenomenon of adaptive cultural processes in healthcare beliefs concerning the second case, which concerns two small Albanian communities in southern Italy (in two small villages). Even if quite isolated, and not completely homogeneous in themselves, they (as Arberesh Albanians) obtained (together with 11 other non-Italian speaking groups) official recognition as a “historical ethnic minority” from the Italian Parliament in 1999 (L. 15 December 1999, n. 482). Such recognition allows these minorities to use their idiom in official acts and indicate measures for sustaining their cultural heritage (32).

Traditional pharmacopeia is part of this cultural heritage. Even if the use of traditional medical practices is declining, in both these villages the use of CAM (particularly, phytotherapy remedies) is perceived as a model of primary healthcare, having a preventive action or an ability to heal minor illnesses (33). On the one hand, new generations have lost most of the traditional knowledge concerning plant and folk medicines (34), and the growing flux of people and knowledge promoted a rapid transition into the Western mainstream culture, even in the field of medicine. On the other hand, various illnesses are still healed with the help of special ritual healers, both through traditional medicinal plants and other non-naturopathic systems: among others, skin diseases, mastitis, nose bleeds, headaches, abdominal pains, etc. (33). Additionally, due to migration flows from Eastern Europe, new practices have spread, adding to and blending in with traditional medicine. Newcomers from Albania brought the ‘Caj Malhit’, a plant they use for the healing of sore throats and coughs, while Ukrainians introduced new phytotherapeutic

decoctions for rheumatism and the recovery from drunkenness (33).

In other words, and similarly to what was mentioned regarding the British Chinese community, people hybridize and negotiate multiple health traditions, and show an eclectic use of both Western and traditional medicine. Instead of any rigid separation between groups and medical traditions, people adopt strategies of inter-mixture to obtain the desired result: treatments that are at the same time effective, accessible, and acceptable.

3. Minorities and healthcare practices: legal challenges and strategies.

The above-mentioned practices of hybridization of medical traditions, as well as the barriers that minorities face in accessing healthcare services, highlight the need for greater participation of minorities in healthcare decisions. To make Western healthcare systems more acceptable and accessible to ethnoreligious minorities, the active involvement of both minority groups and individuals, and their contribution to the decision-making process in healthcare practices, is crucial. From that perspective, we should take into account at the same time the personal level, collective processes, and specific interventions (35, 36).

At the personal level, we should focus on what strategies we may adopt to bolster a transition from feeling powerless to an ability to take initiative in healthcare decisions. Concerning collective processes, the idea of minorities’ empowerment may shed light on strategies to be implemented to leave room for choices rooted in common critical characteristics, such as origin, religion, gender, or cultural heritage (and their interplay). Finally, we should focus on specific interventions to bolster, case by case, shared solutions by stakeholders and people involved in medical decisions. Strategies of empowerment should connect the macro-level representing the community, and the micro-level representing the individual, in a non-organic and changing manner (37).

In other words, the present condition of ethnocultural minorities facing healthcare issues is that of partial powerlessness, at least concerning the limited consideration that Western

health systems take regarding the specific group needs and cultures. As Sadan clarified, powerlessness is rooted both in power relations (between majority and minorities) and in disempowering practices that originate in the social system (36). The changing of these imbalances and practices, by creating alternative organizational aspects and relationships, is thus of utmost importance. However, given that we aim to understand what policies, and what strategies, are better suited to empowering minority groups from the perspective of rights awarded to them, we will explore an approach focused on rights enforcement and rights interpretation. A such approach is a multifaceted approach, through which the micro level, the macro level, and collective processes are jointly taken into account.

3.1. Minorities and healthcare: the personal autonomy.

At the micro-level, Western legal systems may leave room for individual perspectives on healthcare and personal conceptions of health, wellbeing, and dignity, through broader enforcement of the freedom of treatment principle: through a more intense shift from the right to health, into partially different freedom of health. As already recognized in some cases (see for instance the hypothesis of voluntary sterilization: 35) the prevailing definition of health is increasingly centered on the personal experience of well-being, not only in the sense of the absence of specific pathologies but rather on the capacity to achieve personal objectives and to function in social contexts (39; 40, 41).

From this perspective, one can observe that Art. 7 of the European Convention on Human Rights, which recognizes the right to respect one's private and family life, may also serve the protection many claims in the healthcare field (as happened in *R (Burke) v General Medical Council* (2004) EWHC 1879 (Admin)). Analogously, the patient's right to complete and comprehensible information may be interpreted to require a duty of giving information about alternative (i.e. non-traditional) treatment options (42).

To be more precise, acknowledging the freedom of the patient has both a negative and positive meaning. On the one hand, it stems from the patient's right to self-determination, that is the right to accept or refuse any information, analysis,

or treatment, even if that decision will damage the patient's health or lead to premature death. Respect for a patient's autonomy acknowledges his/her capacity to make personal choices, and even if physicians have to explain the consequences of the refusal, and offer reasonable alternatives, no coercive treatment can be allowed and practiced without the free and informed consent of the patient (43).

In a positive sense, the patient's freedom may be understood as freedom *to* treatment, which is undoubtedly much more controversial. In this perspective, patients are allowed not merely to give free and informed consent, but to influence and shape therapies for themselves, even asking for personal ways of treating them, which may be irrespective of protocols. Even if such a positive right to treatment has been rarely recognized, it is however significant that the Darzi's Report, in the UK, states that "a health service without freedom of choice is not personalized", thereby requiring – at least to some extent – that patients are free to set their goals and receive appropriate support to achieve their goals as partners with health-care professionals (High-Quality Care For All – NHS Next Stage Review Final Report, p. 38).

Such freedom, both in its positive and negative sense, may be highly problematic when treatments concern minors. The principle, which is acknowledged in most European countries, is that parents are required to make decisions in the interest of the child, and – at the same time – that states may intervene to protect the minor's interest especially when they are not old enough to decide for themselves. Within this framework, parents' freedom of/ treatment must be balanced with the best interest of the child (and with the minor's wishes, in the case of mature minors). Thus, parents' freedom to choose alternative therapies or even to refuse treatment for their children, according to their fundamental religious freedom, their right to privacy, and their right to raise children as they desire, is counterweighted by the minor's right to health, and by the state's duty of protecting them (44, see also ECtHR, 2010, *Jehovah's Witnesses of Moscow and Ors. v Russia*, App. No. 302/02).

The right to choose what treatment is required or preferred, and what is more consistent with the individual life planning, needs to be put into effect through specific interventions aimed at more effective participation of the patient in

medical decisions. Many strategies might be useful, both increasing providers' awareness of cultural specificities, giving patients adequate information on administrative procedures in their mother tongue and implementing specific interventions for recently arrived migrants, women, children, second-generations, and victims of violence, as well as intervening in areas of particular concern. Good practices are already carried out across Europe (45): for instance, large hospitals encourage the recruitment and training of providers of different ethnic groups, like physicians and nurses, to ensure the presence of personnel that is proficient in the necessary areas in different languages, but also in cultural consultancy (the ability to explain cultural issues both to patients and to staff members) (46). Again, more pro-active strategies are aimed to enable members of minority communities to communicate and achieve full access in public service settings through what is called 'community interpreting' in the UK, or 'interprétariat en milieu social' in France, and 'Sprachmitteln' in Switzerland (45).

3.2. Minorities and healthcare: bolstering shared solutions.

When we shift our attention to the condition of individuals *as* members of larger groups, different interventions aimed at bolstering shared solutions by the people involved are pivotal. This shift is necessary because explanations that "place the onus of culture on the individual are likely to lead to individual-centered interventions at the expense of addressing the structural contexts that reproduce social and economic inequities" (47).

At the same time, however, we should recognize that such groups are neither internally cohesive social entities, nor do they always possess a common agency and interests (48, 49). Protecting cultural minorities as if they were cohesive entities may lead to perpetuating inequalities between subgroups, especially those sub-groups with a lesser capacity to mobilize.

Some good examples can be mentioned, as cases of shared solutions to multicultural challenges in healthcare. These attempts start from the assumption that different meanings of health may be co-constructed through dialogues and negotiations with members of cultural communities, and that such meanings are both

perceived as traditional, and continuously transformed and reshaped (50, 51, 52). Health and healthcare services are thus perceived and shaped not only within the mainstream biomedical model but through the experience of patients *as* members of minority groups: this is done by allowing discursive spaces that create a bottom-up engagement of different people and groups, about health meaning and experiences. It is vital to establish a system of mutual adjustments by both the group and the state (the larger community), to continuously reshape every solution in time, taking the internal development of cultures and traditions seriously into account (53). At the same time, this ongoing dialogue can encourage minority groups to re-examine the elements of their tradition, to reshape these practices and beliefs that turn out to be unsatisfactory.

Unlike the abovementioned hypothesis, in that second case, possible solutions arise as the outcome of mutual recognition, rather than from the individual right to respect for one's private and family life under Article 8 of the European Convention on Human Rights. What is at stake is not simply the patient's autonomy, in its negative or positive meaning, but the public recognition (that is, by healthcare services and health institutions) that people belonging to different cultural minorities require a different understanding of treatment and care.

Many practices across Europe are examples of such a kind of public recognition (54, 55), even if differences in citizenship regimens and political climates concerning migrants and national healthcare laws result in different policies, and lead to varying outcomes (56). Among many measures, we may observe some aimed at broader organizational flexibility, in order to meet migrants' and minorities' needs: not only do hospital units and other local healthcare facilities frequently organize regular staff meetings to deal with the problems arising in migrant healthcare, but they seek resources and funding from Non-Governmental Organisations to overcome state restrictions on treating undocumented migrants, as well as providing cheap or free treatment for them. Again, in many countries healthcare institutions collaborate with social services and families, both to share information and to involve local communities, group authorities, religious leaders, and non-statutory agencies in setting standards and appropriate services (56, 57). For

instance, a study on some orthodox protestant groups in The Netherlands analyzed religious objections to vaccination, resulting in low vaccination coverage: to develop an adequate intervention, an information campaign focused on religious arguments on vaccination has been developed in cooperation with religious organizations, to meet such specific interests and needs (58). Besides this, training programs for staff in different cultural and religious practices are implemented and aimed at the delivery of satisfactory and respectful care to migrant patients, enabling both providers to achieve more appropriate treatment, and patients to better understand and accept medical options. In London, according to actions aimed at improving mammography and pap smears, patients received both a letter from their physician and targeted care from community educators, whose ethnicity matched that of the patients. These health educators provided culturally sensitive educational materials, as well as personal encounters on clinical and administrative procedures (59, 60).

Among other European countries, Scotland has developed some of the most vigorous approaches to improving minorities' health conditions. According to the Race Relations Amendment Act of 2000 and the Fair for All policy, in 2002 the Scottish Executive Health Department required NHS organizations to tackle ethnic inequalities in healthcare in five domains: (i) to energize organizations to deal with minor health issues positively; (ii) to produce information about the population of each NHS board's area; (iii) to acknowledge and overcome barriers to access; (iv) to recruit ethnic minority staff; and (5) to consult minority ethnic communities. As part of this policy, the National Resource for Ethnic Minority Health (NRCEMH) was established in order 'to support the NHS Scotland services to deliver the minority ethnic health agenda'.

In 2009, the European Commission issued a policy paper (Commission of the European Communities, *Solidarity in Health: Reducing Health Inequalities in the EU*. 1–11, 2009) aimed at supporting the member states in tackling health inequalities: among others, the aim is to 'launch initiatives in collaboration with the Member States to raise awareness and promote actions to improve access and appropriateness of health services, health promotion and preventive care for

migrants and ethnic minorities and other vulnerable groups' (p. 8). According to these recommendations, both the Italian Health Ministry and local healthcare units developed guidelines to implement a so-called 'multiethnic healthcare service', also through specific agreements with NGOs and migrant communities (61, 62). That multiethnic healthcare service should: promote intercultural and multicultural organizations; facilitate self-empowerment, through the direct involvement of immigrants; promote better awareness of cultural diversity within the local area; enabling tailored services for migrants' needs, also within psychological and psychiatric consulting (63, 63).

4. From tolerance to recognition, through laws.

Both the broadening of the individual freedom of treatment and the bottom-up engagement of groups for the definition of shared solutions concerning treatment and services may be steps toward a deeper recognition of minorities' identities and cultures. Jointly, these two actions are a crucial means to connect the macro-level representing the community, and the micro-level representing the individual, in a non-organic manner, which may be continuously reshaped and adapted depending on the specific circumstances and needs.

However, to what extent such a double-faceted action is either the outcome of a welcoming aptitude of single states and local institutions or a specific duty resulting from the enforcement of the right to health, is not completely clear. In other words, we should ask whether states and healthcare institutions must implement specific strategies to take minorities' needs concerning healthcare seriously into account, and to what extent these needs must be considered relevant. As we stated above, if the right to health should be interpreted as the right to *acceptable* and *accessible* health, some sort of recognition both of individual autonomy and group needs and traditions must be allowed. But how can we judge state policies and healthcare services? Who is entitled to that judgment, and what criteria may be used? Again, how can we balance the recognition of group needs and traditions, with the right of single members who can be detrimentally affected by that recognition?

I argue that a promising solution stems from the concept of 'vulnerable groups, as used and formulated by the European Court of Human Rights (65): it might be a hermeneutic tool that courts across Europe can use (following the example of the ECtHR), to address state policies concerning healthcare, both considering the substantial aspects of them and focusing on groups as much as on individuals.

Moreover, it is a culture-demystifying approach, which reduces the above-mentioned risk of "Groupism", that is of treating minorities as internally cohesive social entities with common agency and interests. Focusing on individuals as members of vulnerable groups' cultures is not taken as the main (or the most relevant) factor, but only as a kind of claim among others. Identity-based factors are neither excluded nor taken as absolute: they should not be ignored, but many other factors should be taken into account by courts and state institutions (66). Indeed, through their typical ad-hoc answers, courts are the best authorities to judge inter-cultural issues arising from healthcare policies: courts are better attuned to the complex intermixture of factors that shape the life of every person, and the parties that entered the courtroom.

To be more explicit, the ECtHR introduced such a concept with regard to the Roma minority, stating that individuals who belong to some groups need specific forms of protection, precisely because those groups are more vulnerable than others, due to societal, political, and institutional circumstances (*Chapman v. the United Kingdom*, App. No. 27238/95). Some people, due to their specific group membership, are marked by specific and particularly strong forms of vulnerability: the Roma, people with mental disabilities, asylum seekers, and people living with HIV, are more disadvantaged and vulnerable than others: they 'have become a specific type of disadvantaged and vulnerable minority (*D.H. and others v. the Czech Republic* (GC), App. No. 57325/00). What is at stake is that according to the Court's case-law people who belong to particularly vulnerable groups deserve asymmetrical scrutiny: their interests should have *more weight* in the analysis of the proportionality because they belong to a group (no matter how heterogeneous) that is likely to experience harm and deprivation in a particularly hard manner.

However, the Court specified that neither is every disadvantaged group vulnerable in the same way nor does every social or historical circumstance produce the same kind of vulnerability. This is the reason why the Court considers 'particularly vulnerable groups' with specific attention (*Alajos Kiss v. Hungary*, App. No. 38832/06), where the term 'particularly' stresses that specific protections are allowed to specific needs, and that the considered groups are those *more in need*.

Moreover, such a particular vulnerability gives rise to specific forms of discrimination and social disadvantage. Therefore, only a case-by-case analysis of applicants' living conditions can determine if, and to what extent, he/she belongs to a particularly underprivileged and vulnerable group, thus in need of special protection by states and institutions (*M.S.S. v. Belgium and Greece*, App. No. 30696/09). It is not a mere condition of misrecognition that counts, but a *harmful* condition of misrecognition, deprivation, and discrimination (65).

For several reasons, I consider that paradigm promising also with regard to healthcare issues, and to the above-mentioned challenges concerning minorities' needs. First, it advances a more substantial idea of equality: even if some policies that affect people's rights are, from a formal point of view, proportionate, they are likely to reinforce groups' disadvantages and harm. By focusing on groups' vulnerability, some of their specific concerns have to be taken into account in policy-making and judicial interpretation: states and other institutions should provide evidence that these concerns have been seriously considered. This is an additional burden, which becomes necessary in cases about particularly vulnerable groups, and not in every decision about proportionality (67).

Indeed, according to the ECtHR's case law, courts should consider the condition of vulnerability (both of individuals and groups) as a lens through which every type of deprivation and discrimination looks bigger (65). It does not mean that such a balance will always support those people's claims: the ECtHR's case-law often shows its tendency to legitimize states' defensive attitudes against minorities (68). However, through such an argumentative strategy, a state or any other authority in charge should demonstrate that minorities' conditions and vulnerabilities have been taken into consideration because every

decision about state actions and rules regarding healthcare should start from an *aprioristic favor* towards the needs of vulnerable minority groups. When people belong to a particularly vulnerable group, the effects of policies or state action take on a dimension that they would have not taken if the case had concerned a different person.

Second, the vulnerability approach can shift healthcare politics from protection to empowerment, not creating a relationship of dependence, which renders these groups inactive and subject to the state's welcoming attitude (37). It guarantees members of cultural minorities protection of their conceptions and needs, but only to the extent that these identities are judged as a factor related to conditions of particular vulnerability. It marks a distinction between groups that are neither particularly exposed nor weak, that can autonomously exercise their rights, and groups that are more in need. Minorities are not always portrayed as victims and recipients of protection, but as subjects who can act for themselves, if they can.

Additionally, the approach based on vulnerability gives some answers to many concerns about minorities within-minorities. Claims for the right to cultural identity are normally balanced or weighed against individual rights of members, as mutually excluding categories (68). Contrariwise, the vulnerability approach avoids such a balance, since claims are always raised by single individuals in disputes with other individuals or specific institutions. Group belonging or group identities are at stake only to the extent they are the reasons for an individual's vulnerability: there is no opposition between individuals and groups.

Conclusions

The proposed approach makes Western healthcare systems more acceptable and accessible to ethnoreligious minorities, through the active participation and involvement of both minority groups and individuals. If the present condition of ethnic minorities is, at least in part, a condition of powerlessness, such an approach takes into account strategies to bolster a greater ability to take initiative in healthcare decisions, both by individuals and groups. On the one hand, individual feelings and needs are considered relevant as expressions of personal freedom to health: thus, the right to choose what treatment is preferred, and what is more consistent with

individual life planning. The analysis shows what kind of interventions are consistent with this aim, and which are already carried out across Europe, to enable members of minority communities to communicate and achieve full access to public service facilities, to increase providers' awareness of cultural specificities, or to ensure the presence of personnel that is proficient in the necessary areas in different languages and cultural consultancy.

On the other hand, groups are considered relevant stakeholders in the implementation of healthcare strategies rooted in common critical characteristics, such as origin, religion, gender, or cultural heritage (and their interplay), by creating alternative organizational aspects and relationships. In particular, a pivotal role can be played by strategies aimed at creating a bottom-up engagement of people and groups, and by measures aimed at broader organizational flexibility, to meet migrants' and minorities' needs. Healthcare institutions should collaborate with social services and families, both to share information and to involve local communities, group authorities, religious leaders, and non-statutory agencies in setting standards and appropriate services: these actions might improve the access to and the appropriateness of health services, not only for single individuals but also for ethnic minorities and other vulnerable groups.

Finally, the proposed approach clarified that these strategies are not simply the outcome of a welcoming attitude of the Western healthcare system, but may be interpreted as a specific duty resulting from the right to health. If we take the notion of 'particularly vulnerable groups' seriously, as formulated by the ECtHR in its case law, these policies and actions may be consistent with the asymmetrical approach that states and public institutions should adopt in dealing with minority needs. When vulnerable groups are at stake, states and any other authorities in charge should demonstrate that their conditions have been taken into consideration, and every decision about state actions and rules regarding healthcare should start from an *aprioristic favor* towards the needs of vulnerable minority groups.

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