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JUSTICE ISSUES IN BASIC HEALTH CARE AND THE CHALLENGE OF GENETIC MEDICINES A Catholic Perspective for the Indian Context

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The Christian commitment to health has inspired theologians and ethicists to reflect on the importance of health and provisions for health care for people. Today, even though health care has come to be considered a human right, millions across the world, especially in the developing and underdeveloped countries, have little or no access to an acceptable level of health care. Even a fast developing country like India with 1.2 billion people has over 421 million people under the poverty-line who have very little access to health care.¹

In India, on the one hand, there is an active promotion of health tourism by the government which is accompanied by nearly uncontrolled growth of the medical industry – of multi-national pharmaceutical companies, five-star hospitals and high-end treatments. This has made India a favored destination for health tourists from the world over. However, on the other hand we have a huge section of people who have little access to basic health care. Millions are dying of malnutrition and ill-health. The widespread poverty, disease and disability of the people have not discouraged either the governments or the pharmaceutical firms, clinics and

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¹ See JimYardley, "India Asks, Should Food Be a Right for the Poor?" *The New York Times*, August 8, 2010.

hospitals from exploring the possibilities of high-tech medicines like gene therapy.

While developed nations still approach genetic medicines with extreme caution and restrictions, developing countries like India are already practicing gene therapies, without sparing much thought to the many ethical challenges they pose. With tacit permission of the governments, while pharmaceutical companies are investing heavily into genetic medicines, hospitals and clinics are experimenting with gene therapies in the name of treatment. Such practices raise many ethical and theological questions as to what the priority is in a country like India. Should the government ensure basic primary health care needs of the people and shun genetic medicines, at least for the present? Or should the government promote genetic medicines which, besides treating patients for whom conventional medicines or treatments are either not sufficient or are too invasive, has the potential to boost health tourism in the country? Is it right to sideline primary health care in the country?

These are questions that motivated me to do an in-depth study of the health care situation in India through this dissertation. My attempt here is to analyze the health and health care situation in the country from the point of view of social justice, especially the principles of equity, the common good, distributive justice, the option for the poor, subsidiarity, participation and solidarity. In the light of these principles I propose some guidelines or a framework to meet equitably the basic health care needs of all. Taking into consideration the needs of the people, the advancement in the field of science and medicine and the emergence of many medical institutions engaged in the practice of gene therapies, I also propose guidelines for a meaningful or helpful engagement in the development and application of genetic medicines in the country.

The first chapter is primarily an expository one where a critical analysis of the present situation of health and health care in the country is done. While highlighting the positive strides the country has made in health and health care through various health care programs and policies, it also notes the areas that need greater attention to fulfill the health care needs of the people in today's changing circumstances. An important finding of this chapter is the striking contrast between the health care policies and healthcare practices in the country.

The second chapter deals with justice issues in health care. Since the new developments in health care with their highly scientific and technological focus has changed the traditional understanding of health care, justice plays an important role in ensuring equitable access to health care for all. While there are many theories of justice in

health care, I argue in this chapter that the Catholic notion of justice can better promote a more adequate and equitable distribution of health care.

The third chapter is a proposal for basic health care in India from the Catholic perspective based on the principles of justice, especially of equity, the common good, subsidiarity, participation, solidarity and the option for the poor. It is argued that in a country like India, where the health care situation is so complex that a multi-pronged approach is essential for meeting the health care needs of the people, the application of the principles and imperatives of social justice informs and guides the way towards an equitable health care system. The multi-pronged approach employed here emphasizes the importance of the various determinants of health and health promoting factors such as empowerment of people towards participation and health, cleaning up administrative, structural and other anomalies, a political commitment to health care, the public role in financing of health care, and so on. Even though the application of the principles and imperatives of social justice in the complex context of India is a daunting task, it can still pin-point specific areas of operation in the country's health care system that need re-orientation. These are also areas that deserve greater attention and commitment on the part of the government and health care personnel.

The fourth chapter shifts the focus from primary health care to high end medicines like gene therapies and the various challenges posed by genetic medicines. Given the high competence of the scientific and medical community and the availability of a vast variety of patients, the country is in an advantageous position to go into the production, trials and uses of genetic medicines. However, the complexities present in the country, especially its extremes in poverty and riches or its socio-political, class-caste disparities, and the lack of clear and strict monitoring authorities, raise numerous ethical issues.

I argue here that while the possibility of gene therapies needs to be explored, given the needs of the country, it should never be at the cost of basic health care needs of the people of the country, especially of the poor. The Catholic principles of social justice should inform and guide efforts in the formulation of policies, for the production and application of genetic medicines. Only such an informed and guided effort can serve the common good or welfare and well-being of all.

Specific Contribution to the Discussion through this Dissertation

While health care in India has been an area of discussion among some ethicists or moral theologians in the country, there has been very little work of systematic analysis done on the challenges present in the

field of health care. Remarkably, very little, if any, material is available in the country on health care issues. This is one area where my contribution becomes significant, through a thorough analysis of the health care situation in the country, the various policies of the government, the ground realities of new developments, including genetic medicines, the many challenges that cripple the system, and through recommendations for rejuvenating the basic health care system to provide an equitable and acceptable level of health to all in the country. My work, in a sense, is the first attempt of its kind in the field.

Second, I have tried to look at the whole health care situation in the country through the lens of social justice principles and their imperatives. I have argued that the principles and imperatives of social justice would well inform and guide health care efforts towards equitable health for all.

Third, while advocating basic health care for all, I have also kept in mind the changing health care scenario in the country, especially the onslaught of non-communicable diseases, the new developments in genetic medicines, the presence of a large medical and scientific community, the development of five-star health facilities, the country's effort in developing its GDP and the consequent promotion of health tourism and so on. While communicable diseases dominated the health care scenario in the country till a decade ago, today non-communicable diseases have overtaken the disease-debility and mortality scenario. Recent surveys show that while 43% of deaths in the country take place from communicable diseases, 47% of deaths take place from non-communicable diseases. This has encouraged and accelerated research and experiments in the field of genetic medicines. It has been my effort to address the ethical challenges posed by this new scenario. Extending my reflection on to genetic medicines, I show that even the field of genetic medicines should be informed, guided and directed by the principles of social justice.

Paying primary attention to basic health care needs of the country without altogether abandoning the issues in genetic medicines has made my approach more holistic and comprehensive.

Fourth, and last, if my analysis and recommendations made in the context of India, which has a population of 1.2 billion, is found acceptable, there is reason to argue that such recommendations can be applied to other nations, especially to the developing and underdeveloped nations.