Equity and Justice: An Agenda of Ethics in Health Research

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Ethics is an integral part of human activities in multiple spheres of life. Since research is one of the spheres of human life, the relevance of ethics is strongly realized in health research.

Discourse on ethics in health research is normally focused on the principles of ethics universally applied in health research. In the context of Nepal, these principles are well elaborated in the National Ethical Guidelines of Nepal Health Research Council where justice is seen as equitable distribution of burdens and benefits of research among the research participants.[1] This is necessary, but may not be sufficient to address the agenda of equity and justice in health research. Existing disparity in health at the global and national levels requires further elaboration of the concept and its more visible reflection in health research as an ethical principle considering the research is as a system.

Unequal distribution of resources drew the serious attention of the global communities and the World Health Organization Ad Hoc Committee on Health Research at the end of the last century. At that time it was estimated that 90% of the global resources spent on research of health was allocated to the problems of 10% of the world population while the remaining nominal 10% of the global resources was invested in research of health problems of 90% of the world population primarily living the poor countries. Coining this situation as a 10/90 gap Global Forum for Health Research (GFHR) was established with the main objective of correcting this gap in close partnership with WHO.[2] The global research communities widely appreciated the innovation to address the disparity and proposed various strategies for action in several international conferences organized by the Forum for One Decade. A review of the Forum revealed its continuous efforts to improve health research for the poor and health equity. In the review, The Global forum was provided with some feedback and suggestions for the future.[3]

Unfortunately, despite its profound value, GFHR has collapsed now due to several contributing factors that could be resolved.[4] The disparity in the distribution of global resources in health research continues, but we do not know the extent of the gap, as it is pushed into shadow. This is the time now to renounce the voice to speak about the disparity for equity and justice in health research. This voice should be recognized as an agenda of ethics in health research.

Health problems were equated to diseases and posed a challenge to scientists for centuries to find their causes and remedies. Over time, science and research have proved their ability to overcome many of these problems. Today knowledge and skills generated by research have defeated plenty of those diseases, which took life of people in the past. Unfortunately, access to the achievement of health science and research is limited to certain sectors of people in society. A large section of the people is deprived of the benefit of this success resulting in health disparity, which should be related to the ethics in health research from the light of equity and justice.

Over the last three decades, Nepal has achieved significant improvement in the health status of people on average. However, the progress in health is not equal in all sectors of the population. The indicator statistics of gross national average have masked the disparity in health in the country, which can be observed in most of the health indicators. Infant mortality can be indicative of the situation. In 1996 infant mortality rate in Nepal was 93 per thousand live births,[5] of which is reduced to 28 per thousand live births in the year 2022.[6] This reduction can be considered significant and inspiring for the system. However, this achievement of the national average does not provide the true picture of the infant mortality status of the country. There is a wide gap in the highest and lowest infant mortality rates across the different sectors of the population. Analysis of some available information adequately indicates to persistence of this gap over the last several years.

The highest IMR was 124 per thousand live births in Far West Development Region and the lowest was 79 per

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thousand in the Eastern Development Region when the national IMR was 93 per thousand in 1996.[5] Difference was 48%. Surprisingly, this difference between the two Development Regions increased to 78% in 2016 when the national IMR was reduced to 32 per thousand live births.[7] Besides the geographical region, a substantially increasing gap exists between the rich and poor people. In 2006, the infant mortality rate among the richest people was 40 per thousand live births when it was 71 among the poorest with a difference of 64% compared to the national average.[8] Difference between the richest and poorest people increased to 107 % in 2022 when infant mortality rates were 45 and 15 per thousand live births among the richest and the poorest people respectively.[5] This is a clear signal of the fact that if the national average may mask the disparity in the country, the average in the province may undermine the inequality in the region.

The rising disparity in infant mortality status is visibly indicative of the system's failure to maintain equity and justice in health. Health research should be seen as part of the health system to fill this gap.

Improvement in health status was assumed to enrich people's economic situation. However, we have not yet been able to materialize this assumption. Health problems have created a tremendous financial burden on the people. In Nepal, more than ten percent of health service users experience catastrophic expenditure in health.[9] More than one percent of the total population in the country (about 4 hundred thousand people) is pushed below the poverty line. Many have not been able to rise above the poverty line due to health expenditure every year.[10] There are multiple factors contributing to this painful situation. One of them could be the influence of market economic theories in health finance. The health market has converted health services into commodities for sale and health service users into consumers. The market does not recognize equity. The welfare of the market is a mercy to the people who cannot afford the cost. It is an ethical obligation of health research to assess the impact of the concepts of market economic theories in health.

Health research should ask: Are these conversions compatible with the spirit of health rights, and are they relevant to the norm of equity and justice? Answers to these questions may create the need for health research to generate theories of health finance for the attainment of equity and justice in health, displacing theories of market economy applied in health.

Research succeeded in providing tools to reduce health problems and improve the health status of the population. It is time for health research to internalize that all tools are not appropriate for all. Searching for tools that can help a deprived section of the population is not just a technical issue but an ethical obligation for health research. It is obvious that health research alone is not enough to achieve equity and justice, the entire system should be devoted to its achievement. However, health research has an equal responsibility to address the disparity recognizing equity and justice as an ethical agenda of health research.

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