Ethics of health research priority setting

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Pecha Kucha presentation

Lack of research on an endemic noncommunicable disease in Honduras: the case of Mesoamerican Nephropathy (MeN), a bioethical perspective

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Brief description of case study context

Mesoamerican Nephropathy (MeN) is a Chronic Kidney Disease over-represented in disadvantaged populations. It is endemic in the Pacific region, from southern Mexico to Panama, where there are high rates of poverty, poor access to health care, and malnutrition. Despite having no established cause, it is considered an occupational disease, as strenuous working (farmers, miners, brickmakers), exposition to high temperatures, dehydration, and agrochemical exposure have been identified as risk factors, being therefore prevalent in men, with low income and living in rural areas.[1]

The population that is most affected by MeN suffers from inequity: the absence of extended research on causes, histopathological findings, and biomarkers, makes it extremely difficult to identify the disease in its early stages, preventing patients from being treated properly.

Since 2018, only 75 publications related to the subject were found, of which only 2 were longitudinal studies with follow-up of more than 6 months, both led by High-Income Countries (HICs) researchers outside the region, although MeN is considered the leading cause of premature death of previously healthy young men in countries where it is endemic.[2,3]

It can be identified an evident lack of justice for the affected population: diseases that are listed as the top 10 leading cause of death in HICs (and not in LMICs), such as Alzheimer's disease,[4] are extensively studied, offering information and research on prevention, diagnosis, and treatment options. On the other end, MeN is highly prevalent in endemic areas, but there is no interest in research from the for-profit sector, because it is not a burden in HICs, and patients are not likely to pay for diagnostic procedures and therapy drugs.

In Honduras, there are no national statistics available on morbidity and mortality associated with this disease,[5] but it is estimated, based on data obtained from other countries in the region, that the prevalence of MeN in the population group of interest varies from 2 to 50%.[2] Currently, there is insufficient data to effectively carry out prevention actions or to develop specific treatment guidelines for this population group.

Ethical issues

In this case study, the population of interest is located in Low-Middle Income Countries (LMICs) of Mesoamerica, with no incidence of this disease in HICs. In this region, investment in health-related scientific research is not always a priority, because the public health infrastructure is insufficient, and a high percentage of the population does not have access to healthcare services. In addition, the group with the highest risk of developing this disease is characterized

by young men from rural areas with low income, so they do not have purchasing power and are not an attractive target for funders seeking greater economic return.

   1. *Criteria and goals*

The direct and indirect benefits of the research should be considered during research prioritization. The goals for priority settings are to maximize benefits and to reduce inequity, and as described before, both goals are largely balanced for MeN patients, but in this case, we see that the distribution of research resources is unbalanced and depends on profitability.

Up to now, MeN is not a prioritized topic of research, neither for local government nor non-governmental organizations. Local authorities put effort and funds into other research topics, like maternal and infant health, that are more likely to receive international and private funding. Non-governmental organizations mostly use experts' opinions as preferred methods for research priority setting.[6] However, it is not common to include local stakeholders in the decision-making process, for example in the final paper of the last MeN workshop, all participants, except one, were from countries of the Global North.[7]

   2. *Global and local*

As mentioned before, most countries in Mesoamerica do not conduct much research, due to the lack of governmental and international funding. On the other end, the few foreign studies conducted on the topic did not consider all the countries involved, as they collaborated only with 2 of the 7 countries in the Mesoamerican region.[2,3]

For this ethical issue, we must address that traditionally, most of the funds for investigations are focused on wealthy countries with little or no space for LMICs, however, the burden of neglected diseases in those countries have overwhelming consequences on the health care and the economic system.

These studies should be directed by local stakeholders to prioritize investigation about findings that can be applied largely in the population. For example, the definitive criteria for the diagnosis of MeN is kidney biopsy, easily accessible in HICs, but it is not available for the majority of the affected population. Also, local governments should prioritize the investigation of this neglected disease. To do so, all Mesoamerican countries should design a collaboration on the topic, to optimize the quality of the study's design and external funds could be shared in one bigger study, focusing on one common goal.

Conclusions and recommendations
1. MeN as a neglected disease constitutes an ethical dilemma that should be addressed by local governments, prioritizing this vulnerable population. However, since it is a regional problem, a multinational initiative is required that arises from the collaboration of all countries in the region in the design, financing, and execution of studies that contribute relevant information for decision-making.

2. We propose that the James Lind Alliance (JLA) framework could be the best research prioritization method, which focuses on including local stakeholders to identify variables and strategies that are feasible in the context of LMICs, with emphasis on interventions that can be applied in the context of poor rural areas. Also, priority-setting methods and criteria should be developed under an equity lens, to provide governmental and external funding for studies about populations that otherwise would not have research coverage.

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