Feasibility of Global Sleep Research in Rural Areas of Low-and-Middle-Income Countries. The Atahualpa Project Experience

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Changes in lifestyle, including sedentarism, shift work and increased visual contamination, have modified sleep patterns and increased the prevalence of sleep-related disorders in remote rural areas of many low- and middle-income countries (LMIC). However, there is scarce information on the public health impact of sleep-related disorders in these regions and publications lack consistency in their design and use of research tools, which creates barriers for proper comparison of results across populations. Moreover, in the largest studies on sleep-related disorders conducted in LMIC, individuals were interviewed with only one or two questions, which might not reflect the actual magnitude of the problem. In our opinion, the goal should not be to interview tens of thousands of individuals but to study them well by selecting representative populations of different regions to evaluate them thoughtfully and uniformly. Of course, the sample size has to be calculated to reach power at the time of statistical analyses based on estimated prevalence rates of these disorders and their correlates with other conditions of interest.

In 2012, we began an international collaborative epidemiological cohort study to investigate sleep disorders in community-dwelling adults living in Atahualpa, a village of about 3,000 inhabitants that is racially homogeneous and representative – in terms of cultural factors and living habits – of rural coastal Ecuador. The protocol of this study has been described elsewhere (J Stroke Cerebrovasc Dis 2014;23:1030). In brief, the adult population of Atahualpa were identified during yearly door-to-door surveys and consenting individuals were screened with validated field instruments. Then, certified neurologists interviewed suspected individuals, and persons with confirmed sleep disorders have been scheduled for a polysomnography and actigraphy for objective measurement of their sleep complains.

We plan to stay in the village for the prospective evaluation of these patients and further correlation with other neurological conditions (stroke, cognitive impairment) and cardiovascular diseases. It is our initial experience that high-quality sleep research is possible in rural areas of LMIC and may help enhance population awareness on the importance of sleep-related disorders as major determinants of health. The following commentaries aim to provide groundwork for investigators wishing to embark in global research by sharing lessons learned during the development of sleep research in this remote region.

Enculturation

Besides a complete training on human subjects' protection, researchers and field workers must take into account the laws, culture, and traditions of the international site. Clear review of the proposed consent process and the informed consent form must include local language translation issues, and a letter of certification from a translator, as necessary. It is wise to meet with local community leaders or with physicians who have been already working in the village to learn the colloquial terms that natives use to describe symptoms and diseases. This not only provides more understandable written informed consents, but better designed field instruments that will be used for identification of symptoms and conditions. All studies must require a local Institutional Review Board (IRB) approval. Such IRB must be registered with the U.S. Department of Health and Human Services (DHHS) and local health institutions (such as the Minister of Health) in the same way as requested for IRBs reviewing studies involving human subjects conducted in developed nations. In addition, participating academic institutions and their authorities should clarify any concerns regarding how well the study conforms to the local context.

Headquarters Establishment

A community center facility designed for the study is necessary for dwellers to go in case they want to participate or if they develop some complains during the follow-up. Besides empowering interactions between researches and participants, the center will serve as a central archive

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for information, and a place where complementary exams can be performed without risk and under proper environmental conditions. It is not impossible – depending on funding – to construct even more sophisticated facilities such as a sleep unit for evaluating sleep-breathing disorders. In the Atahualpa Project, we built such a unit that has been working under all the required standards as set forth by the American Academy of Sleep Medicine, including interpretation of data by board-certified sleep physicians.

Proper Study Design

The common practice of telephone interviews in population-based studies conducted in developed countries has no value in remote rural areas, where face-to-face interviews are mandatory to get correct information. Indeed, not all research methodologies are suitable for each rural region of LMIC, and even validated instruments cannot be applied directly without going through the phases of translation and cultural adaptation. As an example, some of our studies in Atahualpa suggest that field instruments designed to assess daytime somnolence – such as the Epworth sleepiness scale – might not be reliable in rural villages. The peaceful lifestyle at the rural level provides a scenario for daytime dozing, and some questions may induce people to imagine themselves in situations that may not be habitual to them (driving a car). On the other hand, the use of the Pittsburg sleep quality index seems to be appropriate for assessing sleep-related symptoms in the rural setting. With the use of this field instrument, we have found predictable correlations with cardiovascular risk factors and silent cerebral small vessel disease in the same way as reported from studies conducted in the developed world.

Regional Factors of Interest

Some particularities of remote communities make them unique for assessing specific correlates of sleep-related disorders that could not be investigated elsewhere, even in areas where sophisticated technology and abundant economic resources are available. For example, the beneficial effects of sun exposure on the quality of sleep should better be assessed in tropical regions, where individuals are exposed to 12 daily hours of sunlight all over the year. In addition, the burden of some sleep-related disorders – such as the Willis-Ekbom disease – that have been related to latitude may well be studied in tropical regions to get more insights on pathogenetic mechanisms explaining such geographical variations.

Conclusions

In summary, only well-designed global sleep research programs may provide useful insights on the prevalence and correlates of sleep-related disorders in underserved populations and will allow health authorities to develop strategies directed to reduce their burden at regional levels. Sleep researchers working in LMICs should aim to develop partnership with well-established local and international academic organizations to work with shared commitment for the advance of sleep science in their countries. By strengthening the associations of such institutions, identification of mutual needs and collaborative solutions to global challenges will be facilitated.

Funding: This study was partially supported by University Espíritu Santo – Guayaquil, Ecuador.