

3-1-2013

Attitudes and Beliefs Regarding Participation in Genomic Research Studies: Insights from Argentines Affected with Neural Tube Defects (NTD)

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Recommended Citation

Ariel C. Armony, ed. "Attitudes and Beliefs Regarding Participation in Genomic Research Studies: Insights from Argentines Affected with Neural Tube Defects (NTD)" (2013). University of Miami Center for Latin American Studies Publications.
http://scholarlyrepository.miami.edu/clas_publications/2

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Attitudes and Beliefs
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Insights from Argentines
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UNIVERSITY OF MIAMI
CENTER for LATIN
AMERICAN STUDIES



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Acknowledgments

This project was made possible thanks to the collaboration between the University of Miami's John P. Hussman Institute for Human Genomics (HIHG) and Center for Latin American Studies (CLAS). This study was funded, in part, by the Miami Consortium for Latin American and Caribbean Studies through its Interdisciplinary Research Group (IRG) initiative.

We would also like to thank and acknowledge the support of the Asociación para Espina Bífida e Hidrocefalia (APEBI) in Argentina and the willingness of the focus group participants to openly share their ideas, their personal experiences and their beliefs with us.

Executive Summary

Over the last several years, the field of genetics and genomics has grown exponentially in comparison to other areas of medicine. This area of research extends beyond the reach of traditional genetic diseases such as Huntington's Disease and Sickle-Cell Anemia and focuses on multifaceted diseases including autism, Alzheimer's, Parkinson's, cardiovascular diseases, or cancer. By understanding the complex interactions between environmental factors and the genetic code, we can begin to build a developmental base for the future of genomic medicine. The goal of genomic medicine is to provide individualized and targeted therapies for the treatment of genetic disorders and diseases.

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The success of genomic studies depends on the participation of diverse populations. The representation of all population subgroups is key to ensuring that research results and future interventions are applicable across ethnic groups. For numerous and complex reasons, Latin American populations are generally underrepresented in genomic studies. One solution is to identify new and innovative initiatives to maximize participation of distinct Latin American populations. It is extremely important to develop effective strategies that are both culturally appropriate and specifically planned to encourage greater levels of participation for each Latin American subgroup.

The goal of this research project was to explore personal knowledge, attitudes, beliefs, and perceptions with respect to overall genomic studies and, more specifically, the causes of neural tube defects (NTD). We sought insight from Argentines residing in Buenos Aires and its surrounding areas who are affected by neural tube defects or are related to the person affected.

Using focus group methodology, we were interested in the following:

1. Finding potential obstacles for participation,
2. Identifying factors that could be effective as motivators,
3. Identifying the sources of information that people find reliable for health-related facts, and
4. Identifying forms of effective communication and interaction with families affected by NTD.

The results of this study will help researchers develop initiatives that effectively inform and educate specific groups pertaining to their unique needs, as well as increase the likelihood of participation in genomic studies.

The research team included María Gavier BA, Ricardo Martínez MBA, Evadnie Rampersaud Ph.D., María Ciliberti MPH, Daniela Martínez BS, and Joycelyn Lee Ph.D. This report was prepared by Karie Jo Peralta and Jennifer Garçon, Distinguished Fellows at the University of Miami's Center for Latin American Studies (CLAS), under supervision of Ariel C. Armony Ph.D., CLAS director.

The study was conducted in March 2012 in Buenos Aires, Argentina. Participants discussed several ways that the public gains access to medical information. Sources include the Internet, medical institutions, health organizations, and the media. Participants agreed that the main sources of information about health concerns and medical themes were the Internet, direct consultation with doctors and/or a combination of both. However, participants also expressed that the information gleaned from the Internet sometimes leads to greater confusion. Recognizing that access to the Internet is easier in Buenos Aires, participants mentioned that individuals living in rural areas relied more on radio and television for medical information.

Regarding genetic research, the discussions revealed that the majority of participants did not have a clear understanding of what genetic research is, but this is typically the case when the topic concerns a relatively new area of medicine. There was a general consensus that there is a lack of information, knowledge, and education about genetic studies. Some participants showed concern for the media's lack of interest to promote these types of research activities and inform the public.

Following an extensive discussion about genomic studies and their possible benefits, the majority of participants expressed optimism, hope, and enthusiasm about the possible development of more effective treatments, medicines, or forms of prevention through these types of studies. Participants recognized that the high cost of genomic research impedes conducting studies in Latin America, especially in Argentina, at the same pace as in countries like the United States and Europe. They brought attention to the need for the government, civil society, and businesses to unite in efforts to promote genomic studies.

Participants also pointed out that cultural factors and distrust may influence the decision to participate in medical studies in general. The majority of participants in the study agreed that soliciting blood or saliva samples were more reasonable requests than biopsies or other more invasive procedures.

The participants expressed that the main motivation to participate in genomic studies was the opportunity to benefit from greater knowledge and understanding of the topic. They mentioned that those with a personal connection to the disease would be more motivated to participate, and that offering economic incentives would also make participating more appealing.

The participants agreed that in order to share the importance of genomic studies to the general population, key objectives should include education and researchers should familiarize themselves with the culture of the individuals they hope to recruit. This would allow for the development of group-specific recruitment strategies, which are crucial for success. The strategies that participants find effective to promote genomic studies to a wide-ranging population include: the use of testimonies, the use of celebrities as spokespersons, sharing disease-related statistics, offering economic incentives, and ensuring the public that Argentines will become better represented.

Questions specific to how information is shared among those with NTD were also asked. Participants identified the support group Asociación para Espina Bífida e Hidrocefalia (APEBI) and several public hospitals including the Garrahan Hospital, the Gutiérrez Hospital, and the Posada Hospital as trusted groups and institutions. They pointed out the significance of having distinct disease-specific support groups as an important factor in the quality of the support received. Mass and popular media outlets including the Internet, Facebook, television and radio are also important for dissemination of information.

Families expressed a number of insights and frustrations related to the system of care for NTD. Several families mentioned the lack of causal explanations for neural tube defects and the lack of answers to the questions of those affected. There were divided opinions related to the perceived causes of neural tube defects. All participants affirmed that taking folic acid before and during the first month of pregnancy could reduce risk of NTD. There was concern expressed for the presence of pesticides in food and the potential risks associated with genetically modified foods.

Participants also expressed concern for the medical care of people older than 21 years old who are affected by neural tube defects, explaining that hospitals in Argentina do not treat people with this disease after the age of 21. Within this discussion they described the difficulties they encountered with the medical system in general and expressed their beliefs regarding the government not prioritizing the health care system. The participants agreed that genomic studies should involve the government, academic institutions, community based organizations, businesses, and the public for better results.

The dominant theme was the lack of information and education regarding genomic studies and neural tube defects. The focus group participants highlighted the importance of adequately informing people so that they make educated decisions about participating in genomic investigations. The focus participants suggested educational strategies be tailored to different age groups, their access to communication, and cultural factors. They expressed concern about the lack of explanation for what causes neural tube defects and were concerned about the growth of this disorder in the population. Continuing to explore this topic within the NTD community is fundamental to assisting genomics research stakeholders incorporate recommendations and set short- and long-term goals that can increase the participation of Argentines and other Latin American groups in genomic studies.