

Parental Perception of Barriers to Surgical Care for Neural Tube Defects in Guatemala

Boris Pavic, MS3¹; Graciela Mannucci, MD²; Jorge Lazareff, MD^{1,3}

¹David Geffen School of Medicine at UCLA, ²San Juan de Dios General Hospital Department of Pediatric Neurosurgery, ³UCLA Department of Neurosurgery



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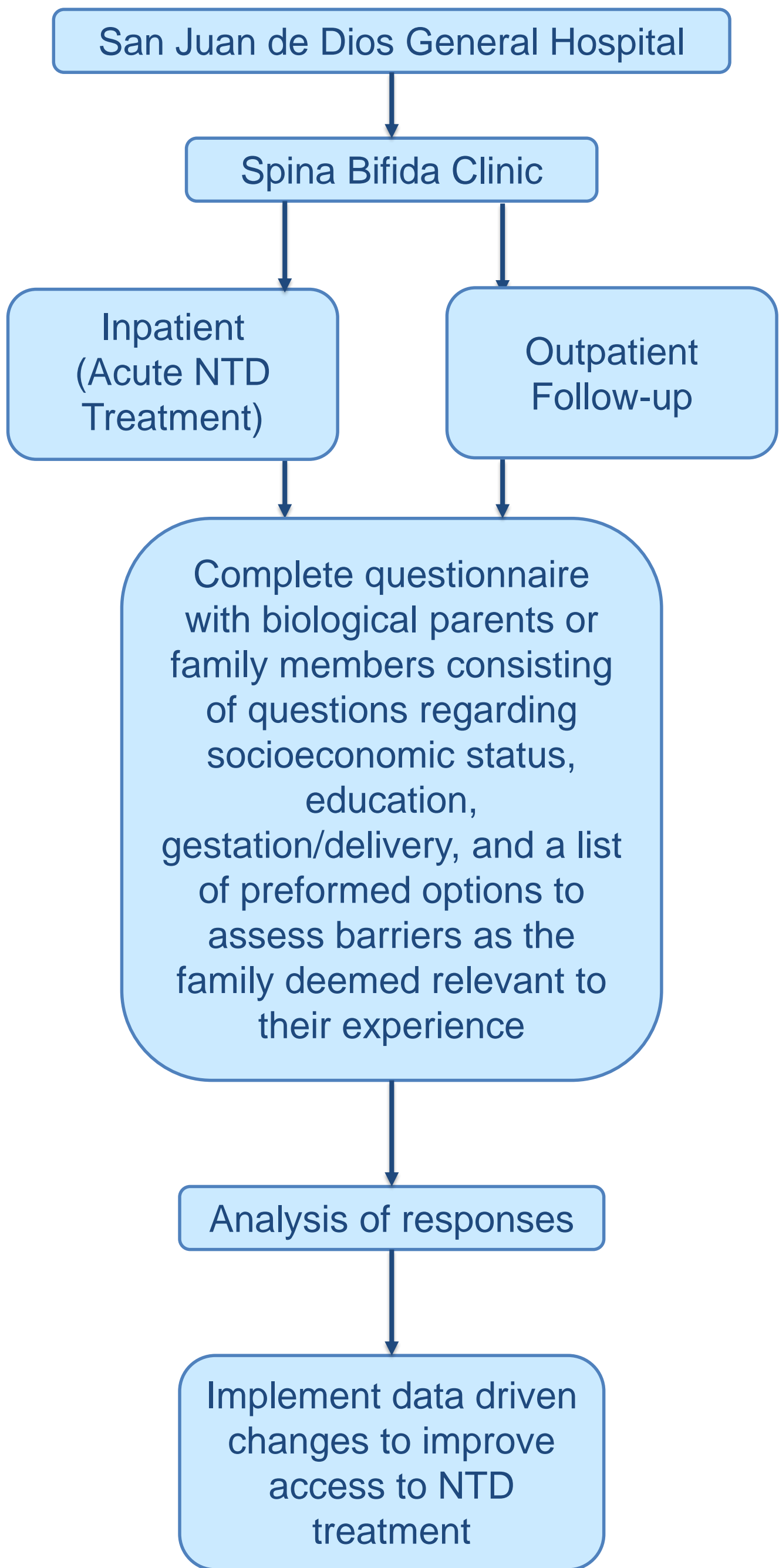
Objective

To define the barriers to surgical care from the perspective of the parents. To the best of our knowledge, this study together with a similar one conducted by our group in the People's Republic of China are the first of its kind.

Background Information

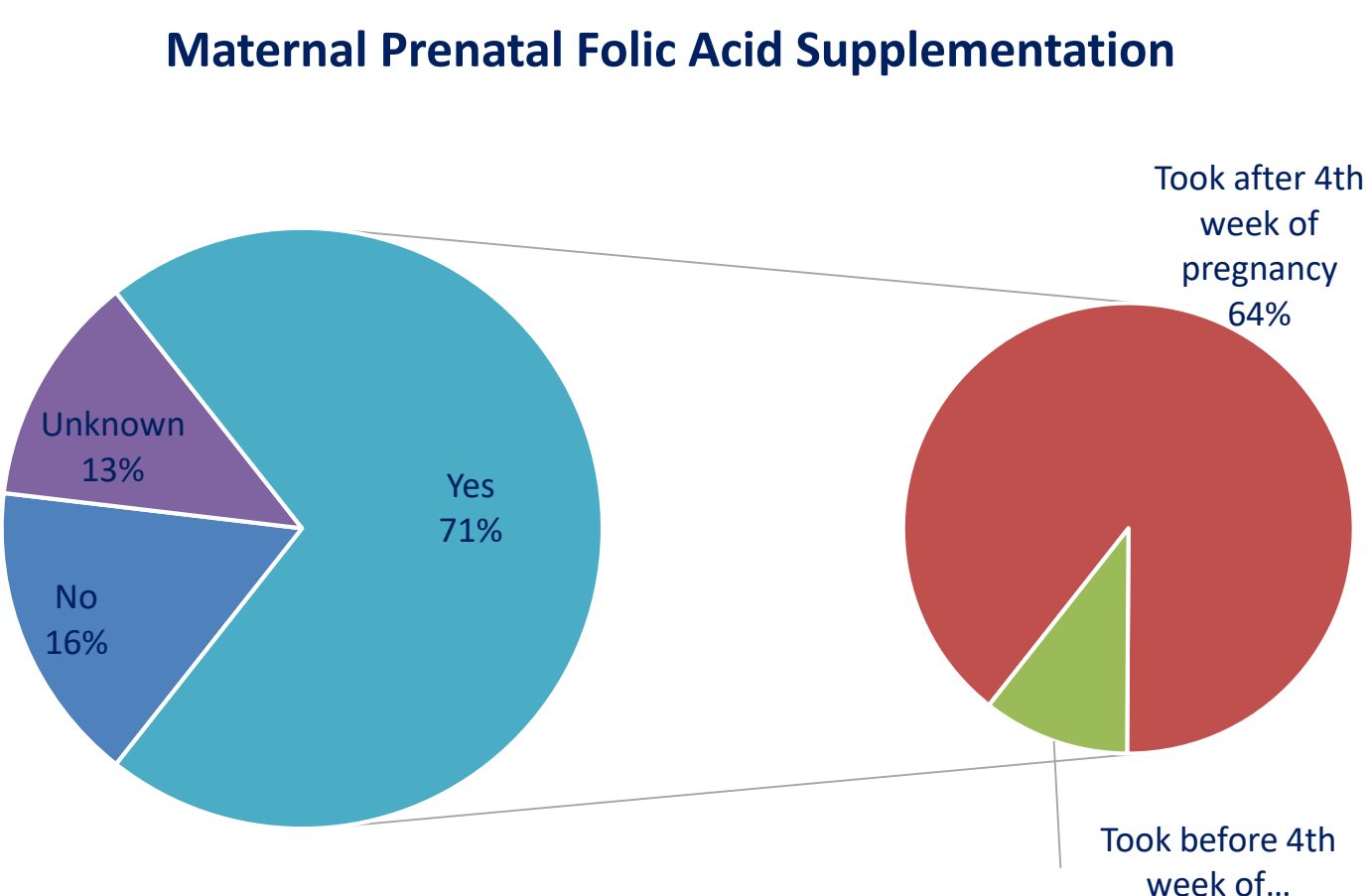
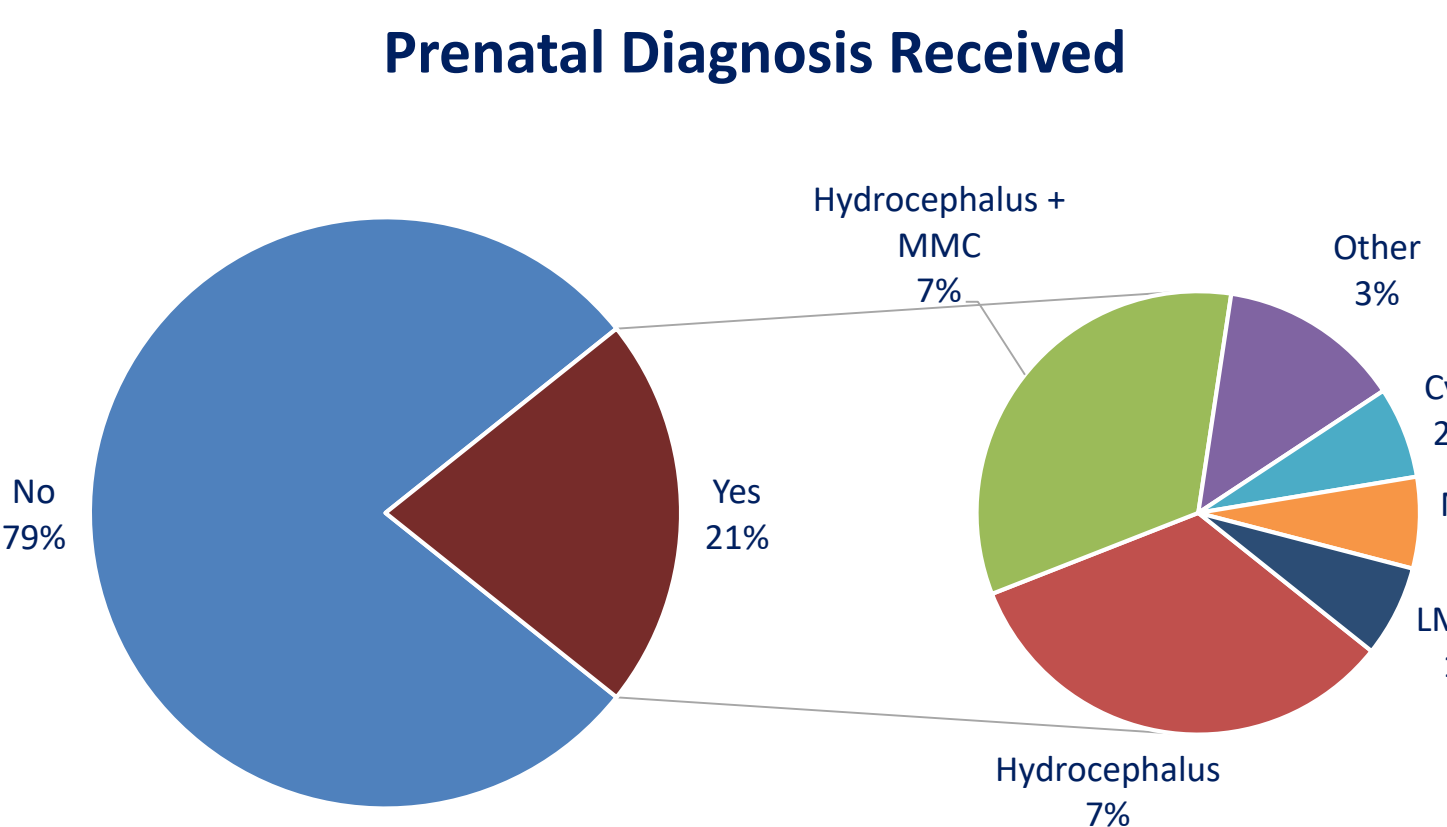
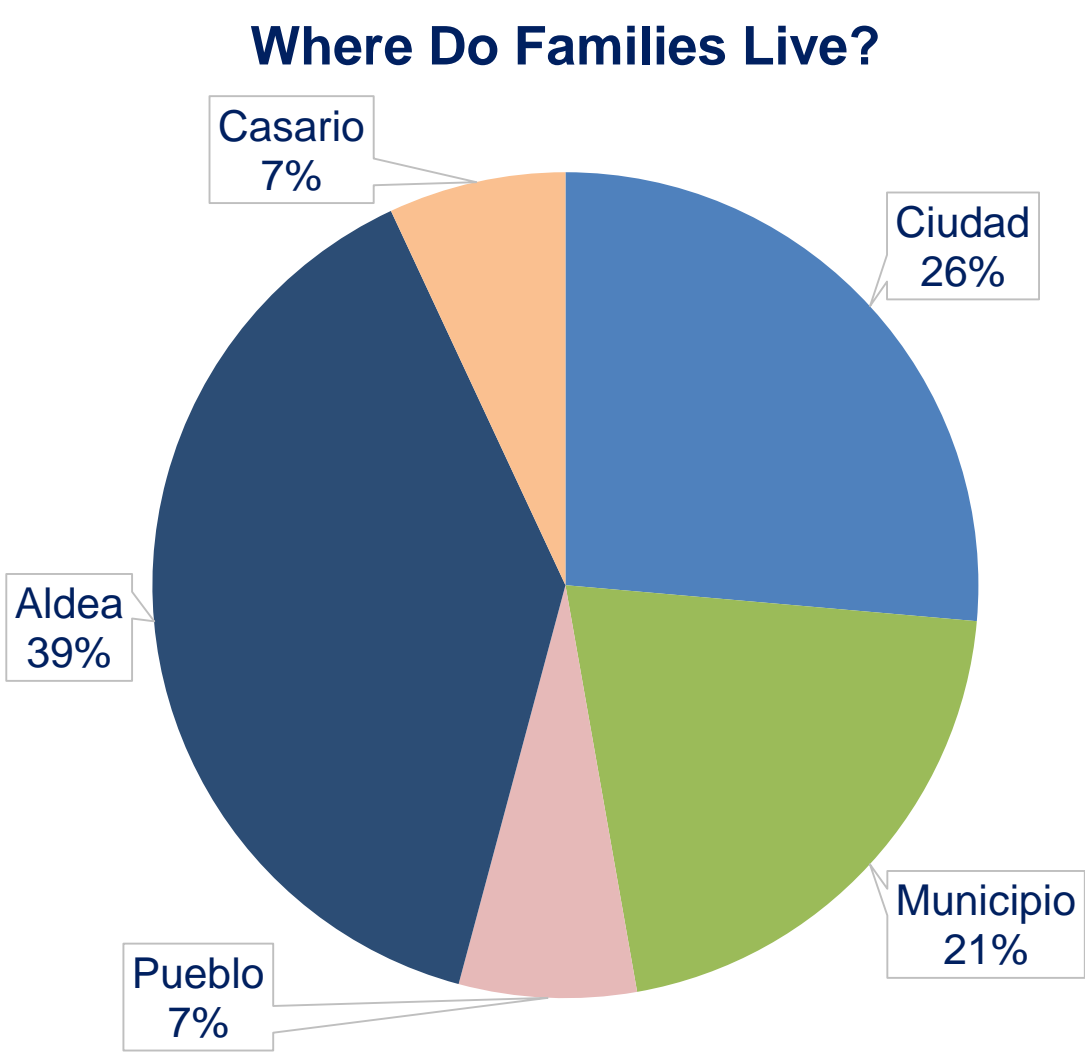
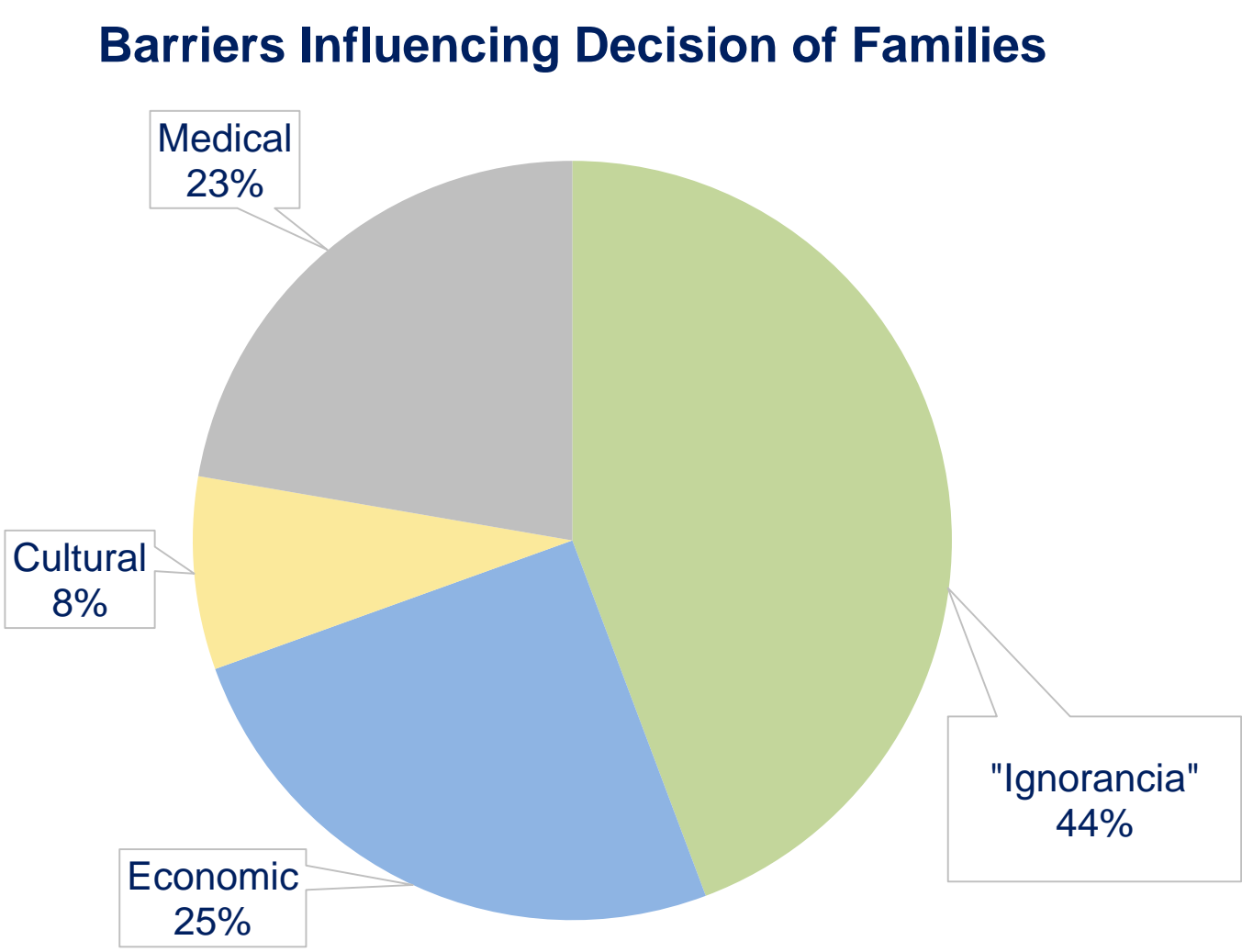
- Neural Tube Defects (NTDs) are the most common congenital malformation
- Its incidence in Guatemala is fifteen times higher than in the United States, where its prevalence is reduced through folic acid and abortion after prenatal diagnosis.
- Although there have been some efforts to prevent NTDs in Guatemala through fortification methods, NTDs still remain a healthcare concern and a large number of patients are not treated following ideal standards.
- Every form of NTD can be diagnosed immediately after birth through a standard physical exam.

Methods



Results

Did any of the following influence your decision to receive treatment initially?	Totals
The child's symptoms were thought to be too severe	51
You did not know enough about the child's condition	39
Fear of the treatment and the side-effects of the treatment on the child	39
The child's symptoms were thought to be not severe enough	15
Family members or friends suggested that you do not seek treatment	7
Lack of available transportation to the hospital	37
Lack of time and work constraints	28
Cost of the treatment and related services	21
Lack of health professionals or health facilities	40
Lack of medication or equipment at the health facility	21
Your doctors did not know to refer you to a specialist	15
Your religious and/or cultural beliefs	25
The child was receiving alternative treatments	3
Other (please specify)	1
	342



Results (cont'd)

- A total of 72 families with children at various stages of the treatment process were interviewed and all completed the questionnaire.
- The analysis yielded that the most common factor as related by the parents were:
 - Lack of understanding of the condition by the parents
 - The lack of knowledge about the condition by the treating physician or lack of medical facilities
 - Not far behind but still not as relevant as the factors mentioned above the parents listed a set of economical modifiers

Discussion

- Our data suggests that understanding about etiology and treatment alternatives of congenital pathologies, need to be part of the medical school curriculum.
- Even with high rates of prenatal screening (90%) and prenatal US (73%) only 9% received a diagnosis of NTD prenatally which shows lack of medical staff competency.
- Our results call for additional resources and methods to help educate both medical professions and communities so that the informed decisions can be made for children with NTDs.
- The efforts for reducing the incidence of NTDs through incorporating folic acid in the diet will not succeed as desired if the population does not have awareness about the disease and the need to maintain adequate levels of folic acid even before conception as seen with 81% took folic acid supplementation but only 11% started before the 4th week with the median time of initiation 10-11 weeks even though 73% of mothers knew that it was beneficial.
- Parents and families are committed to the well being of their children even when having limited personal resources (70% of families yearly earnings are less than \$3500)
- Diseases that are prone to stigma are influenced by cultural and religious beliefs.

Future Project

- Our future plans are to utilize the data obtained from the questionnaires to better understand the barriers (cultural, socioeconomic, political, infrastructural, or educational) to accessing proper neurosurgical care for patients with NTDs in Guatemala and thus reveal some insights to what can be done to improve the current treatment

Acknowledgments

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