Pathways to Autism Diagnosis: Lived Experience of Hispanic Immigrant Families

Anthony Montes de Oca
Wharton Dean’s SUMR Scholar
Team

Anthony Montes de Oca
Penn Undergraduate, C’25
B.A. Biology, B.A. Health & Societies

Stacey L. Bevan, MA, RN
PhD Candidate Penn, CHOP clinician

Margaret C. Souders, PhD, CRNP
Penn Nursing Faculty, CHOP clinician
Hispanic children at risk for ASD face...

- Lower rates of diagnosis
- Later diagnosis
- More significant symptoms
- Less emphasis on developmental concerns
- Less likely to receive treatment
- Lower quality treatment
Project Aims

01
To explore parent’s experience of autism spectrum disorder and early concerns about child behavior

02
To describe interactions with the US healthcare system during the screening and diagnostic process

03
To understand barriers and facilitators to service referral and access following a child diagnosis
Methods

Qualitative approach

- Realist and deductive

Interviews

- Caregivers of autistic children (informed consent and demographic forms)
- Semi-structured interview guide
- Written in English and translated in Spanish

Directed content analysis

- Theoretical framework independently coded by two researchers
  - Utilizing to code interviews
Interviews

- Maximum of 90 minutes
- Culturally adapted interview guide to Spanish
- Tested questions with practice participant before actual recruitment
- Importance of positionality
Qualitative Coding

Macrostructural/Contextual factors

Predisposing factors

Resources (Enabling factors)

Need for healthcare

Health service utilization

General Factors
- Government policy
- Healthcare system
- Social, economic, & Political conditions
- Demographic factors
- Socioeconomic status
- Health beliefs
- Genetic factors
- Financial resources
- Social resources
- Access to healthcare
- Self-reported health
- Evaluated health

Immigrant-specific Factors
- Context of emigration
- Context of reception
- Health service utilization
  - In the homeland
- Immigration status
- Assimilation
- Immigrant ethnic culture
- Homeland-based financial and social resources
- Transnational access to healthcare
- Immigrant-specific health need/conditions
Culturally Appropriate Adaptation

CAREGIVERS OF CHILDREN ON THE AUTISM SPECTRUM NEEDED FOR INTERVIEW STUDY

WHAT ARE THE GOALS OF THIS RESEARCH STUDY?

The purpose of the study is to learn more about the experience of caregivers who have a child diagnosed with ASD. We also want to better understand what is working well in healthcare in the US.

WHO CAN BE A PART OF THIS STUDY?

This study is open to primary caregivers of a child (aged 3-17) who has been diagnosed with autism spectrum disorder in the last year. To be eligible, you must have immigrated to the US and identify as Hispanic.

WHAT WILL PARTICIPANTS BE ASKED TO DO?

In this study, we will ask you about your experiences as a caregiver of a child with ASD. This is a one-time interview lasting about 60-90 minutes in either Spanish or English. This study will take place virtually with a secure video link or in-person.

Participation in the research study is voluntary and will not affect any services that you or your child may be receiving at CHOP. You are free to withdraw from the program at any time.

I WANT TO HELP! WHO DO I CALL?

If you are interested in participating in the study or want to learn more about it, please contact:

Stacy Bean, MA, RN
Study Coordinator
staceybean@upenn.edu
979-676-8828

Visit Research Discovery Finder (www.research.chop.edu/find).

SE NECESITAN CUIDADORES DE NIÑOS EN EL ESPECTRO AUTISTA PARA UN ESTUDIO DE ENTREVISTA

¿CUÁL ES EL PROPÓSITO DE ESTE ESTUDIO DE INVESTIGACIÓN?

El propósito de este estudio es aprender más sobre la experiencia de los cuidadores que tienen un niño diagnosticado con TEA. También queremos comprender mejor lo que está funcionando bien en el sistema de salud en los EE.UU.

¿QUIÉN PUEDE PARTICIPAR EN ESTE ESTUDIO?

Este estudio está abierto a los cuidadores principales de un niño (6 años a 17 años) que ha sido diagnosticado con el trastorno del espectro autista (TEA) en el último año. Para poder participar, usted debe haber emigrado a los Estados Unidos e identificarse como una persona hispana o latín.

¿QUIÉN ES INvolucrado EN ESTE ESTUDIO?

Un personal del estudio le preguntará sobre sus experiencias como un cuidador de un niño con TEA. Le entrevistaremos durante aproximadamente 90 minutos en español o inglés. Podemos reunirnos en persona, por teléfono, o le daremos instrucciones para completar la entrevista por video a través de un enlace de web seguro.

La participación en el estudio es voluntaria. No tiene que participar para recibir atención médica en CHOP. Puede parar la entrevista en cualquier momento.

SERIES DE RECLUTAMIENTO DE ESTUDIO DE ENTREVISTA

¿QUIERO AYUDAR? LA QUÉN LLAMO?

Si está interesado en participar en el estudio o desea obtener más información, llame al:

Stacy Bean, MA, RN
Study Coordinator
staceybean@upenn.edu
979-676-8828

Visite Research Discovery Finder (www.research.chop.edu/find).
Implications

Inform
- culturally sensitive clinical interventions
- and improve the identification of risk factors

Improve
- early and accurate autism diagnoses through screening processes in clinical and community settings

Support
- the creation of immigrant and refugee clinics to evaluate and refer for mental health services
Additional Research Opportunities

Clinical Considerations Paper
- Updating from the last three years
- Clinical considerations for immigrant children at risk/diagnosed with ASD
- Consulted with clinicians
  - Clinical questions
  - Case studies

Sleep Study RCT
- Field visits with caregivers that have at least one child with autism (first 8 weeks)
- Describing and developing clinical care plan for sleeping habits of caregivers and children
Lessons Learned

- Positionality
- Breath of Nursing Profession/Field
- Literature Review
- Writing abstracts
- Exposure to clinical case conferences
- Qualitative and quantitative research participation
- Difference between direct translation and cultural adaptation
Acknowledgments

Stacey L. Bevan, MA, RN
Margaret C. Souders, PhD, CRNP
Adjoa Amoah, CRNP
Shayleigh Page, PhD, CRNP
Sleep Study RCT Team
Eric Macias, PhD

Joanne Levy, MBA, MCP
Wharton Dean’s Office
2023 SUMR Cohort
Lilian Bravo, PhD, RN
Crisma Emmanuel, PhD, RN
Chinwe Nwadiogbu, MLA

Thank you!
References


QUESTIONS???

Thanks for listening!