Down Syndrome in the Latinx Community

Cultural Considerations within a Complex Landscape

Lisa D. Herzig, MD
Assistant Professor

Julia T. Mattson, MD, PhD
Fellow, Developmental-Behavioral Pediatrics

Division of Developmental Medicine
Department of Pediatrics
University of Washington
Learning Objectives

1. What is known
2. Cultural considerations
3. Ways to support
Down Syndrome (DS)

Cause: extra genetic material from chromosome 21 (three copies instead of two = trisomy 21)

Prevalence: about 1 in every 700 babies

Special medical issues: developmental differences/delays, intellectual disability
Other Health Issues

Hearing/vision problems, sleep apnea

Different organ systems affected, including the heart and thyroid

Increase risk of leukemia/GI malformations
Cultural Considerations

Higher prevalence of Down syndrome in Hispanic/Latino community

• Differences in pregnancy termination rates (Natoli et al. 2012)

Multiple layers of bias and discrimination

• Higher rates of death in minority populations (O’Leary et al. 2018)
Cultural Considerations (continued)

“Family management” = how family members incorporate an individual’s unique needs into everyday family life (e.g. Van Riper et al. 2021)
Complex Cultural Themes

Navigation of medical/education systems
Access to resources
Discrimination/assumptions
Language barriers

Our role: promote maximum potential and high quality of life

Sheets et al. 2012
Ways to Support

• Don’t make assumptions
• Take time to learn from families
• Help identify goals and sources of support
• Listen and be compassionate
• Assist with navigation and provide resources
Wrap Up
Resources


Resources (continued)


Thank you for joining us!

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