

PacWest ITAC Learning Modules

Cultural Crossroads in Disabilities



Down Syndrome in the Latinx Community

Cultural Considerations within a Complex Landscape

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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

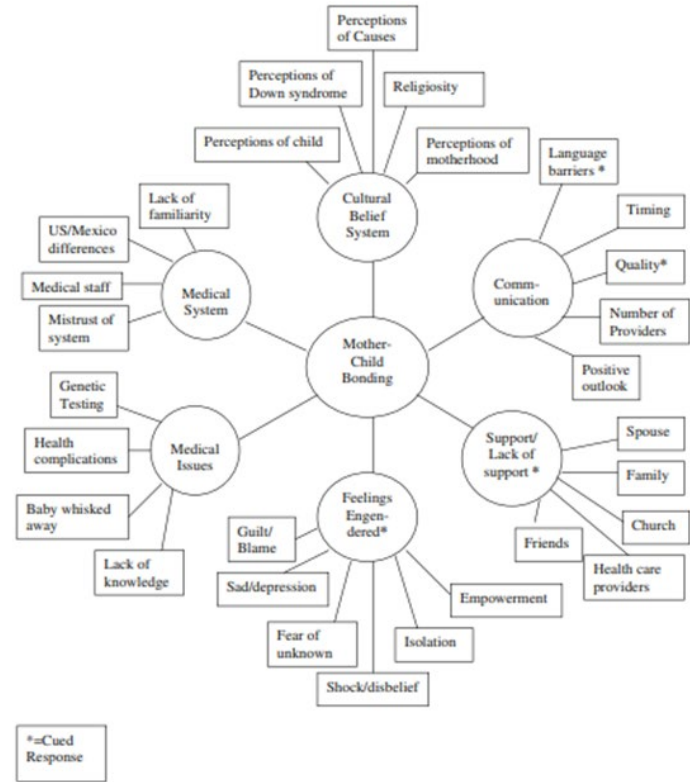
Navigation of medical/education s

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

Interview

Wrap Up

Resources

Arango et al. (2018). Developmental trajectories of children with Down syndrome by socio-economic status: the case of Latin America. *Journal of intellectual disability research : JIDR*, 62(9), 759-774.

Khoshnood et al. (2000). Ethnic differences in the impact of advanced maternal age on birth prevalence of Down syndrome. *American journal of public health*, 90(11), 1778-1781.

Natoli et al. (2012). Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995-2011). *Prenatal diagnosis*, 32(2), 142-153.

O'Leary et al. (2018). Early death and causes of death of people with Down syndrome: A systematic review. *Journal of applied research in intellectual disabilities : JARID*, 31(5), 687-708.

Resources (continued)

Salud America <https://salud-america.org/down-syndrome-and-its-startling-impact-on-latinos-a-closer-look/>

Sheets et al. (2012). Breaking difficult news in a cross-cultural setting: a qualitative study about Latina mothers of children with down syndrome. *Journal of genetic counseling*, 21(4), 582-590.

Van Riper et al. (2021). Measurement of Family Management in Families of Individuals With Down Syndrome: A Cross-Cultural Investigation. *Journal of family nursing*, 27(1), 8-22.

Thank you for joining us!



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