

Reducing risk for neural tube defects among immigrant Latino women in Northern California

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Presenter Disclosure

Daniel Perales

(1) The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

"No relationships to disclose"

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What is Neural Tube Defect?



- An NTD is a birth defect.
- Abnormalities in the development of the spinal cord and brain in the fetus.
- The defects develop between the 17th and 30th day after conception, as the neural tube develops.

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3 Primary Forms of NTDs



- Two most common
 - **Spina Bifida** - Tube that forms the spinal cord and spine does not close properly.
 - **Anencephaly** - much of the brain does not develop. Babies with anencephaly are either stillborn or die shortly after birth
- Least Common
 - **Encephalocele** - sac-like protrusions of the brain and the membranes that cover it through openings in the skull

Source: http://www.nichd.nih.gov/health/topics/neural_tube_defects.cfm

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Epidemiology

- Each year spina bifida and anencephaly occur in approximately 1 of every 1,000 pregnancies (~4,000) in the United States
- An estimated 300,000 newborns are affected by NTD worldwide.

Source: National Center on Birth Defects and Developmental Disabilities

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Epidemiology

- The rate of neural tube defects is higher among Hispanic/Latino mothers:
 - an NTD rate of 6.1 per 10,000 live births among children of Hispanic mothers was significantly higher than the rate of 4.5/10,000 live births among children of non-Hispanic white mothers ($p < 0.001$).

Source: Kirby, R., Petrini, J., Alter, C., et al. (2000). TERATOLOGY 61:21-27.

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Intervention: MayView Clinic Preconception Care Project



March of Dimes Funding



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Priority Population- Mountain View, CA

- Mountain View, CA: just north of San Jose, CA – large Latino immigrant population.
- Latino women, living in Santa Clara County, at higher risk for birth defects: 1.5/1000 live births, compared to 1.4, for Californians in general.
- Many foreign born with varying degrees of health care and little documentation of care.
- Medical chart reviews of prenatal clients found 18% to be Rubella non-immune
- Another survey found that ~60% needed Rubella immunization.
- The percentage of unintended pregnancies among Latino women is higher than the state rate.

Source: Santa Clara County Public Health Department and the MayView Clinic.

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Priority Population- Mountain View, CA

- Women had **barriers to due to beliefs** about family planning, pregnancy and the reasons for birth defects (e.g. illness as “Fate” or “punishment”).
- **Low English literacy** level
- **Highly mobile population:** change address and phone numbers often and difficult to follow.
- Best reached through a **word-of-mouth network**.
- Culturally sensitive **verbal and/or visual communication** most effective method.
- They are **not at risk** for smoking and alcohol use.

Source: Santa Clara County Public Health Department

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Rationale

- Korenbrot, et al, found evidence that **preconception care helps** in rubella immunization and folic acid supplementation to **prevent congenital anomalies**.
- Effective preconception care **depends on changing provider practices in busy clinic environments**.
- MayView providers **needed a protocol, and organizational support** for Rubella Immunization and Folic acid education of women who receive primary care.

References: Korenbrot, C., et al, (2002). Preconception Care: a Systematic Review. Maternal and Child Health Journal, 6(2), 75-88.

Cullem, A.S., Changing provider practices to enhance preconception wellness. Journal of Obstetric, Gynecological, & Neonatal Nursing. 32(4), 543-549.

Moos, M-K., Preconception wellness as a routine objective for women's health care: an integrative strategy. (2003). Journal of Obstetric, Gynecological, & Neonatal Nursing. 32(4), 550-556.

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Objectives

- #1) Clinic staff will counsel 300 Latino women, at risk for rubella, and achieve a rubella vaccination rate of at least 80% for the susceptible clients (240).
- #2) Counsel and give folic acid supplements to 500 women, of which 80% of those who can be followed will report taking an adequate folic acid supplement.

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Folic Acid Sources

CDC: Every woman who could possibly get pregnant should take 400 micrograms (400 mcg or 0.4 mg) of folic acid daily in a vitamin or in foods that have been enriched with folic acid.



Source: <http://www.cdc.gov/ncbddd/folicacid/>

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Methods

- **Purchased** Rubella vaccine and folic acid supplements for the clinics.
- **Developed clinical protocols** for staff to follow for counseling patients about rubella vaccination and folic acid supplementation.
- **Changed the clinic visit forms** to document rubella susceptibility, immunization and folic acid supplementation.
- Conducted a **Focus Group** to select culturally relevant educational materials.
- **Evaluator designed instruments** including:
 - a patient **screening questionnaire**;
 - A tool to **document vaccinations and Folic Acid dispensing**;
 - a **code book** for Patient Encounter Forms to enable electronic data collection.
 - A **protocol for gathering follow-up data** on daily Folic Acid use.
- Clinic Staff also received **training** for program implementation and monthly updates on how the program was progressing and opportunities for improvement.
- Published articles in **Spanish newspaper** -El Observador, on the services.

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Results: 3/04-1/05

- 500 Latino women of childbearing age counseled for Rubella and NTD.
- **Rubella objective:** Expected to vaccinate 240 of 300 women; but vaccinated 183 (61%).
- Dispensed 512 bottles of Folic acid 400mcg.
- **Folic Acid Objective:** Expected 80% of women counseled to take a daily supplement of Folic Acid.
- At follow up clinic visits, most patients were asked, “Are you taking a multi vitamin or Folic Acid Supplement?”
 - 60% reported taking folic acid daily.

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Discussion-Midway Review Challenges

- **Staff were willing** to take the time and trouble to give the care.
- Staff were challenged to give information and screening during **10-15 minute clinic visits**.
- **Women needed time** to make informed choices.
- Sometimes **woman left with no information** and no vaccination or supplement.
- Program Director wrote **notes on charts** to remind staff to counsel women.
- Women sometimes **accepted** a vaccination or supplements when **counseled at a second or third visit**.
- **Needed to train new staff** who were employed by the clinic after the initial training.

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Discussion-Midway Review Challenges

- **Data Collection problems:** coded electronic data reports on the Patient Encounter Forms, generally did not tally with the written logs, questionnaires, and chart documentation of screening and care given.
- **Written logs and chart documentation**, together, resulted in the most reliable data. Hence, chart review is a very important but very time consuming.
- Maintaining staff morale while carrying an increased load because of absent or new staff was challenging.
- Could not reach many of the women who received Folic Acid Supplement when phoned: no answer or the phone was disconnected – mobile population.

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Conclusions- 1/05

- **Patients were eager** and receptive to receive information and treatment.
- **Training worked:** But important to **give staff structured training** at the beginning **and** midway through the program as well as “on the job” – as needed.
- **Staff learned how to make time** for patient care **and** to follow the protocols – a practice norm.
- **Cannot rely on telephone calls** for follow-up - written logs and chart documentation worked best. Important to continuously thank and praise staff for their efforts.

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Conclusions- 1/05

- Anecdotally: “a number of women who became pregnant after receiving this preconception care, felt that they had decreased the risk for their pregnancies.” Janet Hughes, NP, MPH
- “Since 2005, the project continues to operate and is more effectively and efficiently providing pre-conception care to many Latino women in the Mountain View area.” Janet Hughes
- Sustainability: “Clinic Board of Directors approved funding to make this care a permanent part of the service profile” Janet Hughes

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