Using formative research to guide the development of Down syndrome educational materials

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Discussion Overview

- Project overview: focus groups about Down syndrome
- Project results
- Recommendations
PROJECT OVERVIEW: FOCUS GROUPS ABOUT DOWN SYNDROME
Need for Educational Materials

- **Down syndrome:** one of the most common congenital abnormalities
  - 1 in 691 children born each year*

- Lack of current information about Down syndrome available for women**

- New ACOG guidelines***

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Project Description

- Study objective: to inform strategies for educating women about Down syndrome
- Conducted focus groups among women of childbearing age, exploring the following domains:
  1. To understand women’s knowledge, attitudes, and beliefs about Down syndrome;
  2. To explore women’s media habits;
  3. To explore who women perceive to be credible health messengers; and
  4. To explore women’s preferences for receiving information about Down syndrome.
Focus Group Research

- Group interview (5-10 people) led by a professional moderator

- In-depth information gathered in short amount of time

- Good for gathering general information about a topic

- Group dynamics encourage discussion about knowledge, attitudes, beliefs

Study Design and Population

- 24 focus groups, 4-6 women in each group
  - $N=111$
- Held in two cities: Raleigh, NC, and Washington, DC
- Two specific categories of women recruited:
  - Women who have a young child (< 3 years old)
  - Women who plan to have a child in the next year
- Further segmented by:
  - Race, ethnicity (African American, Hispanic, White)
  - Age (21-34 years old and 35-45 years old)
- Ineligible to participate:
  - Women who have an immediate family member with Down syndrome
  - Women working in special education or clinical genetics
## Study Design and Population

### Participant Characteristics and Number of Focus Groups

<table>
<thead>
<tr>
<th>Race</th>
<th>White</th>
<th>African American</th>
<th>Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt; 34 year</td>
<td>35+ years</td>
<td>&lt; 34 year</td>
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<tr>
<td>Women who have a child without Down syndrome</td>
<td>2</td>
<td>2</td>
<td>2</td>
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<tr>
<td>Women without children who plan to have children in the future</td>
<td>2</td>
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Data Collection

- Focus group discussion length: ~90 minutes
- Held primarily in English
- Interview guide organized around the 4 domains
- Short demographic health questionnaire
Data Analysis

- Systematic review of records from all focus groups, including transcripts and observer notes

- Small project team coded according to Constant Comparative analytic framework*

- QSR NVivo used

PROJECT RESULTS
**Results – Participant Demographics Survey**

- **N=109**
- **Race and Ethnicity**
  - African American: 39
  - White: 38
  - Hispanic: 32
- **Age:**
  - < 35 years: 54
  - 35-44: 55
- **Education:**
  - More than high school: 103
- **Employment:**
  - 68.8% employed
- **Marital Status:**
  - 52.3% married
- **Pregnancy History:**
  - 58.7% have had at least one pregnancy
- **Health Insurance:**
  - 87.2% had private health insurance
- **Desired Children:**
  - 93% want future children

*Two women refused to complete the demographic survey at the end*
Results – Knowledge about Down Syndrome

- All participants had heard of Down syndrome

- Most participants knew:
  - Facial features specific to persons with Down syndrome
  - Risk factor: advanced maternal age
  - Likelihood of developmental delays
  - Various types of therapies a child might receive
  - There is no cure for Down syndrome
Results – Knowledge about Down Syndrome

Most participants also said:

- Children will have to attend special education classes
- Persons with Down syndrome remain mentally childlike throughout their lives
- A person with Down syndrome is nice, happy, affectionate, loving, friendly, and always smiling

“I never saw someone with Down syndrome who is unhappy. I always see them as happy and free-spirited.”

[DC, Women Planning Pregnancy, White, 35-45]
Results – Knowledge about Down Syndrome

Most participants did not know:

- The average lifespan of a person with Down syndrome
- If a person with Down syndrome can bear children
- Prevalence data
  - General
  - By race or ethnicity

Many Hispanic and African-American participants said they only saw or knew about Caucasian people with Down syndrome.
Results – Knowledge, Attitudes, and Beliefs about Quality of Life

- Life for a person with Down syndrome:
  - Happy, carefree
  - Naive, gullible
  - Unhappy, frustrated

- Life for an adult with Down syndrome:
  - Can’t live independently – will need helpers, aides
  - Can live independently – can work, have romantic relationships
  - Depends on severity
Results – Knowledge, Attitudes, and Beliefs about Quality of Life

- Your quality of life if you have a child with Down syndrome:
  - Significant changes would occur

- Many negative outcomes cited:
  - Financial issues
  - Increased stress
  - Marital problems
  - Problems with other children in the family
  - Difficulty maintaining a job
Results – Knowledge, Attitudes, and Beliefs about Quality of Life

Would the possibility of having a child with Down syndrome affect your pregnancy plans?

- Yes, it has affected timing of pregnancies
- No, it has not influenced me

We found no meaningful differences between the two broad age groups of women.
Results – Credible Health Messengers

Primary sources for health information:

- **Internet:** Google searches, WebMD, Mayo Clinic, Wikipedia, BabyCenter, Yahoo
- **Health care providers:** primary care physicians, OB/GYNs, pediatricians
- **African-American women:** family, friends
Results – Women’s Preferences Regarding Receiving Information about Down Syndrome

“On this TV show when I was younger, a little boy had Down syndrome and he was very acclimated into normal life. That was my first experience even knowing something about Down syndrome. And seeing how he was performing, I thought, ‘OK, if someone has Down syndrome they can still lead a productive life.’” [RTP, Women with children, African American, 35-45]

Where women want to receive information about Down syndrome:

- Internet
- Health care providers
- Television programming: fictional, documentary
- Hispanic women: graphic novelas
Results – Women’s Preferences Regarding Receiving Information about Down Syndrome

Information to present to pregnancy planners and pregnant women:

- Prevalence of Down syndrome
- Prevalence of Down syndrome by different racial and ethnic groups
- Prevention of Down syndrome
- Risk factors for mothers and fathers
- Average life expectancy
- Information about prenatal screening and testing
- Therapies available for persons with Down syndrome
- Possible health complications in persons with Down syndrome
- Misconceptions about Down syndrome
- Severity spectrum of Down syndrome
Results – Women’s Preferences Regarding Receiving Information about Down Syndrome

Information to present to women more likely or who screen/test positive:

- *Chances of having another child with Down syndrome*
- *Kinds of support/resources available*
  - Treatments available for the child
  - Financial
  - Emotional
- *Pregnancy termination information*
- *Development of a child with Down syndrome*
- *Having a child with Down syndrome "is not the end of the world"*
Results – Women’s Preferences Regarding Receiving Information about Down Syndrome

- Personal stories from families

“It would be good to let parents know that their babies will be different and raising them can be hard, but this won’t be the end of the world.”

[DC, Woman with Children, White, 35-45]

- Pictures of people with Down syndrome
  - All ages
  - Families
  - In everyday life situations
  - All races and ethnicities
RECOMMENDATIONS
Application of Results

- Focus group research is not generalizable to all women
- Saturation of themes achieved
- Results can help to guide materials development
- Results can guide future formative research
Recommendations

- Information to emphasize – what women do not know about Down syndrome

- Information to de-emphasize – what women know about Down syndrome

- Address misconceptions and stereotypes
Recommendations

- Address negative perceptions about quality of life
  - Family stories
  - “Not the end of the world”

- Feature people from different racial and ethnic groups

- Use internet, television

- Health care providers need to educate their patients
Future Research

- More specific exploration of knowledge, attitudes, and beliefs among women of different racial and ethnic groups
- Formative research among women who have a child with Down syndrome
- Preproduction testing with draft materials
Project Team

CDC
- Kara Duwe
- Sonja Rasmussen
- Alina Flores
- Betsy Mitchell

RTI International
- Shelly Harris
- Nedra Whitehead
- Rebecca Moultrie
- Georgina McAvinchey
- Jennifer Alexander
- Paula Eguino-Medina
- Marjorie Margolis
- Julie Kish-Doto
Resources

- **Formative Research:**

- **Focus Group Research:**
Thank you!

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