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Am J Med Genet A. 2012 June ; 0(6): 1355–1362. doi:10.1002/ajmg.a.35340.**Women's Knowledge, Attitudes, and Beliefs About Down Syndrome: A Qualitative Research Study****Denise M. Levis^{1,*}, Shelly Harris², Nedra Whitehead², Rebecca Moultrie², Kara Duwe¹, and Sonja A. Rasmussen¹**¹National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia²RTI International, Research Triangle Park, North Carolina**Abstract**

Women who are or may become pregnant need up-to-date information about Down syndrome (DS). Asking women about their knowledge, opinions, resources, and information needs on the topic of DS is an important precursor to develop effective strategies for education. We conducted 24 focus groups (N=111) in two US cities with women who were recently pregnant (who had a child 3 years old without DS) and women who planned to have a child in the next year. Groups were further segmented by age and race-ethnicity. Questions explored women's knowledge, attitudes, and beliefs about DS; resources used to obtain information about health and DS; and information needs on the topic of DS. All participants reported having some knowledge of DS: facial features, chromosomal condition, and maternal age as a risk factor. Many participants had misconceptions, including the life expectancy for persons with DS, other maternal and paternal risk factors, and the idea that having a child with DS would disrupt their lives. Participants requested stories to help illustrate what life is like for families with DS. Many Hispanic and African American participants said they only saw or knew of Caucasian persons with DS and requested culturally diverse educational materials about DS. Participants said they would seek information on DS from the Internet and from their health care providers. Results suggest that women need tailored materials that contain clinical information about DS as well as information about living with a child with DS. Published 2012. This article is a U.S. Government work and is in the public domain in the USA.

Keywords

Down syndrome; focus groups; qualitative research; educational materials; knowledge; attitudes; beliefs

Introduction

Down syndrome (DS) is the most common chromosomal abnormality present at birth. In the United States, the birth prevalence of DS is estimated to be 1 in 691 livebirths [Parker et al.,

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2010]. The American College of Obstetricians and Gynecologists (ACOG) recommends that health care providers offer all pregnant women screening and the option of prenatal diagnostic testing for DS [ACOG, 2007a,b]. Recently a noninvasive test of maternal blood has become available that provides an accurate (DS detection rate of 98.6% and false-positive rate of 0.20%; www.sequenomcmm.com) prenatal diagnosis of DS without risk to the fetus [Chiu et al., 2011; Ehrich et al., 2011; Palomaki et al., 2011; Papageorgiou et al., 2011]. The availability of this noninvasive testing option might result in an increase in the number of women who receive a prenatal diagnosis of DS.

Women who are or may become pregnant need up-to-date information about DS to ensure that they are able to make an informed decision about prenatal screening and diagnostic testing options [Moyer et al., 1999; Bryant et al., 2006; Rasmussen et al., 2008]. Information about DS is also important for women in the event of a prenatal or postnatal diagnosis of DS [Rasmussen et al., 2008; Pace et al., 2010]. Education about DS could also help to reduce society-level barriers such as integration of people with DS into everyday contexts like school and the workplace [Antonak and Livneh, 2000; Pace et al., 2010]. One recent study [Pace et al., 2010] found that about one-quarter of adults surveyed agreed with the statement that people with DS should attend special schools, separate from other children, and more than 25% felt that including students with DS into mainstream classrooms was distracting.

When developing strategies to educate an audience, understanding the audience's knowledge, attitudes, beliefs, and information needs on a particular topic is an essential precursor. Focus groups are a common method for researchers who want to collect in-depth information from a priority population with an eye toward using the research to develop effective educational materials [Atkin and Freimuth, 2001]. Few research studies have examined women's knowledge, attitudes, and beliefs about DS in recent years, particularly from women in different age and racial-ethnic groups. This study parallels research that was conducted among parents of children with DS and of genetic counselors [Sheets et al., 2011]. Based on results from surveys of parents and of genetic counselors, the authors recommended that balanced information (e.g., clinical information, abilities and potential of persons with DS) be given to parents who receive a prenatal or postnatal diagnosis of DS.

Here we report on findings from focus group discussions conducted among women of childbearing age in two states to inform strategies for educating women about DS. Within the focus groups, we explored the following: (1) women's knowledge about DS; (2) women's knowledge, attitudes, and beliefs about quality of life for persons and families with DS; (3) resources that women use when seeking health information; and (4) women's information needs on the topic of DS.

Methods

Study Design and Population

Women of childbearing age participated in a total of 24 focus groups held in Washington, DC, and Durham, NC in July and August 2010. The two cities were chosen because of the proximity of offices for Research Triangle International, the contractor that assisted with recruitment and conducted the focus group discussions. Two groups were recruited: women

who recently had a pregnancy (i.e., who had a child 3 years old without DS) and women likely to become pregnant soon (i.e., who planned to have a child in the next year). Participants were further segmented into two age groups (18–34 and 35–44 years) and then by race-ethnicity (Caucasian, African American, and Hispanic). Women were ineligible if they had an immediate family member with DS or worked in either special education or clinical genetics.

Participant Recruitment

Participants were recruited by professional recruitment firms. Women were contacted by telephone, made aware of the study topic, and then screened for eligibility.

Data Collection

A female moderator led each focus group. Each discussion lasted approximately 90 min. In anticipation of including Hispanic participants who might prefer to discuss some aspects of DS in Spanish, a bilingual moderator led the groups with Hispanic women. All focus groups were audio-taped and two project team members observed the discussions and took notes behind a one-way mirror.

Questions to guide focus group discussions were developed and organized around four areas: (1) women's knowledge about DS; (2) women's knowledge, attitudes, and beliefs about quality of life for persons and families with DS; (3) resources that women use when seeking health information; and (4) women's information needs on the topic of DS. At the end of each session, participants were also asked to complete a short survey that collected information about demographics and study-related topics. To compensate participants for their time, participants received \$75 cash upon completion of the discussion. The Institutional Review Board at Research Triangle International approved the study.

Data Analysis

Analysis consisted of a systematic review of transcripts and observer notes from all focus groups. One member of the study team coded the data using the Constant Comparative method [Krueger and Casey, 2009]. Data were first grouped together using pre-existing categories that were also used to develop the focus group guide (e.g., risk factors for having a child with DS). Repeated review of the transcripts led to the discovery of emergent thematic subcategories (e.g., maternal age, paternal age, family history, etc.). After establishing thematic categories, the qualitative data analysis program QSR NVivo facilitated the analysis by providing descriptive reports for each category. The project team reviewed all final thematic categories and came to consensus around results. Disagreements were resolved through discussion.

Results

Table I illustrates the overall demographic and other study-related characteristics of focus group participants. Focus group participants (N = 111) were segmented by age group and race-ethnicity [Caucasian: 38 (34.2%), African American: 39 (35.1%), and Hispanic: 34 (30.6%)], thus yielding a relatively even distribution. There was an even distribution of

women with no children (48.6%) and women with 1 child (46.8%). The majority of participants had more than a high school education (e.g., some college and college degree), most had private health insurance, and most reported wanting more children in the future. About 40% of participants reported household incomes <\$50,000. During the focus groups, the majority of participants spoke fluent English; however, a few Hispanic women were more comfortable discussing some aspects of DS in Spanish.

Focus groups results are organized around the following topics: knowledge about DS; knowledge, attitudes, and beliefs about quality of life for persons and families with DS; and resources and information needs. The results describe the overall sample, and differences between segments are noted when present.

Knowledge About DS

All participants reported having some knowledge about DS. Participants had general knowledge about the physical, especially facial, and cognitive manifestations of DS as well as the cause of DS. Fewer participants had detailed knowledge in these areas (Table II). Some participants said that cognitive development depends on various factors including severity of DS manifestations, the child's family environment, and availability of medical and financial resources. Older maternal age was most frequently mentioned as a maternal risk factor for DS, and many participants cited an increased risk at either the age of 35 or 40 (Table III). Other risk factors not associated with DS were also mentioned, including older paternal age, substance use during pregnancy, lack of prenatal care, and environment; differences in some of these responses were found between racial-ethnic groups (Table III).

Participants also had general knowledge that children with DS might require physical, speech, occupational, and behavioral therapies. Some participants wondered if medications were also available to treat symptoms. Across all groups, participants recognized that DS cannot be cured. Most participants also reported that children with DS might need to attend special education classes.

Participants' knowledge of DS was limited in several areas. Many participants said that persons with DS remain mentally childlike throughout their lives. Most participants were unsure about a person's average life expectancy; some thought that it was shortened, perhaps by 40–50 years. Most participants did not know the birth prevalence of DS in the US and were uncertain about their own risk. In three of the focus groups, participants described DS as “common,” due to an increase in women of older maternal age giving birth and medical advances related to prenatal health, pediatrics, and child development. Some participants reported that they never saw adults with DS. Many Hispanic and African American participants said they only saw or knew about Caucasian people with DS.

“Looking at television you would think that there aren't any black children [with DS]. You'd think there would be an Asian child with it.” African American Woman with Young Child; Age 35–45; Washington, DC

“Come to think of it, I've seen very few nonwhite people with DS. I've not noticed Hispanic or black or Asian. Mostly white.” Hispanic Woman Planning Pregnancy; Age 18–34; Raleigh, NC

Most participants expressed uncertainty about whether or not a person with DS can have children of his or her own.

Knowledge, Attitudes, and Beliefs About Quality of Life

Many participants believed that the quality of life for a person with DS depended on his or her environment, and that emotional and financial support could improve the quality of life for a person with DS. When asked what life is like for persons with DS, most participants described the personality traits they associated with DS; nice, happy, affectionate, loving, friendly, always smiling, naïve, and gullible were frequently mentioned personality traits.

“I’ve never seen someone with DS who is unhappy.” Caucasian Woman Planning Pregnancy; Age 35–45; Washington, DC

“[People with DS] are usually very loving and maybe naïve to a certain extent. Nonetheless they are always smiling, very playful.” Caucasian Woman with Young Child; Age 35–45; Washington, DC

Some participants also described persons with DS as carefree because they are unaware of their own differences. Others thought that persons with DS experience problems communicating with others, and this could contribute to feelings of frustration and disappointment.

Responses were mixed across groups when participants discussed their beliefs about the quality of life for adults with DS. Some participants believed that it would be difficult for someone with DS to live without assistance from aides or other helpers. Other participants believed that it was possible for persons with DS to hold jobs, have relationships, and live independently like other adults. Some participants who reported the latter belief cited the example of actors with DS who can learn lines and attend rehearsals and performances just like other actors.

Participants had positive attitudes about persons with DS in the workplace with a caveat that the person needed to be able to perform his or her job duties. Regarding children with DS in schools, Opinions varied. Some believed that all children could benefit from interactions with a diverse group of children and that the presence of children with DS in mainstream classrooms would teach other children empathy. Some felt that including children with DS in mainstream classrooms would distract typically developing children and the teachers. Others said that mainstream classrooms hinder children with DS because they would not receive specialized attention.

Participants also described what they thought their life would be like if they had a child with DS. The majority believed that having a child with DS would cause disruptive life changes. Financial problems and increased stress levels were mentioned in all groups. In addition, participants thought it could be difficult to do everyday activities, such as shopping and going to work. Participants also thought that finding reliable childcare would be more difficult. Most participants also expressed concern that their marriage or relationship with their partner would be adversely affected. Examples frequently cited include disagreements about care for the child and lack of time spent as a couple. Many participants also predicted

that their other children might feel jealous because attention would be diverted to the sibling with DS. Social support (e.g., support groups) was frequently mentioned as a way to relieve stress and conflict. With regard to their career or professional lives, most participants said they would consider leaving their job to provide care for the child. Some thought it would be difficult to get hired if they did not already have a job, and some cited the importance of a flexible employer that understood the need for extra health care appointments during the day.

Participants expressed varying views about whether or not the possibility of having a child with DS had ever influenced their pregnancy plans. The varying perceptions about DS and pregnancy plans were observed across both age groups. Some affirmed that worries about DS influenced their desire to have children at a younger age. Some participants related their worries about having a child with DS at an older age to fears about being unable to provide or find proper care for their child when he or she reached adulthood.

Resources and Information Preferences

Participants offered their thoughts about the most important information about DS to communicate to women. Distinctions were made between two groups of women. Suggested topics for the first group (women who are pregnant or planning a pregnancy) included maternal risk factors for DS, birth prevalence, and life expectancy for persons with DS (Table IV). Suggested topics for the second group (women at higher risk for having a child with DS or who have received a positive screen or diagnosis for DS) included support and resources available for families and development for children with DS (Table IV).

Including photographs of persons with DS of all ages and from different racial-ethnic backgrounds in educational materials was recommended by most participants. Some said that they would like photographs of persons with DS engaging in everyday activities to demonstrate that it is possible to live like a “typical person.” Incorporating family photographs was also mentioned frequently. Most participants also recommended including personal stories written by families who have a child with DS.

“You don't know what life [having a child with DS] is like. [Stories] might help people be more at ease. Stories from families, both positive and negative.” African American Woman Planning Pregnancy; Age 18–34; Washington, DC

“[Include] personal accounts. Put a face on it.” Caucasian Woman with Young Child; Age 35–45; Raleigh, NC

We asked open-ended questions about where participants look for health information and where they would look for information about DS. In general, participants across all groups said they obtained most of their health information from the internet, and almost all participants said the internet would be their primary resource for information about DS. Participants reported using Google most often to search for specific health topics. Participants also gave specific websites they use to seek out health information; commercial websites (e.g., WebMD, BabyCenter, Yahoo, About, CNN, and MSNBC), websites from government and nonprofit agencies (e.g., Mayo Clinic, Centers for Disease Control and Prevention, National Institutes of Health, and March of Dimes), social media (e.g.,

Facebook), Wikipedia, and insurance company websites were frequently mentioned. Many African American participants said they would also consult friends and family.

Most participants recommended that information on DS be placed on a website so that it would be readily available. Most participants also stressed the importance of learning about DS directly from primary care physicians, obstetrician–gynecologists, and pediatricians. Participants with a young child reported receiving a limited amount of information about DS during their last pregnancy.

“When I had my last daughter I wasn't 35, and so they said I wasn't at risk [for DS]. In my head I was thinking, ‘close enough.’ My doctor brushed it off.” African American Woman with Young Child; Age 35–45; Raleigh, NC

“[I] never received any information. [The doctor] just mentioned [DS].” Hispanic Woman with Young Child; Age 35–45; Washington, DC

Participants also recommended using documentary-style television programming or reality shows to inform people about DS. Many participants reported that their knowledge, attitudes, and beliefs about DS were based on television shows, movies, or other media images. Other types of educational materials recommended by participants included pamphlets and brochures, DVDs, books, magazines, ads on public transit, and mass media ads. A few participants suggested having an online weblog (blog) where parents can discuss issues related to DS and post photographs of their children. In one group of Hispanic women, participants suggested creating fotonovelas (illustrated pamphlets) about DS to educate other Hispanic women.

Discussion

Our study found that women have some knowledge about DS, and they also have many misconceptions about the condition. Results suggest that women should be given up-to-date information about clinical aspects of DS and also stories about what life is like for families with DS. Tailoring information is also important to consider because many Hispanic and African American participants said they only saw or knew of Caucasian persons with DS and requested culturally diverse educational materials about DS. The internet and health care providers are important channels to consider for information delivery.

Our results related to participants' knowledge about the cause of DS support a previous study finding. Gilmore et al. [2003] found that the majority of teachers and community members surveyed in Australia knew that DS is a chromosome disorder, and most participants in our focus groups also knew this to be the cause of DS. Our findings related to participants' limited knowledge of medical conditions associated with DS are consistent with the results of a study by Moyer et al. [1999], which revealed that some women were unaware of physical health difficulties children with DS can experience. Additionally, our study found that most participants were unaware of the birth prevalence for DS and were uncertain about their own risk. The majority of participants requested that information about DS include data on birth prevalence by age and race-ethnicity.

associated with DS, and the degree of medical complications associated with DS, likely because this information offers more insight into the quality of life for persons and families with DS.

Participants also recommended using photographs to show the realities of living with DS. Photographs could potentially address the need for diversity in information about DS suggested by focus group participants and elsewhere [Rasmussen et al., 2008]. Additionally, photographs facilitate literacy and comprehension of the subject matter [Houts et al., 2006].

Findings from our study parallel the contents of a booklet that was recently developed for parents who receive a diagnosis of DS (www.lettercase.org). The booklet includes clinical information about DS, information about families with a child with DS, the degree of medical complications, resources for parents, among many other topics. The booklet also contains many photographs of children with DS engaging in everyday activities.

Our results also offer insights about how educators might tailor information about DS to meet the needs of their audience. Tailoring increases the likelihood that an audience will consider and retain the material's contents [Kreuter and Holt, 2001]. Table IV divides women of childbearing age into two groups with corresponding information needs: women who are pregnant or planning a pregnancy and women at higher risk for having a child with DS or who have received a positive screen or diagnosis for DS. Tailoring messages by demographic characteristics, such as by race-ethnicity, might also be considered. For example, many Hispanic and African American participants believed that DS can be caused by the mother's lifestyle, such as drug or alcohol abuse, or lack of prenatal care. African American and Hispanic participants reported seeing mostly photographs of white children with DS and that information is most frequently presented in English. The need for cultural sensitivity in educational materials about DS was emphasized in a Consensus statement developed by the National Down Syndrome Society, National Down Syndrome Congress, ACOG, American College of Medical Genetics, and National Society of Genetic Counselors [Genetic Counseling Program at the University of South Carolina, 2009].

Findings from this study suggest that the internet is a primary health information resource and thus a key channel for educating women about DS, which is consistent with a Pew Research Center study 2011 that recently found that looking for health information is the third most popular online activity among American adults who use the internet. Participants reported regularly visiting certain health information websites, such as WebMD and BabyCenter; partnerships with credible websites might be considered to distribute information about DS to a wide audience. Additionally, many wanted to learn more about DS through television programming, both fictional and nonfictional, featuring persons and families with DS. Participants often cited television shows as one of the bases for their knowledge and perceptions of DS. Printed material was also mentioned; parents who have a child with DS and genetic counselors also recommended this approach for parents who receive a prenatal or postnatal diagnosis of DS [Sheets et al., 2011].

Health care providers are a critical source of information about DS for women [Moyer et al., 1999; Chilaka et al., 2001; Bryant et al., 2006; Skotko et al., 2009]. Participants in this study

affirmed their reliance upon providers, especially their obstetrician–gynecologists, to discuss DS with them and/or provide them with educational materials. However, among the participants who had a young child, few reported receiving substantive information about DS, noting that their providers only mentioned the condition in the context of prenatal screening and/or testing. Recommendations for obstetricians and other providers, in terms of what and how they should discuss prenatal screening and testing as well as DS, is discussed elsewhere [Skotko et al., 2009].

Focus groups are a rich source of data for researchers seeking in-depth information on a particular topic. However, some caution should be taken in interpreting the results. Focus group findings are not generalizable to the entire population of US women. Pregnancy planning status or having a young child, age, and race-ethnicity determined participants' focus group assignments. Assignment by certain shared characteristics creates homogeneity within the groups, aiding in group dynamics and discussion and helping the researchers to identify major differences between groups [Krueger and Casey, 2009]. The characteristics we used were quite broad, and thus within-group homogeneity was not always possible. For example, Hispanic participants were not all fluent in English, indicating differences in American acculturation within this group. Use of broad categorization may explain the limited number of differences in knowledge, attitudes, beliefs, resources used, and information needs found between the groups. Most participants had more than a high school education, which likely influenced results. The study topic was revealed before the focus groups, and it is possible that participants may have researched DS.

Further research is needed among subgroups of women (e.g., women with high school or less education) who had minimal representation in our focus groups. Additional research is warranted to affirm differences between race-ethnicity segments found in our study and to establish appropriate tailoring strategies for educational materials. Once developed, it will also be important to test materials among intended audiences to ensure that they are accepted, understood, and appropriate.

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Table I
**Demographic and Other Characteristics for Focus Group Participants in Raleigh, NC,
 and Washington, DC, 2010**

Characteristics	Frequency n (%)
Total participants who completed the exit survey	109 ^a
Age	
18–34	55 (50.5)
35–44	54 (49.5)
Ethnicity—Hispanic or Latina	
Yes	32 (29.4)
No	77 (70.6)
Race	
Caucasian	54 (49.5)
African American	38 (34.9)
Caucasian and African American	2 (1.8)
Caucasian and American Indian	2 (1.8)
Number of children	
None	53 (48.6)
1–2 children	44 (40.4)
3 children	7 (6.4)
Education	
Less than high school	1 (0.9)
High school	4 (3.7)
More than high school	103 (94.5)
Income	
\$20,000 or less	9 (8.3)
\$20,001–\$49,999	36 (33)
\$50,000	60 (55)
Health insurance	
Private	82 (75.2)
Medicaid	5 (4.6)
Other public	4 (3.7)
Wants future children	
Yes	93 (85.3)
No	10 (9.2)
Unsure	5 (4.6)

^aData missing because two participants did not complete the survey and some survey respondents did not respond to individual questions.

Table II
Quotations Related to Participants' Knowledge of Cause, Physical Manifestations, and Cognitive Manifestations of DS

Cause of DS
“A person [with DS] has a genetic mutation.” Caucasian Woman with Young Child; Age 35–45; Washington, DC
“I know it has to do with a chromosome, 23 or 27. I don't know the numbers.” Hispanic Woman Planning Pregnancy; Age 18–34; Raleigh, NC
Physical manifestations of DS
“They all tend to have that same look. They look alike. Almost like they're siblings. Facial features, you can see that. You can pick them out in a crowd.” Hispanic Woman with Young Child; Age 35–45; Raleigh, NC
“[People with DS have] slanted eyes and the tongue hangs out a lot. The ears might be pointy or something.” African American Woman with Young Child; Age 35–45; Raleigh, NC
Cognitive manifestations of DS
“[Cognitive abilities are] not up to par as to their age, growth, or development. It's delayed in a sense.” African American Woman with Young Child; Age 18–34; Washington, DC
“Academically if they are on the same level, behaviorally it might be different. Like their attention span.” African American Woman Planning Pregnancy; Age 18–34; Raleigh, NC

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TABLE III
Quotations Related to Participants' Knowledge of Risk Factors for DS

Older maternal age ^a : "I just know that as you get older you increase your chances [of having a child with DS]." Hispanic Woman Planning Pregnancy; Age 18–34; Raleigh, NC
Older maternal age ^a : "It's embedded that once I'm 35, I'll have higher risk of having a child with DS." African American Woman with Young Child; Age 35–45; Raleigh, NC
Family history ^a : "If someone in your family has DS, a woman is more likely to have a child with DS." Caucasian Woman Planning Pregnancy; Age 18–34; Washington, DC
Older paternal age: "There is some research related to the age of the male. I don't know if that's true." Caucasian Woman with Young Child; Age 35–45; Washington, DC
Substance use ^b : "Maybe when you're getting pregnant and a drug user, it might affect the way [your chromosomes develop]." African American Woman with Young Child; Age 35–45; Raleigh, NC
Lack of prenatal care ^b : "Prenatal care is very important to prevent babies with DS." Hispanic Woman with Young Child; Age 18–34; Washington, DC
Environment: "There could be environmental factors." African American Woman Planning Pregnancy; Age 35–45; Washington, DC

^a Actual risk factors for DS.

^b Reported primarily in Hispanic and African American discussion groups.

TABLE IV
Important Information to Communicate About DS, Cited Most Frequently by
Participants, Organized by Target Audience

Target audience	Topic
Women who are pregnant or planning a pregnancy	<ul style="list-style-type: none"> Birth prevalence of DS: general, by race-ethnicity Risk factors for DS Average life expectancy Information about prenatal screening and testing: pros and cons, accuracy, possible risks Therapies available to ameliorate sequelae associated with DS Sequelae associated with DS Misconceptions about DS The degree of medical complications associated with DS, spectrum of effects Stories from families about what life is like with DS Having a child with DS “is not the end of the world”
Women at higher risk for having a child with DS or who have received a positive prenatal screen or diagnosis for DS	<ul style="list-style-type: none"> All topics listed above Chances of having another child with DS Kinds of support or resources available: financial, emotional, based in local community if possible Pregnancy termination information Development for children with DS

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