



Focus on

Comments From Maryland Mothers

Who Delivered in 2008

June 2010

“It [PRAMS survey] gives mothers a chance to think about the effect of their pregnancy and helps to offer alternatives for preventive measures. Thank you for allowing me to participate.”

PRAMS mother



“I think a survey is a wonderful idea and good way to reach out to new mothers.”

PRAMS mother



The PRAMS survey asks new mothers about their experiences before, during and after pregnancy in an attempt to improve the future outcome of the health of mothers and infants. Topics include a wide variety of factors that may impact maternal and infant health such as cigarette smoking, alcohol use, partner violence, unintended pregnancy, HIV testing, health care coverage, quality and content of prenatal care, breastfeeding, depression, preconception health, oral health, stresses before and during pregnancy, and medical complications.

While the PRAMS survey collects mainly quantitative data on the mothers' behaviors and experiences, it also collects qualitative data in the form of maternal comments written throughout the survey booklet. PRAMS mothers are given the opportunity to share information on the last page of the survey booklet:

Please use this space for any additional comments you would like to make about the health of mothers and babies in Maryland.

(page intentionally left blank for comments)

Thanks for answering our questions! Your answers will help us work to make Maryland mothers and babies healthier.

Many of the mothers also write comments in the margins of the survey booklet relating to particular questions. All back page and margin comments are entered into a database for future review.

The surveys are available in both English and Spanish. Mothers are mailed a survey about three months after delivery. Those who do not complete a survey are mailed another survey within a month. If no survey has been returned after three mailings, women are called to complete the survey by phone, in English or Spanish.

Women who complete the survey by phone instead of mail are also given the opportunity to share “back page” comments. All comments are recorded verbatim and the phone interviewer can break off from the survey at any time to enter a comment if the mother has more to say about a particular question before getting to the back page comment section (i.e., analogous to margin comments in the mail survey).

Mothers with Comments

Among women who delivered in 2008, 1,713 completed the survey by mail or phone, a 73% response rate.

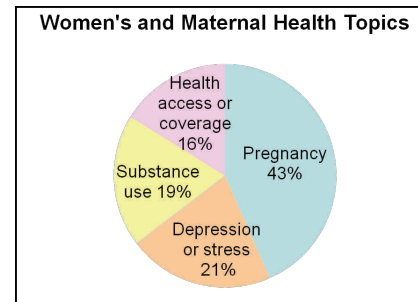
Forty-four percent (n=748) of respondents made a total of 1,654 comments. One-third (n=548) of the comments came from the blank last page of the survey book or at the end of the phone interview. The rest of the comments were inserted next to survey questions. Comments from the back page were given primarily by mothers who were White (56%) or had low birth weight infants (53%) however African American (29%), Hispanic (17%) and teen (15%) mothers were also well represented.

Topics

Many mothers inserted comments next to the survey questions. The comments were usually written to clarify an answer. Questions with the most comments referred to: 1) medical problems during pregnancy, 2) reasons for not getting prenatal care as early as desired, and 3) reasons for not using birth control at the time of conception (responses only by women not trying to get pregnant).

Topics written about on the blank last page of the survey included: 1) **maternal and women's health** (56%) (pregnancy problems/medical disorders, substance use, depression, medical care access), 2) **infant health and outcomes** (18%) (premature birth, special needs, breastfeeding), 3) **survey** related items (14%) (opinions about survey), 4) **quality of prenatal care** (8%), and

other (4%). The most common topic, women's health and maternal health, included comments about stress or depression, substance use, health access or coverage, and preconception, prenatal or postpartum factors (See figure).



Infant Outcomes: Comments about Prematurity, Health, Breastfeeding

"My doctor does not know why I went into preterm labor. For my next pregnancy, she suggests Progesterone shots from 16 weeks to prevent preterm labor. I think women need more education about early labor. I didn't realize what was happening to me and I almost lost my baby because everyone kept saying my baby still needed to "cook". Thank God I kept going to the hospital. "

"I lost my baby at 22 weeks for unknown reasons. We are well off financially and not under major life stress...I did everything I was supposed to do and my baby is still dead."

"My first child was stillborn so I really appreciate research being done to see why such things happen."



"I'm a person of advanced maternal age (42) with the complications of Crohn's Disease. I was never warned about the possibility of preterm labor. What a shock when I went into labor at 31.5 weeks! We are very fortunate to have a healthy baby who only had to spend a month in the NICU...but could have been prevented with education? I'll probably never know, but I wish I would have been warned about the possibility."

"Had twins, 28 weeks. I have a bi-cornial uterus. I barely had enough room for one baby. Baby A was in my cervix at 3 cm dilated for 27 days (bed rest at hospital)."

"I had two doctors attempt to discourage me from breastfeeding stating my type of job wouldn't allow for it. Thank God for the lactation consultants at (this) hospital. They were terrific...better than the doctors."

"I just wanted to say that you can take such good care of yourself during pregnancy and still your baby can be low birth weight... I am a nurse and worked up to almost my due date. I never smoked or "drunked", took my prenatal vitamins everyday, ate healthy and also stayed very active. I felt so bad when he came early. He was so small."

"I don't think the benefits of breastfeeding are strongly enough promoted."

"In the future, I would love to see a lactation specialist help with nursing mothers. I had very little help and support from the hospital while learning to breastfeed my baby. The only support I received was from WIC."

"I have a sick baby [with a pacemaker and Down syndrome] that goes to a Child care program and I think they should make more programs like that. It's an excellent program."

"I believe all women should have their cervix checked for cervical insufficiency during pregnancy as a routine check. I lost my baby due to prematurity because my weak cervix was caught too late."

Women's Health: Comments About Pregnancy

Pre-Pregnancy

"Women should take care of themselves before...pregnancy."

"If that [alcohol, drugs] can be controlled before you get pregnant that is a good thing."

"I would urge young girls not to have babies and to use birth control always."

"Mothers should be able to get health care even if they are not pregnant."

"I think that every woman...should spend time with someone else's child [to see if they]...want to have children of their own."

"When we were told we weren't going to be able to have anymore children we were disappointed. So we put it off and boom we got pregnant."

Prenatal

"I was on birth control and I didn't know I was pregnant until the day I delivered."

"During my pregnancy, I was admitted to the hospital numerous times for kidney stones and swelling of the kidneys."

"Working out truly gave me more energy throughout pregnancy and increased my mood."

"...Medicaid only covers 4 days for a c-section. I was in a lot of pain but they were pushing me out the door. I was vomiting as they were taking me out."

"gestational diabetes and all the extra stuff",
"swelling in my feet",

"amniotic fluid problems and induced because of it"
"preeclampsia with poor weight gain and baby that was small starting at 20 weeks",

"numerous hospital admissions for kidney stones"
[from 5 PRAMS mothers]

"I ate salty food and I was gaining five pounds a week until I developed preeclampsia hypertension. When I got to the hospital, I was really swollen and I learned that my baby was not growing. They had to take her out right away because I got really sick really fast."

"It doesn't matter if you're the healthiest woman in Maryland. Things can still go wrong. I was as healthy as can be when one morning I started bleeding vaginally. I went to the hospital and they told me my placenta had come off the wall. They told me I could die of bleeding to death and my baby would suffocate. They did an emergency C-section. My daughter was born 2 lbs. 2 oz. and was in the hospital for 2 months, 12 days."

Postpartum

"Some new mothers and/or their partners would benefit from basic baby care instructions (ex., info on feeding basics, diapering, sleeping, etc.)."



"I continue to take high blood pressure medications [after having HELLP syndrome during pregnancy]."

"I think there needs to be paid time off for maternity leave. Mothers stress about being able to afford to be off with their newborns."

"Mothers need more time off (at least 6 months) with their newborn. We also need paid leave from our jobs."

"Start a program that would allow high risk pregnant moms to work part-time with income assistance."

"I really think jobs with only FMLA and no maternity paid leave is a problem for pregnant mothers with health issues. I think there should be an organization/non-profit to bridge the gap to help pregnant women with health issues to prevent preemie babies."

"I have 9 healthy, happy children [18 and under]. I look and feel greater today than I did 20 years ago."

"Me encantaria que les siguieran brindando ayuda alas madres después del parto." (It would be great if you could continue to provide help to all mothers after the delivery.)

Women's Health: Comments About Smoking, Drinking, and Drugs



"I am a good person. It's just that I can't stop smoking cigarettes. I did stop smoking weed. As for the alcoholic drinks when I'm with family (well they are drinkers), I didn't want them to know that I was with child."

"...no smoking, no drinking and of course no drugs. You have to be responsible and realize that you are growing a human in your belly and that baby is counting on you for everything. Just think how you would like to be treated."

"In my case as a Latina, we are persons who don't consume a lot of drugs or alcohol."

"If the doctor didn't ask questions about habits, like smoking, I think it is because my baby was my 4th and he knew the answers from the previous pregnancies."

"I have a friend that got pregnant and was scared. Hence, she took Sudafed and dry gin in an attempt to get rid of the pregnancy... Things like this will not be disclosed by mothers. What I think will help is more education and encouragement."



"There are a lot of babies that die because mothers don't take care. They smoke or drink and doctors need to make sure mothers take care of themselves. The alcoholic mothers really should quit drinking during their pregnancy."

"More and more moms are using prescription drugs. I used methadone with my 4th child and she had to be weened off methadone because I abused it. My last child, I was in treatment for my drug abuse. I used methadone 2 days in my pregnancy and he was healthy because I did not use."

"I think all mothers should be drug tested when admitted to the hospital and immediate action should be taken against these women who expose their unborn child to drugs and other harmful products. There is not enough action taken against women who are pregnant and exposing their child to drugs, alcohol, and cigarettes. Our children are brought into this world without a chance. I also feel if our government is providing money/food/housing to these "parents", they too should be drug-tested monthly in order to receive services. It is sad to see nothing being done to women who continue life-threatening habits."

"I had a drug problem that began after my first and second child. I used cocaine while pregnant with my 3rd and 4th child. They are healthy. My 5th child I was clean and sober for entire pregnancy and she was diagnosed with Cerebral Palsy in Sept. at age of 20 months, but my son which is my last baby is healthy as of now and I am still clean and sober since 8/3/95 and I quit smoking in March. Still going strong!"

"I used drugs until I went to a inpatient drug program and they told me I was 12 weeks pregnant. I have remained drug free ever since."

"...some mothers are or were abusing drugs like me. Things like that play a huge role in the way we're taking care of ourselves during pregnancy. We need more places that don't judge and just help."

"En mi opinión en el momento de que una madre que da embarazada tiene el deber de cuidar su salud para que su bebé nasca sano y fuerte. Para eso necesita cuidar su alimentación no tomar mucho como poreje no tomar bebidas alcohólicas, no fumar ni drogas." (In my opinion, at the moment someone is pregnant, they should take care of their health so the baby is born healthy and strong. That is the reason they should not drink alcohol, smoke, or do drugs.)

Women's Health: Comments About Stress, Depression and Abuse

"If your partner/husband is in ANY way abusing you, tell someone, make a safety plan and GET OUT!! Even if your family told you before that you couldn't come home again, tell them what is going on. They may change their minds to protect you and your child. Mine did."

"I don't know what exactly caused my preterm labor, but I had my own stressful situations. Stressors such as losing a home, being ignored by my child's father, not being able to work due to my hyperemesis which led to my car being repossessed...I sometimes think that if I had someone there for me...I would still have my daughter..."

"I went into early labor at 24 weeks. My husband had revealed he felt "disconnected" from me in my 7th month. I noticed an obvious increase in the # of contractions...it was very clear the sadness and stress affected my pregnancy. Boys born healthy and doing well. Husband still source of major stress, but so thankful for boys."

"I am doing this alone without my child's father. The only thing that was good out of the situation is my daughter. I've learned not to cry over spilled milk just to keep it moving. And for young mothers who think that they can't do it alone just remember ...just know you can!"

"After my 1st miscarriage, pregnancy made me very stressed and I lost a total of 4 pregnancies. During this pregnancy, I used acupuncture to relax. It helped."

During my pregnancy, my job made me very depressed. I could not leave because I was pregnant and felt nobody would hire a pregnant woman so I stayed even though I was very miserable. My doctor asked me to reduce my hours at work... Stress causes depression and it can lead to many other problems.

"I have been treated for post-partum depression after each of my pregnancies. For this pregnancy, I started taking anti-depressants 6 wks prior to my due date."

"...fatigue associated with depression from infertility is much more pronounced than any fatigue from pregnancy or new baby issues."



"Depressed because I found out my husband didn't want any more kids and he was not helpful during pregnancy. Felt very stressed out through my entire term....even now I'm still stressing."

"I was currently on Cymbalta when I found out I was pregnant...Dr. took me off the med. as soon as we found out I was pregnant. I crashed emotionally."

"I'm not doing so well because my children's father don't want to help and both of my children are his children and that makes me very depressed along with me losing my job. I trying to hold on with the little money I've got."

"I don't think there is enough understanding or info on postpartum depression. There should be a list of doctors who specialize in this area given to new mothers."

"I hope a newborn baby or new mother meeting or event is held weekly or monthly. Depression is dangerous."

"Had twins, 28 weeks. I had depression really bad while the girls were in the hospital. It was so bad that my face was going numb...Parents of children in the NICU really need someone to talk to for emotional support. I never saw any posters or information on any programs or hot lines for parents going through a hard time in the NICU."

"When we first brought our baby home from the hospital, we were terrified and overwhelmed (and I was depressed), and we had no idea where to turn for help. I wish that hospitals and doctors would provide more information to parents about hotlines and resources for help in the first few weeks after a baby comes home. We may not have been considered "high risk", but we still could have used some help. "

Women's Health: Comments About Health Care Access and Health Coverage

"I was a single woman when my fiance and I found out we were pregnant with twins. Because of my low salary, I was accepted for Medical Assistance. Because of the help from the state, I had a wonderful experience."

"It would have been nice to have my Medicaid back-track to my first prenatal visit...instead it took at least a month or so to even get approved."

"My bills were over \$200,000."

"Mothers who have complications during pregnancy should be helped with bills otherwise they might not seek help and this might lead to different types of problems."

"The state should offer assistance to parent households of multiples...regardless of income."

"I wish it was easier for moms to stay home and raise their children and not have to worry about being able to live off one paycheck. Being a mom is a full-time job, but you don't get paid."

"Necesitamos más comunicación, información y hablar, aparte de leer. Se necesita agilizar los trámites de seguros de salud para atender mas pronto." (We need more communication, information, and talk besides reading. We need to speed up the health insurance paperwork for faster care.)

"...if they can't afford it then why do some people keep having more and more babies?"

"Despite having insurance, it was very expensive (out of pocket expenses) for all of the healthcare visits. Since I was of advanced maternal age, I had to go to frequent visits that added up to a lot of out of pocket expenses- I will have to think twice about having another!"

"... it is astonishing that within the state of MD- fertility treatment is covered however prenatal care is not guaranteed."

"Most of the poverty stricken mothers in Maryland don't get prenatal care because they cannot afford it like me."

"I think health coverage for new moms should last for 6 months to a year after a baby's birth. To have healthy children you need healthy moms."

"The Medical assistance saved me when I lost my job. There is no way we could've afford that. I'm glad it is available."



"I would just like to say thank you for giving me insurance when I needed it because I probably would not be doing so good as I am today if I hadn't had it with all the hospital bills and debts."

"If I had insurance, I would have gone for prenatal care even in my first month, but because I just got my job and my insurance was not yet effective...I started prenatal care late."

"Maryland Medical Assistance Program qualified level should be reviewed so that mothers can be qualified to receive benefits as soon as possible so as to take good care of themselves and the pregnancy."

Oral Health

"The state insurance only covers visit for the pregnancy so we are unable to see a dentist...Babies take all of our calcium so your teeth can become bad.."

"She...did not have dental insurance to get the [extract] or root canal and as a result of it [abcess] this woman went into a coma and ended up losing her child three months later because of the blood infection from the sepsis."

"Necesitamos ayuda en el servicio de cuidado dental mi asistencia médica no me cubria ése cuidado. El serviccion dental es muy importante para la salud del bebé." (We need help with our dental care. Dental care service is very important for the baby's health.)

Prenatal Care: Comments About Quality of Care

Positive

“We believe that the very well trained and thorough doctors and nurses are what made the difference in us having a baby to take home from the hospital. Had someone -anyone not been "on their toes" and checking up on us at 4am I feel in my heart of hearts that we would have lost our precious little girl.”

“The four visits from the in-home nurse were extremely beneficial in relieving many of our anxieties about parenthood and a great help in breastfeeding.”

“Women delivering with midwives have less intervention in a natural process, the care given is outstanding, respectful, and more focus is placed on the needs of the individual.”

“I had an amazing experience at [hospital] after becoming severely pre-eclamptic. The nursing staff was highly competent and all the health care personnel I encountered made me feel safe. All of the classes that I took through this hospital were informative and helpful.”

“I just wanted to say that I was very pleased with my doctor and I was at [hospital] and they took great care of me and my baby even though she was almost four weeks early and weighed 4 pounds. They don't know why she was early or so small but they took great care of her and she is very healthy now.”

Negative

“During my whole pregnancy period, my doctor never talked to me about important things that I needed to know about. Everything I learned came from a very good book and internet.”

“Waiting time in Ob/Gyn offices are very long especially if you have other children with you.”

“Improved communication between doctors in group practices regarding patient cases, especially high risk pregnancies is needed.”

“Why do all the trainees have to come in and check me I guess it was ok but this is awful. My doctor wasn't there.”

“I was a high risk pregnancy and our Ob/Gyn abandoned us to move to another state with no warning. We were not informed by her office until we showed up for an appt...We did not stay with the practice and switched...”

“I had to have my son without pain medication due to the fact that my doctor kept sending me home saying that I wasn't in labor and just had the flu!”



“I hope this survey helps. However, I don't believe that all new mothers will take the time to fill out this survey and that certainly will skew the results.”

“I hope that my answers truly are a help to another mother and child.”

“Thank you for this most important research.”

“I think this is wonderful what you are doing. I didn't know about PRAMS until now.”

Summary

Maternal health and women's health were the most common topics that elicited comments from mothers. Their comments included opinions and information about medical problems, alcohol and drug use, stress, depression, health access, maternity leave, and contraception—from the preconception, prenatal and postpartum periods. Other topics that received many comments included infant health, breastfeeding and the quality of prenatal care.

As these comments reveal, qualitative data can provide insight into the behaviors and experiences of survey respondents. While it cannot be generalized, such data are a valuable resource to identify and describe mothers' perceptions, attitudes, and experiences before, during and after pregnancy that might not be captured with quantitative data collection methods.





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PRAMS Methodology

Data included in this report were collected through the Pregnancy Risk Assessment Monitoring System (PRAMS), a surveillance system established by the Centers for Disease Control and Prevention (CDC) to obtain information about maternal behaviors and experiences that may be associated with adverse pregnancy outcomes.

In Maryland, the collection of PRAMS data is a collaborative effort of the Department of Health and Mental

Hygiene and the CDC. Each month, a sample of 200 Maryland women who have recently delivered live born infants are surveyed by mail or by telephone, and responses are weighted to make the results representative of all Maryland births.

This report is based upon the responses of 1,713 Maryland mothers who delivered live born infants between January 1 and December 31, 2008 and were surveyed two to nine months after delivery. Comments were received from 748 of the mothers who responded to the survey.

Limitations of Report

The comments in this report are based on the mother's perceptions and recall of her circumstances before, during and after pregnancy. Some of these comments may therefore reflect events that occurred over 1 1/2 years prior to the survey. A survey such as PRAMS is also subject to social desirability and response bias. Women with unhealthy or undesirable risk factors or behaviors may not comment about these situations accurately. They are also least likely

to respond to a survey. Women with low literacy levels may be less likely to write comments than those with high levels. Comments may also be interpreted in a different way than the author had intended and due to their qualitative nature are not generalizable.

PRAMS only surveys women who have had a live birth. We do not obtain information from women whose pregnancies resulted in an ectopic pregnancy, stillbirth, miscarriage or other non-viable outcome.



Maryland Department of Health and Mental Hygiene
Center for Maternal and Child Health • Vital Statistics Administration

Martin O'Malley, Governor; Anthony G. Brown, Lieutenant Governor; John M. Colmers, Secretary

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