

Pregnancy and MS: A roundtable discussion.

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Pregnancy and MS

A Roundtable Discussion

Because MS is typically diagnosed during the child-bearing years, a common concern among women with the disease involves questions about pregnancy and childbirth. Studies have shown that MS does not have adverse effects on the course of pregnancy, labor, or delivery; in fact, MS symptoms may even improve during pregnancy. There also is no evidence that pregnancy and childbirth affect the overall course of the disease. However, there are several areas of concern that may significantly impact the treatment of pregnant women with MS. In the following roundtable discussion, several MS experts gathered to discuss the issues facing pregnant women with MS and those who care for them.

Participants

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Robert Herndon: How do you initially approach women with MS who are interested in having children?

Judy Wollin: My suggestion would be to sit down, talk through the issue, and ask the woman what she is concerned about. For instance, find out if she is primarily concerned about

conception, relapses, medication, breastfeeding, or delivery. It is better to identify what the woman wants to know rather than to jump in and just guess at what should be addressed.

Michelle Keating: One of the most common concerns that I hear from women relates to the long-term implications of pregnancy on the disease. We can provide them with some very important information up front. For instance, pregnancy does not pose any long-term risks or increase the progression of the disease or disability for women with MS.

Nicki Ward: When a woman with MS announces to her friends or family that she is planning to become pregnant, she may be subject to much misinformation due to lingering myths or misconceptions. I feel it's important to present up-to-date evidence and general facts surrounding pregnancy and MS. For example, I discuss studies showing that MS does not have adverse effects on the course of pregnancy, labor, or delivery. In fact, some women report that their MS symptoms improve during pregnancy.^{1,2}

The Need for Support

Deborah Miller: It may be important to explore a woman's motivation for having a child, her partner's thoughts about having a child, and what additional support she may have available. We have to help pregnant women with MS prepare for the fact that their experience with a newborn may be different than that of many other women, and that they may have to share that parenting more with their partners. They may also need the help of family members.

Robert Herndon: When a patient is planning pregnancy, the clinician needs to get the husband or the significant other in to the office and discuss the issue with that person as well. In other words, the partner has to be supportive and should know what to expect.

Deborah Miller: It is unfortunate, but we can't pretend that every baby born to women with MS arises from a happy marriage. There is also the issue of single mothers. We have had a couple of very disabled single women with MS who have wanted to have a baby all their lives and they decide to go ahead with it. In those cases it is really important for the woman to consider who her primary support is going to be and to get that person involved. We really need to be attentive to people in these nontraditional circumstances as well.

Robert Herndon: That also relates to the issue of social isolation, which is common in people with MS in general.

Judy Wollin: Pregnancy reduces mobility and social integration and increases fatigue, so pregnant women and new mothers with MS are often more isolated than other people with the disease. This is important to discuss in the planning stage. If the woman is unable to go out, she should plan to get people to come to her.

Deborah Miller: Women with MS often lack a peer group, and pregnant women with MS have even less of one. I think it's a good idea to try to put them in contact with other women who have had this experience and discuss how they managed it. Some of the most complicated cases involving pregnancy that we have had to deal with in our clinics involve single women who are cognitively impaired and may not even be able to identify the father of the child. There are serious concerns about such patients' ability to adhere to treatment recommendations. There may even be additional legal concerns regarding whether they would have the opportunity to raise the child.

Robert Herndon: This issue needs to be discussed with the rest of the family in most cases. I would add that physical disability is a far less severe problem with pregnancy than cognitive disability. For some women, the ability of the mother to care for the child mentally and emotionally is much more important than her ability to care for the child physically, as long as adequate help is available.

“Will I Give MS to My Baby?”

Suzanne Smeltzer: Of the many concerns I have encountered among pregnant women with MS,³ one of the main worries is whether or not they can transmit MS to their offspring.

Robert Herndon: What do you tell patients who are concerned about whether their child can inherit MS or somehow acquire it vertically?

Suzanne Smeltzer: I think that the statistics are very reassuring. It is important to carefully review the family history at that time; the numbers you present are really going to depend on family history. That's the time to step back, do a careful family history, and then educate based on the available information.

Robert Herndon: The risk of a first-order relative getting MS ranges from 1% to 5%.⁴ We do not have good statistics for a multiplex family where there are two or three cases of MS, but the risk there is higher. In isolated cases, we usually can say the risk is not above 3%.

Judy Wollin: The caveat is that these are population statistics and they may not turn out to be the person's experience. It is little comfort to a person with MS that her child's risk is low, if in fact the child does develop MS.

Suzanne Smeltzer: One of the things that may or may not

be reassuring to some people is that the likelihood of their child having cardiac disease or some other medical condition is much higher than the risk of contracting MS.

When to Stop Disease-Modifying Therapy

Michelle Keating: The other important concern I hear from women planning a pregnancy involves the proper time to stop treatment with disease-modifying drugs. I advise that, based on the studies, it is probably a good idea to be off these drugs for three months before conceiving.⁵

Suzanne Smeltzer: Studies suggest that the risk to the fetus varies depending upon the treatment the woman is receiving. A recent study suggests that many drugs prescribed for MS are not safe during pregnancy or lactation.²

Robert Herndon: If the issue of pregnancy is discussed before the woman goes on medication, it may influence the decision about which disease-modifying drug to use. We know that the interferons are abortifacient. If a woman is planning a pregnancy, the clinician may want to recommend glatiramer acetate (Copaxone[®]) for disease modification, because it is categorized as class B for pregnancy by the FDA. Whether to continue the drug through the pregnancy should be determined on a case-by-case basis.

Nicki Ward: In the UK, some women with MS are currently going through their pregnancies on glatiramer acetate therapy, so the results of this observation are going to be quite interesting. Coyle⁶ reviewed data from 21 global trials with glatiramer acetate and identified 345 pregnancies among women taking the drug. Ninety percent discontinued when they learned they were pregnant, so they were mostly exposed during the first trimester. Of 215 that were followed, the rates of miscarriages or birth defects were in keeping with the risk to the general population.

Robert Herndon: Another important issue involves the use of chemotherapeutic agents. Drugs such as mitoxantrone (Novantrone[®]) may cause significant damage to genetic material. Male patients will sometimes bank their sperm, and the option for women to have their eggs harvested is offered in some centers. If someone is going to take mitoxantrone and the couple is planning a pregnancy afterward, this is definitely something that needs to be considered.

Michelle Keating: Outcomes data on mitoxantrone in reproductive issues are limited. One risk of taking mitoxantrone is amenorrhea. The question is not only whether a woman can become pregnant after receiving treatment, but also if there might be any long-term effects on the child. We have to admit that this is an area where we don't have much information. Certainly the possibility of saving eggs should be discussed.

Suzanne Smeltzer: Studies have shown that women who have been put on heavy doses of chemotherapy for breast cancer can become pregnant.

Michelle Keating: We have some reassuring data about chemotherapy in general. Based on our experience with chemotherapeutic drugs, we have not seen any problem, per se, with the infants. However, I agree that this area requires much more research.

Should Pregnant Women With MS Be Considered High-Risk?

Robert Herndon: Do you think that pregnant women with MS should be considered as having high-risk pregnancies?

Deborah Miller: It seems as though anyone who has any sort of medical issue gets put into a high-risk category. For some women, greater anxiety may develop because of this categorization. I'm not sure it's always appropriate.

Suzanne Smeltzer: I agree. I don't think it is appropriate most of the time. It should be of concern if somebody has a significant disability associated with MS. In general, however, somebody who is able to ambulate without any difficulty and is functioning well should be not perceived as high-risk, because it typically turns out to be a normal delivery for the most part. There are some obstetricians and neurologists who automatically believe that if a woman has MS she should have a cesarean section. In general, I don't think that's necessarily justified.

Judy Wollin: I believe anxiety may have a lot to do with it. The mother's concerns about the impact of pregnancy on her MS, inadequate prenatal care, anxious family members—all may add up to a cesarean. C-sections at a patient's request, in the absence of a medical indication, is also an increasing phenomenon. In addition, fatigue, spasm, and poor mobility may all contribute to concerns about a woman's ability to labor normally, even though research suggests that women with MS carrying singletons are no more likely to experience complications, with the possible exception of maternal anemia.¹

Robert Herndon: One concern I have with some of my pregnant MS patients is thrombophlebitis. Pregnant women are at risk for this condition. If mobility is significantly impaired, the risk of developing thrombophlebitis is significantly higher. Precautions should be taken for those who have impaired ambulation or who use a wheelchair.

Michelle Keating: Additionally, some women believe they cannot have an epidural because of their MS. Even though epidurals are not contraindicated in MS, some health care workers may believe that an epidural would pose to these women.

Robert Herndon: There is not any increased risk from an epidural in women with MS because it involves the peripheral and not the central nervous system. The problem is that if the patient has an epidural and then has paralysis afterwards, the paralysis may be blamed on the epidural, even though it is unrelated.

Suzanne Smeltzer: Some women have told me that their

anesthesiologist has refused to give them an epidural because of fear of a lawsuit down the line if anything happens. If a woman goes in with the expectation that she is going to have an epidural and then finds out that she cannot, it can be very disturbing. It is not what was planned, discussed, or agreed upon and yet the anesthesiologist is the one who is making the decision.

Medications During Pregnancy

Suzanne Smeltzer: One of the other questions that women have asked me, particularly women who have moderate-to-severe disability, is what happens if they need treatment during pregnancy. In other words, will they be able to take any of the non-immunomodulating drugs for their MS symptoms?

Michelle Keating: We counsel them depending upon what stage of the pregnancy they are in.

Robert Herndon: There are a variety of issues, ranging from the use of steroids to muscle relaxants and other drugs in pregnancy. We have information available in the prescribing literature for all of these drugs. However, many of them are not advisable in pregnancy, so one has to take great care.

Suzanne Smeltzer: Many women believe they should not be taking any medications during pregnancy. However, if the woman has a history of urinary tract infections, she is likely to have an increase in these infections during pregnancy. She should be advised that treatment is necessary because the infection is more dangerous to the fetus than is the medication. An appropriate antibiotic needs to be prescribed for women with MS who have had a history of urinary tract infections.

Deborah Miller: Communication with the obstetrician is essential because pregnant women with MS are uncommon in most OB/GYN practices. There may be either a cavalier attitude about the woman being on disease-modifying therapy or there may be a desire to stop all drugs. It is essential for MS practitioners to be proactive in contacting the obstetrician and working with that person to develop a consistent understanding about the approach to medication use during the pregnancy.

Suzanne Smeltzer: I agree. One thing women have told me is that when they have asked their neurologist for advice on taking or stopping medications, the neurologist often tells them to ask their obstetrician. The obstetrician may not know what to tell them and sends them back to the neurologist. If we could get the neurologist and the obstetrician to communicate with each other and also with the woman, it would be an important step.

Nicki Ward: MS nurses can coordinate case conferences. In the UK, midwives don't see many pregnant women with MS and when they do they are often concerned about their lack of expertise surrounding the disease. The way forward is obviously for the MS nurse and the midwife to work in partnership in the care of women with MS.

The Immediate Postpartum Period

Michelle Keating: Another controversial issue that comes up with pregnancy in MS is the immediate postpartum period. The question is not only when to start immunomodulating treatment again, but whether something preventive can be done, such as administering intravenous immunoglobulin (IVIG) immediately postpartum.

Robert Herndon: We know that the risk of an attack is increased approximately 20% to 40% in the first three months postpartum. That is the reason why some clinicians may want to take preventive actions. Solumedrol and IVIG have been used postpartum, but there are no good studies on these drugs. If a patient does go back on disease-modifying drugs, it may be necessary to modify or avoid breastfeeding. Studies have shown that breastfeeding alone does not increase the risk of an attack.

Nicki Ward: The safety of steroids in breastfeeding mothers has not really been determined either. We advise women to build up a bank of breast milk in the freezer prior to steroid therapy. They can restart breastfeeding when the course of steroids is completed.

Suzanne Smeltzer: Practically speaking that would work, but I think the reality is different for many women.

Deborah Miller: That's why it's important to help people plan for such things during the pregnancy, before these decisions have to be made.

Robert Herndon: Another important postpartum issue is fatigue. Breastfeeding can compound the fatigue that already comes with MS. If the woman has to get up and breastfeed during the night and be responsible that aspect of infant care, she is really going to be extraordinarily tired.

Deborah Miller: I was going to add that any new mother is going to be fatigued.

Judy Wollin: Yes—you don't need MS to be fatigued during the neonatal period. Interestingly, one study found that women with MS were twice as likely to be readmitted to the hospital in the three months after delivery. Strong support and close monitoring during this time are recommended by the authors.¹

Robert Herndon: I usually advise that the patient's partner do most of the feeding at night, if at all possible. Additionally, there should be someone else in the home during the postpartum period to help take care of the baby. If the woman chooses to breastfeed, she should probably get a breast pump so the partner can get up and do some of the night feedings.

Michelle Keating: Or, alternatively, the husband can bring the baby to the mother in bed so she doesn't have to get up.

Suzanne Smeltzer: I've had women tell me that they would not tell their physician that they were having an exacerbation in

the postpartum period if they could get by with it, because they know that the first thing that the neurologist or the obstetrician would tell them is to stop breastfeeding.

Suzanne Smeltzer: Is there an increased incidence of postpartum depression in women with MS?

Robert Herndon: I am not aware of any particular increase in the incidence of postpartum depression in MS. Of course, depression is more common in people with MS regardless of pregnancy status.

Some Final Thoughts

Michelle Keating: What is the one most important thing you would recommend women with MS who are pregnant or are planning a pregnancy?

Judy Wollin: Build social support from early on. If they already have other children, they will need even more support.

Nicki Ward: The more planning that the couple can do from the start, the better because they will cope better knowing that they have an infrastructure in place. We usually suggest that women develop a plan, especially regarding getting help with childcare. We advise them to write down names and numbers of friends and family who offer their help, as well as organizations that specialize in helping new mothers with disabilities. If they hit a crisis, they have this prepared. Also, in the UK, men are allowed four weeks of paternity leave. We advise the partners of pregnant women with MS not to use up all their leave right after the baby is born, but to save some of it in case a relapse occurs a little later on. When couples have a plan, they naturally feel they are more in control.

Michelle Keating: The most important thing I would tell them is not to be afraid to have children, and not to be afraid to alter their lives because they have MS.

Suzanne Smeltzer: I would also remind women that they need to enjoy the pregnancy and not worry themselves all the way through it, because in most cases it is going to be a normal pregnancy. **MS**

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