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Special thanks to Judith Pratt Rossiter, MD, Director of the Perinatal Center, Saint Joseph Medical Center, Towson, MD for being an invaluable resource in the creation of this booklet.

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Date: Feb 2007

OBSTETRIC ISSUES

Transverse Myelitis, Acute Disseminated Encephalomyelitis and Neuromyelitis Optica

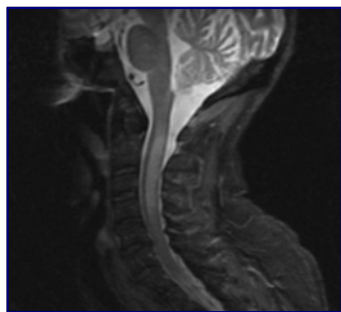


Introduction

What are Transverse Myelitis, Acute Disseminated Encephalomyelitis and Neuromyelitis Optica?

Idiopathic Transverse Myelitis (TM) is an acute inflammation of the spinal cord, usually involving a limited segment. Neuromyelitis Optica (NMO/Devic's disease) involves inflammation and demyelination of the optic nerve and spinal cord. Acute Disseminated Encephalomyelitis (ADEM) involves demyelination in the brain and spinal cord. The extent of damage varies from case to case, therefore, the amount of disability associated with these conditions is variable. Some patients recover from the initial attack with little or no disability. Others, however, are left with sensory symptoms, such as pain or paresthesias (tingling), motor weakness, paraplegia (inability to move legs) or quadriplegia (inability to move arms or legs). The information presented here, therefore, is applicable to all of these related conditions. Throughout this guide we will speak in the context of TM, but this is meant to apply to any patient who has had spinal cord inflammation/demyelination. Some patients have a risk of disease recurrence and should discuss this with a physician.

Is there a known genetic basis for TM, NMO and ADEM?
Should this impact a woman's decision to become pregnant?



Preconception/Conception

Does TM affect the ability to conceive?

The reproductive cycle of women with TM should not be compromised. Conception issues, which arise in the general population, can also exist in women with TM. Any difficulty in conceiving should be addressed by a gynecologist or fertility expert. The chance of early miscarriage, occurring before 12 weeks gestation, is thought to be as high as 20% in the general population. This should remain the same for women with TM. If a woman has been diagnosed with an autoimmune disease, such as Systemic Lupus Erythematosus, the risk of miscarriage may increase and this should be discussed with an obstetrician.

The Transverse Myelitis Association (TMA) is a not-for-profit international foundation dedicated to the support of children, adolescents, and adults with a spectrum of rare neuro-immunologic disorders including: Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO), Optic Neuritis (ON) and Transverse Myelitis (TM).

Founded in 1994 by family members and persons with these diagnoses, the TMA was incorporated on November 25, 1996 in the state of Washington and we became a 501(c)(3) organization on December 9, 1996. The TMA currently has over 9000 members from more than 80 different countries.

OUR MISSION IS:

To support and advocate for individuals and their families diagnosed with rare neuroimmunologic disorders of the central nervous system

To promote awareness and to empower patients, families, clinicians and scientists through education programs and publications

To advance the scientific understanding of and therapy development for these rare disorders by supporting the training of clinicians-scientists dedicated to these rare diseases and by supporting basic and clinical research

If you are interested in becoming a member of The Transverse Myelitis Association, receiving information about TM and other rare neuro-immune diseases, or contributing to the efforts of the TMA, please contact us by email at info@myelitis.org or by phone – 1-855-380-3330

Your tax-deductible contributions to the TMA are greatly appreciated.

Please send contributions to:
The Transverse Myelitis Association
1787 Sutter Parkway, Powell, OH 43065

There is a known risk for depression in people suffering from Transverse Myelitis. Therefore, it is important to be aware of the risk of depression occurring during the postpartum period. If a woman has previously or is currently being treated for depression, it is imperative to recognize the probable need for treatment during the postpartum period. Warning signs/symptoms of depression may include: feeling very sad or anxious, frequent crying, lack of appetite, not taking care of oneself, sleep difficulties, not feeling like performing normal daily activities, trouble concentrating, feeling hopeless, excessive worry, not caring for the baby, thoughts of suicide or self harm. It is very important to communicate openly and honestly with your health care provider about any concerns you may have. Remember, depression is treatable.

Summary

Transverse Myelitis, Acute Disseminated Encephalomyelitis, and Neuromyelitis Optica are not contradictions to becoming pregnant. There are definitely risks involved, but these can be managed. Becoming pregnant will definitely increase the number of physicians involved in a woman's care. This will require an additional component of coordination for which the woman is ultimately responsible. Preconception planning is a very valuable tool in optimizing pregnancy outcome. Careful evaluation by your obstetrician and your neurologist can help identify potential challenges and how best to manage them.

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No specific studies have been done to determine if there is a genetic link to TM, NMO, or ADEM. In studies done on another demyelinating disease, Multiple Sclerosis, a familial tendency has been seen. If a genetic risk does exist, it would only involve an extremely small increase in the absolute risk of developing TM, NMO, or ADEM, as compared to the general population. The chances that a parent with one of these conditions will have a child similarly affected is extremely rare.



Is preconception ed for women with rologic diseases?

counseling recommend- TM and other rare neu-

Yes, preconception counseling with a perinatologist is recommended. A perinatologist is a physician who has completed a fellowship in Maternal-Fetal Medicine. A high-risk obstetrician is the same as a perinatologist. However, be aware that some obstetricians refer to themselves as "high-risk" without having completed any additional training. It is important to know the difference when selecting a provider. A consultation with a high-risk OB/perinatologist can help a woman determine the level of care required as related to her specific needs. This would include a determination of which type of provider is most appropriate, i.e. certified nurse midwife, general obstetrician, or high-risk OB/perinatologist.

What danger does medication use during pregnancy pose to a developing fetus?

The medications, which a woman is taking prior to conception, need to be evaluated on an individual basis by an obstetrician or perinatologist. Any decisions involving medication changes or discontinuation should be made jointly by the obstetrician and neurologist and may involve a psychiatrist (depending on the medications). There is always a question of risks versus benefits. The effects of many medications on a developing fetus are unknown due to the lack of investigational studies on pregnant women. Many known risks are derived from studies done on animal fetuses or case reports representing very few human pregnancies. Individual medications must be evaluated on a case by case basis. Medication usage may also be an issue, with regard to breastfeeding. Many medications are excreted in breast milk. This is an important consideration, though many medications may be safely used while breastfeeding. You may need to consult a lactation nurse or pediatrician with these concerns.

Pregnancy



What complications could women with TM and related conditions possibly face during pregnancy? What must obstetricians be aware of when managing the care of a patient with TM?

Mobility Problems: This complication is dependent on the individual's level of function. If mobility issues exist, such as balance problems or spasticity, they may become worse as the pregnancy advances. The growing fetus will change the woman's center of gravity, which can create difficulty with balance. If difficulty ambulating develops, it may become necessary to depend on assistance from a walker or wheelchair in the second and/or third trimester of pregnancy. It is very important to prevent falls, which may cause injury to the mother and/or fetus. Keeping safety in mind, remain as active as possible during pregnancy. Physical therapy may be helpful, if mobility is decreased.

Deep Vein Thrombosis: A deep vein thrombosis (DVT) is a blood clot which usually develops in the leg. It is potentially life threatening should it move from the leg into the lungs. Pregnancy increases clotting potential. A pregnant woman's inability to ambulate on a regular basis could increase the risk of developing a DVT. Continued movement can decrease the risk of developing this complication. It is important to attempt to remain as active as possible, pursuing physical therapy if warranted. The obstetrician caring for a pregnant patient with limited mobility needs to assess the potential need for heparin prophylaxis to reduce the risk of DVT both during pregnancy and postpartum. Signs and symptoms of DVT may include swelling in the suspected leg, warmth, redness and tenderness.

Urinary Tract Infection: Frequent or chronic urinary tract infections (UTI) can be a common problem in women with TM who experience bladder dysfunction. A pregnancy has a high potential to exacerbate this problem should it already exist. If self-catheterization is being performed it will most likely be necessary to increase the frequency of catheterizations as the pregnancy progresses. This is due to the increased circulatory volume of pregnan-

cord lesion, her personal physician/obstetrician should be asked for a recommendation on which health care facility is best for delivery.

Postpartum



What are some important concerns during the postpartum period?

Bladder distention is a common occurrence in the immediate postpartum period. Bladder assessment is crucial. The bladder can sometimes become traumatized during delivery leading to an inability to void. If a woman was unable to void spontaneously during pregnancy and prior to delivery, an indwelling catheter should be considered instead of repeated catheterization due to perineal tissue damage and swelling present after a vaginal birth.

Constipation is another common occurrence during the postpartum period. It is important to establish and/or continue a bowel regimen during the immediate postpartum period to avoid constipation.

Is breastfeeding possible?

Breastfeeding is definitely possible and should be considered if desired. Any mobility restrictions of the mother, of course, would need to be evaluated in relation to the ability to breastfeed. Medications taken during pregnancy or resumed during the postpartum period need to be evaluated for any contraindications to breastfeeding.

Why is awareness of postpartum depression important?

tinuous fetal monitoring is necessary. Regional anesthesia, such as epidural or spinal can be effective in treating ADR.

Several steps can be taken to help prevent the onset of ADR. Bladder catheterization should be performed using a topical anesthetic. Constipation should be avoided. Vaginal/cervical exams should be performed minimally. Cold stirrups and speculums should not be used unless absolutely necessary. Regional anesthesia given at the onset of labor can help prevent ADR from occurring.

What is Pregnancy Induced Hypertension and how is it different from Autonomic Dysreflexia?

It is important to mention another condition not uncommon during pregnancy called Pregnancy Induced Hypertension (PIH) or Pre-eclampsia, which may present with symptoms similar to that of ADR. PIH can begin suddenly or gradually. Spinal cord dysfunction is not a known risk factor for PIH. The known triggers of ADR do not cause PIH. Its cause is unknown. It can cause mild or severe elevations in blood pressure. It can also cause an elevation in levels of uric acid, liver function tests and a decrease in platelets. It also can cause proteinuria (protein in the urine). These abnormalities are not present in ADR. Women with PIH are at increased risk for seizure. PIH is treated with an intravenous infusion of Magnesium Sulfate and usually resolves within a short time after delivery.

Is epidural or spinal anesthesia safe for women with TM and related disorders?

Epidural and spinal anesthesia is thought to be safe for women with TM and related disorders. An epidural or spinal can actually be very effective at preventing the onset of autonomic dysreflexia, should a woman be at high risk for ADR. It is recommended that a pregnant patient seek a consultation with an anesthesiologist before labor to discuss potential risks and concerns for care during labor. There is no evidence to suggest that an epidural increases the risk of flares of spinal cord inflammation.

What type of medical facility can provide the best care for women with TM during labor and childbirth?

The type of medical facility in which a patient should seek care is highly dependent on the level of spinal cord dysfunction. A very important concern is a woman's risk for developing the life threatening complication of autonomic dysreflexia. If this is a concern, care should be obtained in a tertiary health care facility. This is a health care facility that provides a highly specialized, highly technical level of care. It will be capable of providing continuous hemodynamic monitoring during labor and delivery and provide specialized care as needed. If a woman is not at risk for ADR, due to the location of the spinal

cy, hence, increased perfusion to the kidneys. The weight of the growing uterus on the bladder and ureters can also cause problems with urinary reflux. This can lead to a higher risk for bladder and kidney infections. The obstetrician should evaluate the need for prophylaxis with antibiotics to decrease the occurrence of UTIs and pyelonephritis (infection involving the kidneys).

Constipation: Constipation is a common problem for pregnant women. If a woman with TM has been experiencing problems with bowel dysfunction/constipation it will most likely be exacerbated during pregnancy. The growing uterus makes the space in which the digestive system exists compressed, progesterone (a pregnancy hormone) slows the motility of the GI tract, and iron supplements used to prevent anemia can cause constipation. It is very important to maintain a diet with adequate fluid intake, high fiber and plenty of fruits and vegetables. It may also be necessary to take a stool softener, if recommended by an obstetrician.

Anemia: Anemia, a reduction in the concentration of hemoglobin in the blood (red blood cells), is a common condition of pregnancy. Depending on the severity, an obstetrician may recommend iron supplementation, other vitamin supplements, or diet changes, depending on the exact cause. If a woman is already experiencing anemia due to a chronic inflammatory disease state, it is very important to have this issue addressed by an obstetrician early in pregnancy.

Preterm Labor: Preterm labor (PTL) is the onset of regular uterine contractions and/or cervical changes between 20 and 37 weeks gestation. Women with TM, generally, should not be at a higher risk for occurrence of pre-term labor, however, they are at higher risk for being unable to detect the signs and symptoms of PTL. This risk is dependent on the level of sensory function present. The ability to perceive contractions is related to the location of the spinal cord lesion. Lesions below T11 will permit sensation of uterine contractions and pain. Lesions at T6-10 may allow contractions to be perceivable, but not painful. A lesion at T6 or above will inhibit the woman's ability to perceive contractions. If altered sensory perception exists, it may not be possible to feel the contractions, cramping sensations, backache, or upper leg pains sometimes associated with PTL. It is important for the obstetrician to give instruction on uterine palpation techniques and provide cervical assessments during the late second trimester and third trimester, possibly through ultrasound examination or vaginal exams. Home monitoring with a portable tocodynamometer (uterine activity sensor) may also be considered to assess for recurrent contractions, should PTL occur. Note: Frequent/chronic urinary tract infections can increase the risk of PTL (see section on UTI).

How could the hormonal changes experienced during pregnancy and the postpartum period impact my condition?

Though there are no published reports addressing this issue for women with TM, NMO, and ADEM, in studies conducted on women with another demyelinating disease, Multiple Sclerosis, it seems that the second and third trimester of pregnancy actually causes a natural decrease in autoimmune activity. This pregnancy-induced state should actually help reduce the risk of an inflammatory attack. During the immediate postpartum period, however, the risk could increase, especially for women who have had NMO, recurrent TM, or ADEM. Medication management is critical in the immediate postpartum period.

Labor and Delivery



How is the process of labor different for women with TM and related disorders?

The actual process of labor, in which the uterus contracts to produce cervical dilatation, is no different for women with TM. Labor is an involuntary process. As with any labor, there exists the possibility of failure to progress to full cervical dilatation (10 cm). There is also a possibility that the fetus will not descend into the pelvis due to reasons, which may include, size of the fetus, size and shape of the woman's pelvis, and position of the fetus. If a woman labors and achieves full cervical dilatation and the fetus descends into the pelvis a vaginal delivery is possible. This can be obtained whether or not a woman is able to push during the second stage of labor. If pushing is not possible, a vaginal delivery can be facilitated by the use of forceps or vacuum extractor. This method of "passive second stage" is commonly used for women with other medical conditions, such as heart disease. If labor does not progress and/or the fetus fails to descend into the pelvis to enable a vaginal delivery, a cesarean section may be necessary. A cesarean section might also be warranted during labor, if the fetus shows an intolerance to labor for any reason. This is not a risk factor specific to women with TM.

What is Autonomic Dysreflexia? Why is it potentially the most serious complication for women with TM and related conditions during pregnancy and labor?

Autonomic Dysreflexia (ADR) is a potentially life-threatening complication of labor. It results in rapid onset of hypertension (increased blood pressure), which varies in severity, and may also include bradycardia (low heart rate). ADR is caused by reflex signals of the spinal cord from below the affected lesion, traveling up the spinal cord uncontrolled. These reflex signals would normally be met by a return signal from the medulla and hypothalamus (brainstem and brain), above the affected lesion, but are not because the opposing signal cannot travel down through the affected lesion. ADR is a complication seen in patients with spinal cord lesions at T6 or above. This risk is somewhat related to the completeness of the lesion (partial or complete transection). Other related symptoms may include: feelings of anxiety, headache, goosebumps, sweating, respiratory distress, increased heart rate, irregular heartbeat, and nasal congestion. Maternal hypertension and bradycardia can affect the fetus causing decreased blood flow to the fetus (uteroplacental vasoconstriction), decreased fetal oxygenation (fetal hypoxemia), and lowering of fetal heart rate (fetal bradycardia).

What can trigger Autonomic Dysreflexia during pregnancy and labor?

Autonomic Dysreflexia can be triggered in several ways, which include the following:

- Vaginal/Cervical examinations
- Uterine Contractions
- Pain
- Episiotomy
- Insertion of a urinary catheter, manipulation of the catheter, or obstruction of the catheter
- Bladder distention
- Constipation, bowel obstruction, and other GI problems
- Temperature changes below the level of the lesion such as hot or cold applied to the feet; placing feet in cold stirrups; use of a vaginal speculum.

How is Autonomic Dysreflexia treated? Can ADR be prevented?

Rapid recognition of symptoms is critical. Treatment should consist of removing the trigger, if possible. Rapid acting antihypertensive medications to lower blood pressure should be readily available. Constant and extensive monitoring to include blood pressure, heart rate and rhythm, and respiratory status. Con-