

Medical Home Telephone Conference

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Menstrual Hygiene Management for the CSHCN Population
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We think that this is an issue for parents when their kids get to be adolescents but in my experience is that they are worried very early on when they realize their child has a disability and that someday their child is going to have menses. This is something that should be brought up before puberty. Try to remember in girls in earlier childhood when there is an appropriate time to segway into this topic to mention to families and ask them what they have been thinking. My conversations are not usually that in depth other than to indicate that sometimes some girls with disabilities seem to manage their menses just fine so for some it may not be an issue at all but for other girls it is a significant issue but there are options we can discuss at that time to try and make the process easier for them. If they want a little more detail I might talk to them briefly about what the options are. The other thing I think is important to explain to parents that we do expect their child to go into puberty and we expect it to be timed appropriately and if we are seeing early signs of puberty or not seeing any signs of puberty you need to be aware and pay attention to that. It's not unusual for me to see a patient for consultation for other reasons and they may be a 20 year old and they haven't progressed through puberty. While Sometimes this is a relief for people but at the same time you have to look at what are the medical issues going on that this person hasn't moved into puberty and is this something that needs to be treated like hypothyroidism. We need to be aware that puberty is a normal developmental process that we should expect to happen in most individuals with disabilities. I usually talk about menstruation early in childhood and then again when there are early signs of puberty which typically in a girl is breast budding. There are a lot of kids with disabilities that develop pubic hair very early on but no other signs of puberty and this really isn't true puberty. The stage where there is breast budding is where you can know that the child really is moving into puberty. It's helpful to tell parents that typically menses are about a year and a half to two years after you first start noticing changes so they don't need to be worried that any day my child's period is going to start, they have time to think about it and prepare.

In the individual child how do we prepare? What are the factors that go into deciding whether to allow this individual to manage their menses or whether to suppress the menses. Here are some important factors:

- Hygiene
- Sensory integration issues (if they don't like the feel of their pad they rip it off when they get to school). Getting them to tolerate menses can be difficult. Some kids are so anxious about it. Example a young girl asks her mom to call the doctor every time she has her period because she

thinks something is wrong and they have been through this over and over but the daughter can't get over the hurdle of thinking that this means she is sick.

- Also, a lot of kids perceive their pads as diapers, so you will have a child who is continent who is no longer continent because they perceive they have been put back in diapers.

One of the bottom line questions is "How is this process going to affect their teens independence"? There are some teens that with the appropriate support are going to manage their menses easily and other teens may never be able to handle it affectively but whose independence isn't going to be diminished by having somebody else manage their menses. And then there is a big group in the middle who are continent, who are managing their toileting and their other hygiene and this is sort of the breaker and they just can't handle their menses. They go from somebody who can go to school independently and maybe live in a group home to an individual who may be restricted from that because they can't handle this process. This is a situation where menstrual suppression might be very helpful.

Also an important question is "How does the family feel about managing the child's menses"? If you have a child who is diapered it may not be a big deal to manage this teen's menses but a lot of this relates to the perceptions of the family. Some families see it as an invasion of the child's privacy to have other people managing that, some families feel like they are comfortable with it but they don't feel comfortable asking other people who are working with the teen to manage it. Other families may not have a problem with putting a tampon in or putting a pad in the diaper. Some families haven't even realized it's ok, so when they realize it's a normal process it's not a big deal and it's natural and it's ok to ask whoever is managing the toileting at school to manage the menses as well.

Another factor is if there are somatic problems that come up with the menses. Problems with abdominal pains may be a reason to suppress menses. Also there may be behavioral issues that exacerbate with cycling that needs to be managed although instead of suppressing menses, treating PMS may be a better way to go for some kids.

Every family seems to have a concern with sexual victimization. It's a great opportunity to open this up for discussion with families. Are they worried about that and most often the answer is yes. Then having a conversation with the parents about what can they do to minimize the risk of their child becoming victimized. That may be a topic for another phone conference. It is important for families to realize that birth control does not prevent victimization it prevents pregnancy. Putting a child on birth control, while it might be important for menstrual management and might be important in terms of preventing pregnancy if they are really worried about their child's risk of victimization they also need to do other things to prevent victimization.

All of these issues go into the decision to manage menses and it is not a light decision nor is it a final decision. Some families might opt to suppress for a year or two until their teen is a little more mature, other families' might opt to try and manage the menses and if it doesn't go well then try and suppress it. It is important to let the families know that whatever they decide to do the decision isn't permanent. It is not a light decision when you start suppressing menses. For some kids it goes easily and for other kids they either gain weight, have persistent spotting, or other issues come up. So it is not like we say we should suppress everybody because there are several issues to look at when deciding to suppress menses.

If a family and the child want to have menses "what supports are out there to help them"?

- First thing is to see if anybody in the home can model having menses. Unfortunately by the time a teen starts having menses a lot of mothers are no longer able to model that for them and it is difficult to ask a sibling to do that. If a mother or adult woman can model the normality of it for a teen with mild or moderate mental retardation it would be very helpful.
- Educational level of teen.
- Putting it in the teen's IEP at school as part of their health education should be considered.
- Also building a team at school who is going to be the support for the teen. Where is she going to have supplies, where is she going to have a change of clothes if she needs them, who is going to help her during the day, who is going to be her contact person if she has a problem and can she have a code word with that person to indicate why she needs help without having to be embarrassed publicly? Again putting a support in place, a lot of kids can do this, it is a hurdle for typical kids who have their menses very young so I think schools need to be prepared to support kids.

If the decision is made for suppression there are several options:

- Medical options are Depo provera or a regular birth control pill cycling without placebos. With the Depo provera there is weight gain for a subset of kids and maxes out about 10-14 pounds. That is not a minor weight gain especially if you are already dealing with an obesity issue. A lot of kids whose parents felt they gained weight but when I plotted our their growth chart they stayed on the same projectory they had always been on. The parents perceived it was the depo but it was the child's pattern already.
- The contra-indications are the same for the depo as if you are using it for birth-control. Depo can be used in most patients. Besides the weight gain another common side effect relevant to the population we are talking about is that it can cause some irritability in a subset of patients. It is pretty rare but if you are dealing with a patient with cognitive disability, irritability can be quite difficult to manage. Occasionally I will opt to put

child on oral depo for a couple weeks as a test to see what side effects it will cause before giving an injection. The other concern about depo is that it suppresses estrogen not completely but fairly low and may put an individual at risk for osteoporosis. We know that you are gaining your biggest bone mass during your early teen years so if we are suppressing your estrogen at that time that may be a big concern. There is no good data about that and so how to handle that concern is variable. If I think a child is at high risk for osteoporosis such as CP I will try to avoid Depo. If I have to use Depo I will often get a baseline bone density and repeat that in a couple of years to see what the bone density is doing if they stay on the Depo. Breakthrough bleeding is another side effect. It takes the third injection before you suppress 80% of women so during the first 6-9 months there is going to be lots of spotting for some women. If the spotting persists after 6 months it is often helpful to add a little estrogen to stabilize the endometrium and that might be helpful for your bones so there are ways to manage the spotting for some.

- Oral contraception pill. You can either completely suppress menses so you skip all placebos or you can opt to have a menses a couple times a year. You can have the parent schedule it over Christmas break or summer break so the child is having menses but they are predictable they are only during a couple of times a year and the family can be there to support them. Either way works, when you try and completely suppress you often get a lot of breakthrough bleeding however other times when you let there be a couple of periods you never get them completely suppressed and you are always dealing with breakthrough. The choice of birth control pill is a 20 microgram pill because some of the pills have 30 micrograms of estrogen and when skipping placebos 30mcg. would cause your overall dose of estrogen over the month to be higher. In the trials of Seasonal, a 30 microgram pill marketed for women who only want to have a period four times a year, there was a higher incidence of clotting events. So try to stay with a 20 mcg pill. Some people talk about using the patch but it is equivalent to a 30 microgram pill so right now it is not recommended to use the patch. There is a website, www.noperiod.com, which provides information aimed at women who want to suppress their period. I think it is from the University of Washington who are doing research in that area. Contraindications are obviously if you have a contraindication to estrogen which most commonly is a history of stroke in families or thrombotic event and dealing with breakthrough bleeding.
- Other options medically are Lupron that completely shuts down gonadal access and is about \$1,000 a shot once a month. That will only get approved by an insurance company if you have tried everything else and failed and if it is clearly medically indicated such as having seizures every month with their periods and it has to be suppressed. It will usually be managed by an endocrinologist.
- Surgical options include hysterectomy. The role of uterine ablation is hotly debated because it actually is relatively permanent and can be viewed as

a hysterectomy and at the same time can have a lot of breakthrough bleeding so the role of uterine ablation is still not clear. "When can you ask for a hysterectomy or uterine ablation?" Generally in most states you have to get court approval for either of these. Courts at times will agree for that to happen but what the courts will ask for is that you have to show it is in the child's best interest, clear reasons why this child cannot have their menses and you've exhausted medical options. I have been in that scenario where a child can't have estrogens because of a medical reason and progesterone did not work for this teen and every time she had a period she became suicidal so it was clear it was in her best interest. Those are the situations where the courts will have a hearing and consider it. If a family wants to go that route what they need to do is contact the Guardianship Association of Utah that maintains a list of experienced lawyers who can do the paper work for this. You need a lawyer who knows this process because if all of your ducks are not in a row it won't happen. There is a cost involved with the lawyer fee and filing fees. If the judge for some reason feels the teen needs her own representation that increases cost additionally because then you have to pay for a lawyer for that individual to act as a guardian ad litem. So the amount of cost varies depending on how the court proceeds. It is possible for some cases to get court approval to move forward with a hysterectomy. We all know the historical reasons why the court system is involved. During the 40's and 50's when hysterectomies were performed on a young adult who was just acting out because quote it was in her best interest not something that was really appropriate to be doing.

Those are the major issues. Any questions?

One speaker suggests "You don't need a court order for a uterine ablation. One family she dealt with spoke to their doctor they thought it was medically necessary with this young woman who would rip off her sanitary pad and they had it done."

Lisa: I think it depends upon the individual surgeon doing the procedure, specifically the procedure has the same anesthesia risks and permanent effect on fertility as a hysterectomy so if they are using it that way they are going to say we need a judges order. Others may say court papers are written about hysterectomy but not uterine ablation so we can do this and no one is going to give us a hard time so there is no standard way to approach this. I think the only issue is when the clinician is worried about the legal ramification about how it is going to be viewed. It varies. In terms of long-term management of menses it is not clear about how an ablation fits in.

Bob Terashima: In your experience how comfortable have people in schools been in becoming involved?

Lisa: So far it seems to be pretty easy to get hygiene education into the IEP. Can we talk about what menses are, can we make this a normal biologic process

for this teen. Most schools are going to stop short about going into information about pregnancy but it is also pretty easy to build a team to help in terms of if she has some leakage, change of clothes or a bathroom you can use or someone you can go ask for help. For kids in diapers it is whatever the families says goes. I have had schools go both ways some who did not like managing them and wanted someone to suppress them and brought that up with the parents and other schools that felt strongly about the naturalness of periods and that is was wrong to suppress and spoke out against that. In our society there are so many personal beliefs that can come up about menses that can be very personal to individuals involved but I don't think I have ever had a teen that the school did not realize that they ultimately had to support this teen if she is having menses. They can't just say sorry it is not our problem.

There is one thing I talk to parents about in terms of sexual victimization prevention at a school. It should be defined who is allowed to help the child with toileting and it should be very clear that it is this person and this person not whoever is around to help but a certain two or three people and this should be the same with menses.

Other issues that come up with teens when I talk about menses is insuring calcium intake because that is the time they put on the most bone density, they also may need a multi-vitamin because of the folate issues particularly teens who may have unplanned pregnancies insuring they have iron in-take. Acne, dandruff, body odor, body hair can be issues that people may not pay attention to. Nobody has said to the family that there are treatments for that. We need to be aware of all of those issues that teens struggle with being relevant in a kid with disability as well as a kid without because they are social barriers for that teen.

Final issues If the decision is made to suppress menses you will want to get a bone density and the only place in town this can be done in teens and children and interpret them in a way that means anything in teens is the Center for Pediatric Nutrition Research at the University of Utah. That is where they should be referred. If you refer them to where your colleagues send adult women you will get a number back but you won't know what to do with it because there won't be any norms for their age and gender comparisons

Does a teen need a pelvic exam? Not for suppression, only if there seems to be problems like pain or discharge. For suppression you only need an external genital exam and a pregnancy test (urine or serum) If a child needs a pelvic exam you may try an ultrasound for a teen who may have trouble with cooperation. If the child needs sedation for an exam it is a good idea to have the pediatrician talk to the Rapid Treatment Unit clinicians to set up some sedation times but the clinician needs to be available to do the exam. Center for Safe and Healthy Families can do sedation exams and have done some for reasons of diagnoses and not victimization because they are the only ones in town with that

ease of availability to do that. Certain GYN's in town are willing to see teens with disabilities but their capacity to provide sedated exams are variable.

Next Phone conference Tuesday November 29, 2005, Genetics Counselor. What they have to offer, when we might refer directly to the counselor, and what support they might provide to the medical home about specific genetic diagnoses

Attendees: Lisa Samson-Fang, Barbara Ward, Lisa Lee, Robert Terashima, Kathy Heffron, Karen Talke, Amy Moore, Sandra DeBry.