What is Spina bifida?

- Means “open spine”
- It is a spinal cord malformation
- It is the most common, permanently disabling birth defect in the U.S.
- It happens in the first month of pregnancy
Pregnancies in Women with Spina Bifida

- Prospective qualitative study looking into the process of pregnancy in women with Spina Bifida
- 14 SB patients who had successful pregnancies
  - So far, 6 women have agreed to participate in study
- Phone interviews, chart review, and the use of i2b2 to enhance our research
Pregnancies in Women with Spina Bifida

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Purpose

The purpose of this qualitative study was to gain insight into pregnancies in women with Spina Bifida. Educating ourselves on the risks, complications, and outcomes will provide better patient care for women transitioning into adulthood.

Methods

- Prospective qualitative study
- IRB Approval
- University of Alabama at Birmingham’s (UAB) Spina Bifida clinic
- Phone interviews and retrospective chart review
- 139 adult females
- 14 females had pregnancies (10%)
- 6 were successfully contacted and consented our study sample

Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>N=6</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myelo</td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Lipomyelo</td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Age at Pregnancy</td>
<td>21.97±4.79</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>Presence of Shunt</td>
<td>3</td>
<td>50</td>
</tr>
</tbody>
</table>

Discussion

**Figure 1. Mobility & Continence Trends**

During Pregnancy:
- 3/6 had a decline in mobility
- 2/6 had a decline in continence; 1/6 had an improvement

After Pregnancy:
- 6/6 returned to baseline in mobility
- 3/6 returned to baseline in continence; 2/6 declined; 1/6 improved
- Mobility ranges from full function to wheelchair user
- Bladder and bowel regimens include: bladder catheterization (50%), cranberry pills, Docusate™, bowel enemas and MiraLAX™.
- 33% had difficulty catheterizing while pregnant
- 33% had bladder augmentations (prior to pregnancy)

Most common complications:
- 66.7% had UTIs while pregnant
- 50% Preeclampsia

Results

<table>
<thead>
<tr>
<th>Variable</th>
<th>n=6</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intent for Pregnancy</td>
<td>5</td>
<td>83.3</td>
</tr>
<tr>
<td>Conception Assistance*</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td>Folic Acid Before Pregnancy* (n=8)</td>
<td>2</td>
<td>25</td>
</tr>
<tr>
<td>Folic Acid During Pregnancy* (n=8)</td>
<td>7</td>
<td>87.5</td>
</tr>
<tr>
<td>Number of Pregnancies:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>4</td>
<td>66.7</td>
</tr>
<tr>
<td>Multiple</td>
<td>2</td>
<td>33.3</td>
</tr>
<tr>
<td>Miscarriages</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Complications during Pregnancy*</td>
<td>5</td>
<td>83.3</td>
</tr>
<tr>
<td>Epidural</td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Delivery Methods (vaginally)</td>
<td>3</td>
<td>50</td>
</tr>
<tr>
<td>Delivery Complications</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td>Gestational Age</td>
<td>37.43±2.07</td>
<td></td>
</tr>
<tr>
<td>Neural Tube Defects in Child</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

*Conception Assistance in the form of herbals.
*Folic Acid dosing is 4 times OTC dosing.
*Complications include constipation (1), incontinence (2), preeclampsia (3), and gestational diabetes.

Limitations

- We do not know how many of the 135 women attempted to get pregnant or were able to get pregnant.
- Small sample population

Conclusion

There have been 8 successful pregnancies in our adult SB population. None of these pregnancies resulted in NTDs. High rate of preeclampsia was noted as a complication. Prior to transition, folic acid teaching should be reinforced.

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i2b2 Steps

- Using the Find Tool we searched by Name.
i2b2 Steps: Key Words

- **Group 1:** Spina Bifida, Any Myelomeningocele Code
- Before pulling into query we made sure to select only disorder codes not procedure codes
i2b2 Steps: Key Words

- Group 2: Pregnancy, Obstetrics, Abortion
- We wanted to cross reference for these keywords
i2b2 Steps: Run the Query
Steps for i2b2

• Prior to getting these patients through i2b2, our team tediously went through every female patient in our Adult Spina Bifida clinic population by hand.

• With using i2b2 we found that not all adult female spina bifida patients who became pregnant attend the Adult Spina Bifida Clinic.

• Out of the 10 patients i2b2 found, 4 were new patients
i2b2 Steps

- IRB approval to obtain the patient list.
  - List was received within a 5 day timeframe
- It was in the format of Excel spreadsheet containing the following variables:
  - Medical Record Number
  - First Name, Middle Name,
  - Last Name
  - Address
  - Phone Number
  - Email Address
  - Vital Status
  - Birth date
  - Sex
  - Age in years
  - Race
Benefits of Using i2b2

1. Feature in i2b2 with ability to use an AND not an OR
   - Allows the researcher to be more general
   - Provides more specific results
Benefits of using i2b2

• 2. The ability to query the Medical Record
• 3. Also allows you to review and run past queries from previous sessions.
Benefits of i2b2

4. The speed in which i2b2 can deliver results.
   - Originally 139 patients EMR were searched.
   - i2b2 results were instant.
   - Technology improves research efforts.
     - This infrastructure allows potential for future collaborations.
Challenges of i2b2

- You must be a UAB employee to access.
- Requires familiarity before becoming a proficient user.
- Some patients we found initially were not included in i2b2.
Next Steps for our Research Project

• Conduct phone interviews with patients from i2b2 search.
• Extend study to include future patients seen at UAB.
• Continue biannual i2b2 search to screen for potential study patients.
• Write manuscript to share results.
• Larger Vision: use results to improve clinic teaching related to pregnancy and sexual health education.
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