Healthy Mothers and Healthy Babies:

BRIDGING THE GAP IN PERINATAL CARE FOR WOMEN WITH SPINAL CORD INJURY

Melanie Basso, RN, MSN, PNC(C), Senior Practice Leader-Perinatal, BC Women’s Hospital and Health Centre, Vancouver, BC
Karen Hodge, BSW, Consumer, Social Worker, Sunny Hill Health Centre, Vancouver, BC
LEARNING OBJECTIVES

Our goals:

- Explain the process used to identify gaps in perinatal services for women with spinal cord injury
- Display the tools/resources developed to address these gaps
- Describe the research being conducted to better understand the experience of lactation for women with spinal cord injury
- Provide strategies to apply new knowledge to future clinical experiences with women with spinal cord injury
ETIOLOGY OF SPINAL CORD LESION

- **Traumatic/Mechanical**
  - MVAs: 47 percent
  - Falls: 23 percent
  - Violence/ gunshots: 14 percent
  - Sports accidents: 9 percent

- **Ischemic Injury**
  - Viral myelitis, hematomas, vascular malformations, neoplastic

- **Congenital**
  - Spina bifida, tethered cord, ALS
SPINAL CORD INJURIES

- Quadriplegia: typically above C8
- Paraplegia: typically below T1
- Complete injury:
  - loss of motor and sensory function below the lesion
- Incomplete injury: many variations
  - some preservation of sensory or motor function below the lesion
WHAT WE KNOW

- 330 women with traumatic SCI of childbearing age in the registry within Canada
  - RHSCIR data 21Nov 2013

- The perinatal journey for women with SCI and their families is not a smooth one
PREGNANCY & SCI

- No contraindications to pregnancy
- Excellent maternal and neonatal outcomes
- Pregnancy not known to worsen the outcome or current state of SCI
- No increased risk of fetal anomalies, unless hereditary SC lesion
- Each woman with SCI is unique and requires individualized care
While women with SCI are definitely having babies, there is currently little evidence based published research to guide clinicians in the care of women with SCI during the perinatal periods of pre-conception, pregnancy, labour/delivery & postpartum.
A Brief Intro: how our group came to be

http://www.youtube.com/watch?v=q2iKL2609Gg&list=UUDvZfbRLaWlsP-8uiZcDO6w
THE SPINAL CORD INJURY PERINATAL INTEREST GROUP

Kate McBride (RN)  Melaine Basso (RN)
Dr. Stacy Elliott  Lynsey Hamilton (KT)
Shea Hocaloski (RN)  Melanie Basso (RN)
Chris McBride PhD  Karen Hodge & Family
OUR FIRST STEPS

- A one-day workshop was held in Vancouver, BC in November 2013 with the goal of initiating a collaborative process to address gaps in knowledge and best care practices for perinatal care for women with SCI.

- The workshop was funded by a grant from the Rick Hansen Institute. The overall intent was to produce recommendations and action plans to move the standard of care and consumer educational opportunities forward.
IDENTIFYING AND INVITING KEY STAKEHOLDERS

National Sexual and Reproductive Health Meeting

- Care providers
- Consumers
- Researchers
- Community Partners

- Knowledge Generation Priorities
- Research streams
- Clinical Application priorities
- Maternal/fetal health guidelines
- Sperm Retrieval Guidelines
- Policy Change Priorities
- Communications
  - Medical
  - Community
  - Government
  - Consumers
Prior to the workshop an online survey was conducted amongst identified content experts and stakeholders from across Canada.

Ethics approval was obtained from UBC’s Behavioural Research Ethics Board.

19 respondents (63%) completed the survey.

4 members of the project team conducted an independent review of the survey results to identify the recurring themes.

Together all reviewers reached a consensus of the themes that spanned the perinatal phases.
MAIN THEMES IDENTIFIED

- Lack of Knowledge for both consumers and care providers
- Need for Collaboration both between the consumer and health care providers and amongst health care providers throughout the perinatal journey
- Issues in Access to services and information
RECOMMENDATIONS FROM THE WORKSHOP

- Perinatal care in SCI is a true priority area that requires immediate attention.
- Action must be taken to address the workshop themes through knowledge generation; improved access, and promotion of a collaborative approach to care.
- Workshop participants envisioned a “roadmap” to guide and empower consumers and health care providers (HCP) through the perinatal journey.
CLINICAL CONSIDERATIONS
AUTONOMIC DYSREFLEXIA (AD)

- Uninhibited sympathetic response to strong sensory input below the level of the lesion
  - Headache, sweatiness, flushing, piloerection, nasal stuffiness, blurred vision, “feeling of doom”
  - Sudden rise in Blood Pressure
    - sBP can increase above 200 mmHg!
  - In severe cases: CVA, haemorrhage, MI, death
  - OB: Uteroplacental vasoconstriction
    - Fetal hypoxia and bradycardia

- Most significant medical complication for persons with SCI (Injuries above T6)
AD TRIGGERS

- AD most commonly presents during Labour; however can occur at any time
- Common Triggers
  - Bladder: over-distension, UTIs, catheter insertion
  - Bowel: constipation
  - Skin: one position too long, awkward position, pressure points
  - Heat: unable to sweat below level of injury
  - Uterus: contraction pain
  - Vagina: VEs, episiotomy discomfort
AD VS PRE-ECLAMPSIA

- **AD**
  - Acute onset
  - Synchronous with uterine contractions
  - Normal lab values
  - Urine: No protein
    - +/- norepinephrine
  - Treatment
    - Remove offending stimulus
    - Regional anesthetic
    - Acute anti-HTN therapy

- **Pre-Eclampsia**
  - Variable onset
  - Independent of uterine contractions
  - AbN bloodwork
    - Liver enzymes, platelets, uric acid
  - Urine: (+) Protein
  - Treatment
    - Anti-HTN therapy
    - IV MgSO4
    - Delivery (if severe)

Adapted from Pereira 2003
**AD TREATMENT**

- **Acute Treatment**
  - Identify cause and alleviate
  - Consider Antihypertensive Medications
    - nitro patch, hydralazine
  - Regional anesthesia: spinal or epidural
  - General anesthesia
  - Urgent delivery by AVD or C/S as necessary

- **Recommend**: Early Regional Analgesia in Labour
RISK OF DVT

- There is little or no evidence for providing VTE prophylaxis
- Many clinicians identify women with SCI as being at risk for developing a DVT
- New SOGC Guidelines (2014) do not include SCI as a risk factor
RISK OF UNATTENDED BIRTH

- Plan frequent appointments in the weeks leading up to due date
- Teach women (and partners) to monitor uterine activity (ie feeling for contractions, timing of tightenings, labour vs. braxton-hicks, signs of AD)
- Internal exams or transvaginal US to monitor cervix changes
- Discuss planned induction prior to 40 weeks gestation
PLANNING FOR DELIVERY

- Unless there is an obstetrical indication for c-section, most women with SCI are able to have a vaginal birth.

- Planning includes:
  - Egg crate mattress (prevent skin breakdown)
  - Epidural prior to or early in labour
  - Monitoring for signs of AD
  - Possible need for AVD due to ↓ ability for maternal pushing effort
POSTPARTUM CONSIDERATIONS

- Recovery after delivery (vaginal birth is preferable)
- Reconditioning to resume activities/transfers
- Breastfeeding challenges (depends on level of lesion)
- Resuming medications that were stopped or reduced during pregnancy
- Assess for AD and treat accordingly
- Coping with fatigue/pain while caring for a newborn
- Risk for postpartum depression is ↑
INTERPROFESSIONAL COORDINATED COLLABORATION WITH BOTH OB AND REHABILITATION PROVIDERS

- Important to have a Team Approach
  - Primary Obstetrical Caregiver, Medicine: Hematology, Respirology; Urology; Neurology; Rehab Medicine; Anesthesia
  - Physiotherapy, Occupational therapy
  - Nursing staff
  - Public Health Nurses
  - Social Work
  - Doulas/Postpartum Doulas
  - Family and Social support!

- Detailed Care Plans Very Helpful
NEWLY DEVELOPED RESOURCES
LAUNCH OF OUR CONSUMER-ORIENTED BOOKLET AND BROCHURE

PREGNANCY & Spinal Cord Injury

sexualhealth.sci-bc.ca
Contributed parenting with a disability related content for new Pacific Postpartum Support Society Postpartum Self Help Guide
INTERNATIONAL LACTATION SURVEY FOR WOMEN WITH SCI
PRELIMINARY RESULTS OF SURVEY

Respondants
- 52 women with SCI
- 54%, (28/52) had SCI at or above T6; 24/52 below T6
- 51/52 attempted breastfeeding
- 78% of women with injury above T6 reported insufficient milk production
- Whereas 35% of women below T6 reported the same
  - This was a significant difference.

Results
- Autonomic Dysreflexia (AD) during breastfeeding reported by 38% of women with high level SCI.
- Duration of exclusive breastfeeding was significantly shorter (2.8 mos) in the high level injury group compared to the low injury group (6.5 mos)

Theodor Holmgren; Shea Hocaloski; Lynsey Hamilton; Iris Hellsing; Stacy Elliott; Claus Hultling; Andrei V Krassioukov
SURVEY CONCLUSIONS, SO FAR

• There is scarce and inconsistent research on women’s experience with lactation and breastfeeding following SCI.
• Our results provides data which uncovers the understanding that level of injury may impair women’s ability to breastfeed.
• AD as a complication to breastfeeding is much more common than existing literature would suggest, and this should be addressed in all women with a high SCI who are planning to breastfeed their children.
CASE STUDY
IMPROVED CARE FOR NEW MOMS WITH SPINAL CORD INJURIES

- 29 year old female with T7 AIS-A (ASIA Impairment Scale) since 2011
- Her initial injury was secondary to a motor vehicle. Tragically, in addition to the loss of her mobility, her infant son of two months died in the accident.
- A team of healthcare providers was constructed, including a perinatologist, psychiatrist, OB clinical nurse specialist nurse practitioner, SCI sexual health nurse, rehabilitation nurse, community health nurse, inpatient and community occupational therapists, as well as a social worker.
- This team met three times throughout AA’s pregnancy in order to assess equipment needs, plan for a safe delivery, organize postnatal home personal care, and provide newborn baby support.
- Discharged home in 6 days following delivery with supports in place.
POSSIBLE FUTURE DIRECTIONS FOR OUR GROUP

- Foster connections formed in the workshops to strengthen relationships and collaboration with external partner organizations
- Examine Lactation Survey Results to determine strengths and areas of need to improve care for future moms with SCI
- Develop education materials for health care professionals (i.e. online course for family physicians, health care professional-oriented handouts)
- Pursue further avenues for content dissemination
SMALL POPULATION
BIG IMPACT

 COMMITMENT
is what transforms a promise into reality.
ABRAHAM LINCOLN
OUR HOPE:
HEALTHY MOTHERS WITH SCI + HEALTHY BABIES = HAPPY HEALTHY FAMILIES
OUR CONTACT INFORMATION

- Melanie Basso  RN MSN PNC(C)
  Email: mbasso@cw.bc.ca
  Phone: 604-875-3799

- Karen Hodge  MSW, RCSW
  Email: info@adaptability.ca
  Phone: 604-788-8413