FASD Prevention: Women and Pregnancy

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Session Goals
- What are we trying to prevent and why?
- Who is responsible for prevention?
- What are the strategies for prevention?
- Do the strategies work (evaluation and outcomes) and are they sustainable?

Safest not to drink in pregnancy or planning pregnancy

- No known safe amount or time to drink in pregnancy
- Need to address why women drink, not just the drinking
What are we Trying to Prevent and Why?

- Preventing FASD
- Diagnosis of FASD
- Impact of Alcohol use from a Woman’s Perspective

Preventing FASD

Prenatal exposure puts fetus at risk for brain damage but not diagnostic of FASD

- Complex interaction between maternal alcohol use pattern, maternal biology, fetal susceptibility, non-linear relationship
- Impact of postnatal factors (Perry)
- Incidence 9.1 per 1000 live births, higher in high risk populations
- Economic burden: $344 million annual cost in Canada for individuals under 21 years (Stade)

Diagnosis of FASD

- Multidisciplinary team to determine evidence of organic brain damage and strengths deficits functional profile to link to resources
- Confirmed alcohol is key but birth mothers may not disclose due to stigma
- FASD impacts function across the lifespan with different supports needed at different ages
- Preventing secondary disabilities by interventions
- Lack of diagnostic services for adults with FASD
Impact of Alcohol Use from a Woman’s Perspective

- Who is Drinking Alcohol?
- Addictions in Pregnancy
- Impact on Woman Herself
- Listen to Her Story

Who is Drinking Alcohol?

- 76.8% Canadian women drink
- 15% younger women 18-19 age group are heavy drinkers
- 11% 20-24 age group are heavy drinkers

(2004 Canadian Addictions Survey)

Who is Drinking Alcohol?

- 12-14% of Canadian mothers indicated alcohol use in their last pregnancy
- >90% knew alcohol not recommended in pregnancy

(Doll and Roberts 2006)
Who is Drinking Alcohol?

- 11.6% of pregnant women reported alcohol use currently
- 3.7% binge pattern and 0.7% heavy drinking

(CDC US data 2004)

Who is Drinking Alcohol?

- >90% of women in Alberta aware that no alcohol is best in pregnancy
- 20% admitted to alcohol use during pregnancy
- Knowledge does not equal actions – Why?

(Alberta data Tough 2006)

Who is Drinking Alcohol?

- Older women 30+ years of age, college educated, higher income, consuming alcohol before pregnancy
- Risk by occupation
- Unplanned pregnancy, low self esteem, smoking
- Intergenerational: family history of substance abuse
Who is Drinking Alcohol?

- Less than high school education (80%)
- Poverty (45%) and unemployment (75%)
- Current partner uses substances (25%)
- Currently experiences domestic violence (46%)
- Poor social networks (20-35%)

Addictions in Pregnancy

Recent history:
- Arrested on alcohol related charges 50%
- Had mental health problems 58%
- Involved with child protection in past 3 years 65%

Childhood history:
- In foster care as child 60%
- Abused as a child 88%
- Had a parent with substance abuse issues 88%

Impact on Woman Herself

- Susceptibility to health issues
- Ability to parent
- Risk for subsequent pregnancies with prenatal alcohol exposure
- Life choice decision making
- “Diagnosis for Two”: diagnosis of child with FASD should link back to the birth mother with supports
Listen to Her Story
- Abuse in childhood, in foster care
- Domestic violence, partner substance abuse
- Mental health
- Poverty, housing
- Education lack
- Loss of connection to culture
- No positive support systems

Prevention
- Who is Responsible for Prevention?
- What are the Strategies for Prevention?

Who is Responsible for Prevention?
- Physicians, Health Care Providers, Psychosocial Team
- Collaborative, Multisectorial, Holistic, Cultural Focus
- Women Centered, Listen To The Women’s Stories, What About Their Children
Health Care Providers

Women report they…
- Preferred receiving information about reproductive health by verbal discussion
  - With health care provider 92% but only 37% obtained
  - Compared to pamphlets (74% wanted and 49% obtained)

(Tough)

Health Care Providers

Women report their…
- Preferred sources:
  - Physicians 97%
  - Nurses 83%
  - Midwives 65%
  - Mothers 62%
  - Friends 59%

(Tough)

Health Care Providers

Physicians reported that...
- 94% knew about FASD
- <50% consistently discussed alcohol use with women of child bearing age
- Only 54% felt prepared to care for pregnant women who had substance abuse problems

(Tough 2002 Survey of Physicians and Midwives in Canada)
Health Care Providers

Physicians reported that barriers were:
- Training
- Time
- Financial
- Lack of screening tools
- Lack of knowledge of resources
- Women not disclosing due to stigma
- Stereotyping

(Tough 2002 Survey of Physicians and Midwives in Canada)

Biopsychosocial Team

Need for Multidisciplinary Team Approach
- Opportunity for FASD Networks in Alberta
- Holistic, multisectorial, collaborative, multiple points of contact in reproductive years
- Physicians, mental health, addictions, social workers, employment counselors, housing, etc
- Cultural sensitivity (Masotti: data on Urban Aboriginal women; involving the grandmothers)
- Woman centered plus child focused

What are the Strategies for Prevention?

- Four Levels of Prevention
- Key References on FASD Prevention
- Level 1: Primary, Universal, Raising Awareness
- Level 2: Secondary Targeted “Conversations”
- Level 3: Specialized Prenatal Supports
- Level 4: Postpartum Supports
Four Levels of Prevention

- Primary
  (Universal, raising public awareness)
- Secondary
  (Targeted, for all women of child bearing age and their support networks)
- Tertiary
  (Specialized for women most at risk for an alcohol exposed pregnancy)
- Postpartum supports to maintain positive changes for mother and child

Key References on FASD Prevention

- Informed by a working group of experts in the field
- Public Health Agency of Canada
- Four part model of prevention
- Excellent web based resources

Key References on FASD Prevention

- Double Exposure: A Better Practices Review on Alcohol Interventions During Pregnancy, prepared by Tessa Parkes, Nancy Poole, Amy Salmon, Lorraine Greaves & Christine Urquhart
- www.hcip-bc.org
- Act Now BC Healthy Choices in Pregnancy
- Systematic review of literature and better practice approach to inform policy and point to areas of future research
Level 1: Primary, Universal, Raising Awareness

- Message, Approach and Themes
- Barriers
- Research

Level 1: Message, Approach And Themes

Message of risk of drinking in pregnancy or in planning pregnancy, including what is FASD
- Social marketing: posters, labels, campaigns
- Engagement of broad range of people for social change
- Community development to reduce stigma and blame
- Resources for more information and help
- Develop system of support across sectors

Level 1: Message, Approach And Themes

- Should benefit ALL and be a starting point for discussion
- Where: health centers, community programs, social service agencies, restaurants and bars, media, school curriculum under healthy life choices and reproductive health
Level 1: Barriers

- Awareness does not mean change in behaviors and actions
- No clear pathway for supports in every community
- May increase not wanting to disclose due to stigma
- May not reach most at risk due to isolation, mental health issues, unable to make change alone in addressing the complex “why women drink” factors

Level 1: Barriers

- Over-focus on women as the problem and not emphasizing the benefits to her health and a healthy pregnancy outcome
- Responsibility of the woman’s support network and partner not always emphasized
- Cost and benefit not measurable

Level 1: Research

- Canada Northwest FASD Research Network (www.canfasd.ca)
- NAT on Prevention: lead agency
  Saskatchewan Prevention Institute, Robin Thurmeir
- Electronic library catalogue of all primary messaging resources
Level 1: Research

- Limited evaluation of effectiveness, who listens and what actions
- Research planned on social marketing to change behavior
- Tools to evaluate outcomes need to be used

Level 2: Secondary Targeted “Conversations”

- Message, Approach and Themes
  - Method - 3 Tiers
  - Barriers/Research

Level 2: Message, Approach and Themes

Conversations brief counseling with ALL women and girls of child bearing age AND their support networks

- Themes:
  - Pregnancy planning and contraception
  - Asking about alcohol use with screening tools or conversation
  - Asking about stressors
  - Asking about support systems
**Level 2: Message, Approach and Themes**

Incorporate into ALL encounters

- **Who and where, multiple touch point with consistent messaging**
  - Regular health care: physicians and team members in health care networks
  - School based: L Baydala Alexis Project
  - Community workers: Saskatchewan Speakers Bureau and Youth for Action Project
  - Pharmacy: Pharmacists engaging with women, Alberta project

**Level 2: Method - 3 Tiers**

Tier 1 - Screening

- Use of tools: TACE, TWEAK, AUDIT, MAST asked directly or computer based
- Conversations: nonjudgmental, supportive, respectful, build trust and relationships, remove stigma of disclosure, cultural and contextual

Tier 2 - Brief Counseling

- Screen for readiness to change
- FRAMES: (Miller) Feedback on current alcohol use, emphasis on client Responsibility, clear Advice to make change, Menu of options, Empathy, and Support
- 5 A's: (Whitlock) Assess, Advise, Agree, Assist, Arrange
- www.MDcme.ca learning module for physicians
Level 2: Method - 3 Tiers

Tier 3 - Motivational Interviewing

- Based on goal setting with the woman and self-efficacy with focus on her well-being as well as a healthy birth outcome
- Based on stages of change theory; (Prochaska) precontemplation, contemplation, determination and preparation, action, maintenance, relapse
- Need time and skill set

Level 2: Method - 3 Tiers

Tier 3 - Motivational Interviewing

- Need network of resources to connect to: mental health, addictions, enhanced resources for women, housing and shelters, dealing with domestic violence, child assessment and care (previous child with FASD?)
- The HELP guide for professionals through Enhanced Services for Women [www.aadac.com](http://www.aadac.com)
- DVD from ACT Now BC through [www.hcip-bc.org](http://www.hcip-bc.org)

Level 2: Barriers/Research

- Need for training for professionals and to measure uptake into practice – Alberta experience in tool development
- No one screening tool used consistently: research supports the TACE, self report screen followed by interview better than direct asking
- No one size fits all approaches, need to consider needs of population, community and cultural differences
Level 2: Barriers/Research

- Women more likely to abstain if partners and supports reduced drinking: modeling, encouragement, engaging in healthy choices together
- Women more likely to abstain if white, married and had post secondary education
- Brief interventions reduces use of alcohol in pregnancy but control group also reduced (Chang 2005) impact of being in a research project

Level 2: Barriers/Research

- Brief interventions increase use of contraception (O’Connor and Whaley 2007)
- Long term impact of Brief Interventions on sustained alcohol reduction or abstinence not known and factors of stress may change with subsequent pregnancies
- Studies did not set the intervention in the context of the woman’s life

Level 3: Specialized Prenatal Supports

- Message, Approach and Themes
- Specialized Prenatal Supports
- Examples of Specialized Prenatal Supports
- Research
**Level 3: Message, Approach and Themes**

Specialized and holistic supports for pregnant women or at risk of becoming pregnant and are using alcohol

- Woman centered
- Accessible, respectful, culturally relevant, comprehensive care across systems
- Case manager, mentor, trusting relationship, single point of contact
- Not mandated – woman wants help
- Integrated with services for their children (McMaster study)

**Level 3: Specialized Prenatal Supports**

**Elements of program**

- Crisis intervention
- Psychosocial and substance abuse assessment
- Individualized treatment plan development with the client
- Home visitation
- Parenting capacity and education
- Infant and child development assessment
- Transportation to appointments
- Help with financial
- Housing and legal issues

**Level 3: Specialized Prenatal Supports**

**Elements of program**

- Dealing with domestic violence
- Connecting to addiction treatment that is woman focused in the context of their family and retaining custody of their children
- Access to health needs including preconception and prenatal care
- Help in dealing with healing from past issues that may be multi-generational
Level 3: Examples of Specialized Prenatal Supports

P-CAP Parent Child Assistance Program, Theresa Grant, Seattle Washington

- Mentorship model established 1991 based on relationship building
- Home visitation with 3 years intensive supports
- Entry criteria of high risk substance abusing mothers who are pregnant or 6 months postpartum
- Staff of paraprofessionals who have overcome similar experiences

- Research has shown cost effectiveness compared to cost to support 1 individual with FASD in their life; 65% had reduced risk at exit from program
- Improved maternal physical and mental health
- Improved parenting, more permanent child custody
- Less pregnancies in succession and more access to contraception

- Multiple mental health comorbidities
- Many of the women are FASD themselves but never diagnosed
- Women with FASD need more supports: external brain across their life not just 3 years, shift from won’t to can’t by others, help to access diagnosis (Step by Step CSS Edmonton)
**Level 3: Examples of Specialized Prenatal Supports**

Examples based on P-CAP model

- **First Steps, CSS Edmonton, Alberta**
  - Use professional with social work background
  - Recent evaluation by Rasmussen, Badry, Hennevekd

- **StopFAS Manitoba**

- **Sheway, Vancouver, B.C. specialized delivery**

- **Breaking the Cycle, Ontario (Motz 2006)**
  - [www.breakingthecycle.ca](http://www.breakingthecycle.ca) mother and child

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**Level 3: Research**

- Failed to find evidence that home visitation reduces risk of continuing drug or alcohol use
- Definite benefits included increased attendance in addictions programs
- Improved contraception use
- Reduction in non-voluntary foster care

Cochrane review of the home visitation model (2005)

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**Level 3: Research**

- Many of the evaluation reports were of poor methodology and did not detail the drug and alcohol treatment component or provide long term follow up of clients: small sample sizes: different populations
- Qualitative research and interviews with women and the mentors support the benefit of the programs

Cochrane review of the home visitation model (2005)
**Level 3: Research**
- Points to the need for more rigorous research with consistent methods: Canada Northwest FASD NAT on Interventions with high risk women

Cochrane review of the home visitation model (2005)

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**Level 4: Postpartum Supports**
- Message, Approach and Themes
- Examples of Postpartum Supports
- Target Audience
- Barriers
- Research

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**Level 4: Message, Approach and Themes**
To initiate or maintain positive changes for mother AND child after delivery (Woman focused)
- Prevent postpartum relapse
- Continue with supports around addictions
- Health maintenance including nutrition, exposure to violence, healthy support networks
- Dealing with stress of child rearing and prevention of child abuse
- Recognizing and help with postpartum depression
Level 4: Message, Approach and Themes

To initiate or maintain positive changes for mother AND child after delivery (Child focused)

- Access to basic health needs and appropriate stimulation and protection from violence
- Developmental screening and access to Early Interventions
- If alcohol exposed, monitor for FASD and refer to team for assessment at appropriate time

Level 4: Examples of Postpartum Supports

- Fir Square, Crab Tree, Sheway in Vancouver
- Breaking the Cycle, Toronto and New Choices, Hamilton, Ontario
- Incorporated into First Steps in Alberta
- StopFAS and Interagency FASD Manitoba
- Intertribal Health Authority Vancouver Island using postpartum discussion approach based on OAR (Own, Act, Reflect)

Level 4: Research

- Involved meta analysis of integrated treatment programs for substance using women and their children
- Effectiveness and moderating factors of treatment outcome
  - Review of 119 studies
  - Presented at International FASD Conference, March 2009
- To be published

CIHR study from McMaster 2007-2008, Niccols et al
Level 4: Research

- Traditionally there is a disconnect between women’s health, addictions services and children’s services
- Integrated programs offering services in centralized setting for both woman and child compared to standard care: reduced maternal substance use and longer length of stay in support program with moderate effect size for both

CIHR study from McMaster 2007-2008, Niccols et al

Level 4: Research

- Improved maternal empathy at 3 months and child’s social competency at 6 months
- Need for better design study, larger samples. More longitudinal data, also qualitative information

CIHR study from McMaster 2007-2008, Niccols et al

Next Steps

Do The Strategies Work?
Where To From Here?
Do The Strategies Work?

- Project evaluation
- Measuring outcomes and replication in other sites
- Sustainability of outcomes over time
- Cost effectiveness compared to cost of FASD across the lifespan
- Informing policy and public attitudes

Where To From Here?

Examples of Better Practices are available but need:

- Replication in different settings and subpopulations
- Development of standard measures of outcomes and evaluation methods
- To connect clinical practice to research and back to clinical practice (Knowledge Transfer)

Where To From Here?

Examples of Better Practices are available but need:

- To not lose the cost of FASD across the lifespan in both dollars and personal burden in analysis of cost benefits of prevention programs
- To focus on “WHY” women drink and not just the drinking
- To consider woman, child and family
Where To From Here?

Examples of Better Practices are available but need:

- To engage women in what is working and not
- To engage with Aboriginal women and leaders in understanding their needs (Honouring Ourselves and Healing Our Pasts (Salmon & McDiarmid)) and in research
- Participation in research: Canada Northwest FASD Research Network

Reference

- Contact Information
- Source Material

Contact Information

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Source Material


Source Material

- Tough, S et al:
  - Attitudes and approaches of Canadian providers to preconception counseling and the prevention of Fetal Alcohol Spectrum Disorders Journal of FAS International 2005: 3e 3

Source Material

- Tough, S et al: (continued)
  - Are women changing their drinking behaviors while trying to conceive? An opportunity for preconception counseling. Clinical Medicine and Research 2006: 4(2) 97-105
Source Material

- Alberta Health Services AADAC: Services for Women: www.aadac.gov.ab.ca

For Information on Upcoming Sessions in the Series: www.fasd-cmc.alberta.ca

Please Take the Time to Fill Out The On-Line Evaluation

Thank You!