South-Eastern Norway Regional Health Authority Resource Center for children with prenatal alcohol/drug exposure

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Neuropsychologist
Overview

1. The Norwegian health system
   - Sørlandet Hospital, Arendal

2. Prenatal drug exposure
   - Diagnostic method
     - Prevalence in Norway

3. Regional resource center
   - Why in Sørlandet Hospital – Arendal/Background

4. Aim and directives of the Regional Resource Center for children with prenatal alcohol or other drug exposure
   - Educational courses
   - Diagnostic clinic – multidisciplinary assessment
1. The Norwegian health system
Sørlandet Hospital, Arendal
2. Prenatal alcohol/drug exposure

Diagnostic method and prevalence of FASD/PDE in Norway
Prenatal alcohol/drug exposure

• FAS – Fetal Alcohol Syndrome (ICD-10: Q86.0)

• FASD: Fetal Alcohol Spectrum Disorder (including FAS).

No diagnostic code related to the effect of other prenatal drug exposure (PDE) past the neonatal period.
Diagnostic methods/systems: Bertrand et.al. 2004; Hoyme et.al. 2005; Chudley et.al. 2005, Astley et.al. 2013 (validation study); Landgraf et.al. 2013 – German guidelines)
The 4-Digit Diagnostic Code (1997)

The description of FASD is based on the presence and degree of 4 key criteria:

1. Growth retardation
2. FAS facial features
3. CNS abnormalities/dysfunction
4. Degree of alcohol exposure

http://depts.washington.edu/fasdPN/htmls/4-digit-code.htm
4-Digit diagnostic code

Child with Moderate growth restriction, severe FAS facial features, definite CNS dysfunction and alcohol exposure indicating high risk during pregnancy.

The 4-Digit Diagnostic Code 3444 inserted in the grid is one of twelve 4-Digit Codes that meet the diagnostic criteria for FAS.
Prevalence: How many children are there in Norway with FASD/PDE?
Prevalence

- 0,5-1,5 pr. 1000 FASD?
- White paper 30 (2011): 60-120 FAS,
- 600-1200 FASD?

These numbers may be an understatement
(45% of Danish women and 25% of Norwegian women confirms some alcohol consumption during pregnancy (Andersen, 2012; Alvik, 2006)

- Women are older before first pregnancy – well established pattern of alcohol consumption

• Prevalence of Prenatal Drug Exposure (other than alcohol)
  - Unknown
  - Estimate: 30-60 children yearly?
Children adopted from East Europe to Sweden

- 71 children adopted to Sweden.
- 52% FAS/pFAS/ARND
- 23% learning disabilities/mental retardation
- 9 % Autism
- 51 % ADHD
- 34 % Developmental coordination disorder

Conclusion

- Prevalence numbers in Norway are uncertain
- Larger and well designed studies are needed
3. Regional Resource Center –
Prenatal alcohol/drug exposure.

• Why in Sørlandet Hospital, Arendal?
• Background
• Aim and directives
Why in Sørlandet Hospital – Arendal?

- Department of child neurology and rehabilitation has worked with FASD since 1996.

- Referrals from: Family doctors in collaboration with the Child protective services, adoptive- foster- and biological parents.

- One of few departments focusing on older children.

- Educational courses aimed at medical doctors, psychologists, primary health services, parents/guardians
2005: The Directorate of Health established an Expert group:

- “there is a need for a team with specialist competence regarding alcohol during pregnancy that are able to diagnose FAS/FAE”.

2011 White Paper 30 (A unified drug policy)

- Pointed to lack of diagnosis of FASD/PDE
- Interventions needed for this group of vulnerable children.
Is a center really needed?

• Yes – we think so!
• The children that nobody wants?
• Complex problems
• Challenging diagnostic process
• Few Norwegian scientific papers
• No studies on interventions/treatment in Norway
• Link between FASD/PDE research and clinic
Application sent from Sørlandet Hospital to the South-Eastern Health Authority in November 2012


Established September 1st. 2015, official opening 27th November 2015.
1. Primary Aim
   - collect, systematize, and share knowledge regarding the diagnostic process, assessments, and interventions

   - This will be achieved through:
     - Educational courses
     - Initiate the development of guidelines for the diagnostic process, assessment and follow-up
4. Aim and directives cont.

Establish a network for health professionals who perform clinical assessments of children with prenatal alcohol or prenatal drug exposure.

Teaching community health workers how to identify, follow-up and provide interventions to children with FASD.

Develop educational material that will be used to train local community health workers.
4. Aim and directives cont.

- Evaluate and share knowledge about relevant intervention / treatment methods
- Initiate multi-center research projects related to FASD
- External funding will have to be obtained
Educational courses 1-2

1. **Educational seminars** aimed at community service providers

2. **Diagnostic courses** aimed at medical doctors (general practitioners, neurologists, pediatricians, child psychiatrists) and psychologists (clinical and neuropsychologists).
Educational courses 3-4

3. **Individual patient courses** are developed and targeted to a specific child with FASD/PDE.

4. **Intervention seminars** aimed at both community and specialist health care professionals as well as special educators.
Diagnostic clinic

- Primarily local patients
- Will accept referrals from the rest of the South-Eastern Health Region
- Diagnostics and assessment will be done in close collaboration with those health professionals that are to follow the patients locally.

Local health professionals are welcome to participate during the assessments.
Referrals

- Children 2-18 years of age
- Referral from the specialist health care services (hospital departments)
- Confirmed alcohol/drug exposure
- Informed consent
Clinical evaluation

- In- and outpatient services
- Admitted to the Pediatric ward
- Feedback: Families prefer to be admitted to the hospital and go through all assessments during 2-3 days rather than outpatient services requiring several visits.
Multidisciplinary team

- 100% Head of department/senior researcher
- 100% Clinical neuropsychologist
- 50% Child Neurologist/senior researcher
- 50% Social worker
- 25% Pediatric physiotherapist
- 20% Child Psychiatrist
- 70% Secretary
Multidisciplinary assessment
Social Worker

• Establish contact with the family at time of referral
• Adaptive Behaviour assessment with the Vineland adaptive behaviour scales (VABS-II), interview. (Crocker et al., 2009; Streissguth et al., 2004; Astley, 2013).
• Reduced adaptive behaviour relative to general cognitive ability (Streissguth, et.al. 1996)
FASD and adaptive behaviour

- Vineland adaptive behaviour scale:
- Comparably reduced across the FASD spectrum

Susan Astley et.al. 2013
Mutidisciplinary assessment
Child Neurologist

- Neurological examination
- 4-digit code assessment (child neurologist)
- MRI
- Genetic screening
Correlation between FASD and epilepsy – what do we know?

Thorsten Gerstner MD
Neuropediatrician
Sørlandet Sykehus, Arendal, Norway

• Seizures are observed with a frequency of 3–21% in children with fetal alcohol spectrum disorders (FASD).

• However, seizure types and electroencephalography (EEG) features are poorly described.

Camfield & Camfield, 2015; Berg, 2010; Nicita, 2014
Publications on this?

- **Nicita F et al.** *Seizures in FASD: evaluation of clinical, electroencephalographic and neuroradiological features in a paediatric case series.* Epilepsia 2014

- **Sun et al.** *Binge Drinking During Pregnancy and Risk of Seizures in Childhood: A Study Based on the Danish National Birth Cohort.* Am. J. Epidemiol. 2009

- **Bell SH.** *The remarkably high prevalence of epilepsy and seizure history in fetal alcohol spectrum disorders.* Alcohol Clin Exp Res. 2010

- **Cassano et al.** *Risk of febril seizures in childhood in relation to maternal cigarette smoking and alcohol intake.* Am. J. Epidemiol. 1990

- **Vestergaard et al.** *Prenatal exposure to coffee, cigarettes and alcohol an the risk fo febril seizures.* Pediatrics 2005

Publications on this?

- These 6 publications are all we know about the correlation between epilepsy and FASD.

- Nicita from 2014 is the only one investigating the characteristics of seizures and EEG findings in patients with FASD – with a very limited number of children.

- To improve the knowledge of clinicians who are managing patients with FASD, the aim should be to get a systematic overview regarding this important neurological issue.
And we?

- All of our patients undergo a standardized EEG registration: "FASD protocol"

- A standard 23 channel EEG assessment which takes 2 hours to complete. EEG electrodes are placed according to international 10-20 system. Simultaneous video recording.

- The assessment includes hyperventilation and photostimulation and a period of 30 minutes with closed eyes
Clinical neuropsychologist

• Primary disabilities
  – include intellectual disability and learning disorders (Lebel et al., 2012; Kodittuwakku, 2009).
  – even without global cognitive impairment, neuropsychological deficits are still prevalent (Quattlebaum, 2013)
  – deficits in attention, concentration, and impulse inhibition (Olson et al., 1998)
  – variability in functioning from day to day
<table>
<thead>
<tr>
<th>Cognitive domain</th>
<th>Test</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>General cognitive ability</td>
<td>Wechsler Intelligence Scale for Preschool children (WPPSI-IV)</td>
<td>2-7</td>
</tr>
<tr>
<td></td>
<td>Wechsler Intelligence Scale for Children (WISC-IV)</td>
<td>6-16</td>
</tr>
<tr>
<td></td>
<td>Wechsler Adult Intelligence Scale (WAIS-IV)</td>
<td>16-18</td>
</tr>
<tr>
<td>Attention/executive function</td>
<td>NEPSY-II: Animal Sorting, Auditory Attention and Response Set, Inhibition, and Statue (Rasmussen et al., 2013)</td>
<td>2-16</td>
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<tr>
<td></td>
<td>Trail Making Test 1-5 (Glass et al., 2013) and Color-Word Interference Test (Delis-Kaplan) (Astley et al., 2009)</td>
<td>6-18</td>
</tr>
<tr>
<td>Language</td>
<td>NEPSY-II: Comprehension of Instructions (Rasmussen et al., 2013), Phonological Processing, Repetition of Nonsense Words, Word Generation (Glass et al., 2013).</td>
<td>2-16</td>
</tr>
<tr>
<td>Visual-spatial processing</td>
<td>Beery-Buktenica Developmental Test of Visual-Motor Integration (Astley et al., 2009)</td>
<td>2-18</td>
</tr>
<tr>
<td></td>
<td>NEPSY-II: Arrows, Geometric Puzzles, Picture Puzzles.</td>
<td>2-16</td>
</tr>
<tr>
<td>Sensorimotor</td>
<td>NEPSY-II: Fingertip Tapping, Imitating Hand Positions, and Visuomotor Precision.</td>
<td>2-16</td>
</tr>
<tr>
<td>Social perception</td>
<td>NEPSY-II: Affect Recognition and Theory of Mind</td>
<td>2-16</td>
</tr>
<tr>
<td>Learning and memory</td>
<td>NEPSY-II (Rasmussen et al., 2013)</td>
<td>2-16</td>
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<tr>
<td></td>
<td>Wechsler Memory Scale III will be used for those between 16 and 18 years of age.</td>
<td>2-16</td>
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<tr>
<td></td>
<td>Rey Complex Figure Test and Recognition Trail (Astley, 2009)</td>
<td>6-18</td>
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</table>
Multidisciplinary assessment
Child Psychiatrist

• Comorbid disorders are frequent in children with FASD/PDE and increase with age (O’Connor et al., 2009; Pei et al., 2011).

• Norway: 47 children with FAS and 50 children with PDE.
  – FAS: 89% ADHD, PDE: 100% ADHD.
    » Elgen et al. 2007
Child physiotherapist

• Children with FASD have increased risk of gross motor deficits (Lucas, et.al. 2014)
• Poorer fine-motor abilities (Doney et al., 2014) (Duval-White et al., 2013).
• Movement Assessment Battery for Children, second edition (MABC-2) (Henderson et al., 2007)
• Motor Function Neurological Assessment (MFNU) (Stray et al., 2009).
Why it is so important to diagnose children with FASD at a young age.
Long term prognosis
Secondary disabilities (n=415 adults with FAS/FAE)
(Streissguth et.al. 1996)

- Psychiatric disorders 94%
- School dropout 43%
- Criminal record 42%
- Institutionalized 60%
- Alcohol/drug abuse 30%
- Unemployed 80%
- In need of social services 80%

Increased risk of secondary disabilities in those with IQ over 70.
«Closer to home»: Berlin

- 37 adults, mean age 20.5 years
  - 22 FAS, 15 FAE
  - Lower IQ and more behavioural problems than controls
  - 70.5% dependent on help on a day to day basis (could not live independently)
  - Only 13.5% obtained a degree after secondary education

Spohr et al. 2008
Results from Sweden (Ragnmar et.al. 2015)

Adults (18-47 years of age)
FAS n= 79, Controls 3160, (122 fostercare)

<table>
<thead>
<tr>
<th></th>
<th>FAS</th>
<th>Controls</th>
<th>Fostercare</th>
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<tbody>
<tr>
<td>Special education</td>
<td>25%</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>49%</td>
<td>85%</td>
<td></td>
</tr>
<tr>
<td>Disability</td>
<td>31%</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Social services</td>
<td>28%</td>
<td>3.4%</td>
<td></td>
</tr>
<tr>
<td>Foster care</td>
<td>81%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Psychiatric problems</td>
<td>33%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sentenced</td>
<td>28%</td>
<td>20%</td>
<td>55%</td>
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<tr>
<td>In need of medication (sleep, anxiety)</td>
<td>57%</td>
<td>26%</td>
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</tbody>
</table>
Protective factors  
(fewer secondary disabilities)

- FAS
- Diagnosed before 6 years of age
- Stable home without violence
- At least 2.8 years in each foster care placement.
- Developmental delay recognised (received help).
- Basic needs met for at least 13% of life

- Streissguth et al. 1996.
"Self-evaluation of Health-related Quality of Life"
• Canadian study

• 126 children with FASD 8-21 years

• Interview about health-related quality of life: sight, hearing, language, cognitive function, pain, emotion

• Results: values between 0 and 1, the latter being perfect health.
Results

- 0.47 for FASD
- 0.93 controls
Same interview performed in children born with extremely low birth weight (below 1000 grams) aged 12-16 years.

This group had a high prevalence of disabilities (reduced sight, deafness, cerebral palsy, learning disorders, low IQ)

Mean score 0.87

Stade, 2006.
Ethical challenges

• Ethical challenges
• Mother-child relationship
• Whom is to know about the diagnosis?
Thank you for your attention.

Any questions?

fetal alcohol syndrome. cured.

Learning disabilities, behavioral problems and other effects of Fetal Alcohol Syndrome are 100% preventable. Simply don’t drink during pregnancy. mofas.org