Prenatal alcohol and adverse childhood experiences: impact on neurodevelopmental outcomes

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Professor of Public Health
Overview

- Introduction to prenatal alcohol exposure and FASD
- Prevalence of PAE and FASD in the UK and elsewhere
- Early traumatic experiences and neglect
- Series of studies looking at the combined and separate effects of PAE and ACE
  - Systematic reviews
  - Clinical population
  - Survey
  - Lab studies
  - Qualitative
- Conclusions
Acknowledgements

DR RAJA MUKHERJEE

DR ALAN PRICE
Foetal Alcohol Spectrum Disorder (FASD)

- Range of neurodevelopmental conditions caused by prenatal exposure to alcohol
- Alcohol is a teratogen
- Advice on drinking in pregnancy has been inconsistent at best
- There was a time when doctors recommended alcohol in pregnancy (1960s)
- NHS advice until 2016 was ambiguous
FASD – the range of diagnoses

- Foetal Alcohol Syndrome (FAS – about 10% of cases)
  - Identified in 1970’s
  - Facial features
  - Low birthweight, microcephaly
  - Low IQ, learning difficulties
  - Cognitive and behavioural problems

- The wider range, AKA FASD/ARND/NDPAE (about 90% of cases)
  - No craniofacial abnormalities
  - May be some physical problems
  - IQ tends to be in the average range
  - Cognitive and behavioural problems
Presentation – mostly brain-based

- **Physical signs include:**
  - Low birthweight
  - Small head/brain – microcephaly
  - Small stature
  - Craniofacial anomalies including 3-4 facial features
  - Problems with organs, joints

- **Neurodevelopmental presentation:**
  - Poor academic achievement
  - Sensory dysfunction
  - Problems with emotional regulation / arousal
  - Executive dysfunction (planning, attention)
  - Hyperactivity, impulsivity
  - Difficulty with mathematics and other abstract reasoning
  - Difficulty with daily living, adaptive functioning
  - Problems with social communication
A spikey profile
Alcohol consumption in pregnancy

- UK estimated 4th highest rate of alcohol consumption in pregnancy
  - Republic of Ireland 60.4%
  - Belarus 46%
  - Denmark 45.8%
  - United Kingdom 41.3%
  - Russia 36.5%
  - USA 14.8%

Meta-analysis Popova et al, 2017
Estimated prevalence of FASD

- Problem with quality of evidence in UK
- Best data from analysis of longitudinal cohort – McQuire et al (2018)
- Estimates prevalence of FASD somewhere between 6% and 17%
- Active case ascertainment (ACA) – gold standard
  - Being conducted now by University of Salford
  - Small scale – Greater Manchester only

ACA in other countries:
- USA 3-4%
- Croatia 4-6%
- South Africa 6-20%
- Italy 2-4%
- Norway 3%
- Canada 3%

Meta-analysis Popova et al, 2017
Low to moderate exposure - controversy

- Evidence for harm caused by low to moderate exposure has been inconsistent, leading to ambiguous advice / newspaper headlines

- Impact of PAE is moderated by genetics, metabolism of alcohol, age of mother, number of pregnancies, diet of mother, genetics of biological father

- Randomised trials are not possible, so much of what we know comes from observational studies

- Confounding variables – people who drink a little tend to be better off than people who don’t drink, so this can skew the data

- Mendelian randomisation studies show no alcohol better than small amount
Early traumatic experiences

Trauma
• Physical, sexual or psychological abuse
• Neglect, privation or abandonment
• Death or imprisonment of a parent
• Witnessing violence

Outcomes
• Learning difficulties
• ADHD
• Speech and language
• Relationship problems
Effects of neglect

• Romanian study: being adopted after 6 months → developmental delays. Even if some catch up seen not as good as those adopted < 6 months (Rutter et al 1998)
• Neglect associated with difficulties with behaviour issues, emotional issues, cognitive problems, medical sequelae which remain later in life (Kauffmann 2009)

Overview—De Bellis 2005

○ Romanian study showed significant neglect
○ Tizard and Hodges 74 and 77 with lesser levels of neglect showed improvement with no significant cognitive deficits
○ PTSD common
○ Effects on myelination and corpus collosum found but studies never controlled for pre-natal alcohol
Development of attachment (Schaffer and Emerson)

• 0 - 6 weeks: Asocial; in both social and non social situations will make responses

• 6 weeks – 7 months: Indiscriminate attachment; Begin to seek social contact but from anyone. By 3 months a preference towards main carer is being established

• 7-9 months: Specific attachment; preference for one person established

• 10 months +: Multiple attachments: Babies begin to develop attachments and can transfer security

Slide credit: Raja Mukherjee
Attachment styles

Secure
Avoidant
Ambivalent
Disorganised

Reactive Adjustment Disorder
- Inhibited
- Disinhibited

http://www.practicenotes.org/v19n3/identifying.htm

Slide credit: Raja Mukherjee
Surrey and Borders Partnership
Attachment and PAE/ FASD – systematic reviews

• Higher rates of insecure attachment in children with FASD (Molteno et al., 2014)
  • abuse and neglect, leading to a disruption of the normal parent/child relationship
  • as a result of the permanent brain damage from alcohol exposure in utero (Burd et al., 2003).

• 8 Studies (2 included diagnosed FASD)
  • 2 FASD studies: no effect
  • PAE studies: mixed findings on attachment with most showing more insecure attachment (disorganised type) irrespective of initial parenting

Wray, Palod, Mukherjee (unpubl);
Bamidele, Cooper, Mukherjee, Cook, (in prep)
Relationship Between PAE and Attachment

Wray, Palod, Mukherjee (unpubl); Bamidele, Cooper, Mukherjee, Cook, (in prep)

- Some improvement with good consistent parenting
- All studies had methodological issues
- None stratified by intellectual level or level of exposure
- Needs more research

(O'Connor, Kogan, & Findlay, 2002)
Attachment and Autism / ID research

De Schippers 2006: Dutch Study of attachment behaviours
  ◦ Some attachment behaviour established
  ◦ Variations in the attachment behaviour seen

Schuengel 2007 attachment to parents with Child ID
  ◦ Attachment behaviour less clear
  ◦ Percentage children secure attachment lower

De Schippers 2008: Observation study Dutch Schools
  ◦ Secure attachment behaviour less characteristic
  ◦ Higher the developmental age the more attachment behaviour seen

Rutgers (2007) Attachment and parenting comparing ASD, LD and normal controls,
  ◦ Parenting not found to be cause of attachment problems in ASD group
Attachment Summary

• Limited studies with FASD

• Where have been done
  • More likely to be disorganised
  • Irrespective of parenting

• Limitations by level of disability

• Damaged underlying brain means typical attachment not always seen

• Biology appears to be influenced prenatally and leads to vulnerability that is impacted by experience

• Not always the parents fault

Slide credit: Raja Mukherjee
Impacts of Trauma and PAE: systematic review

- What is known about the impact of both traumatic experiences and FASD together on cognitive and behavioural development in children?

- 5 papers in final synthesis

Exploring the impact of Neglect and FASD

Slide credit: Raja Mukherjee
Exploring the impact of Neglect and FASD

Slide credit: Raja Mukherjee

PAE
Both
Neglect

Outcomes
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>n</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyter 2012 (quasi-experimental, n=106)</td>
<td>Clinically significant language delays and social communication difficulties in both groups.</td>
<td>‘Both’ group had more language delays than ‘just trauma’ group.</td>
<td>No significant difference between groups in social communication.</td>
</tr>
<tr>
<td>Coggins et al 2007 (cross-sectional, n=573)</td>
<td>Substantial comorbidity between PAE and trauma.</td>
<td>Sample as a whole had poor language and social communication.</td>
<td>No relationship between trauma and severity of outcomes.</td>
</tr>
<tr>
<td>Henry et al 2007 (quasi-experimental, n=274)</td>
<td>‘Both’ group had more delays/deficits in: attention, memory, language.</td>
<td>No difference between groups in: visual processing, motor control.</td>
<td>‘Both’ group had lower verbal, non-verbal and composite IQ scores.</td>
</tr>
<tr>
<td>Koponen et al 2009 (cross-sectional, n=38)</td>
<td>Full sample had high levels of cognitive and behavioural problems.</td>
<td>Being older when removed from abusive home predicted more cognitive and behavioural problems.</td>
<td>More traumatic experiences predicted attachment and behavioural problems, but not cognitive deficit.</td>
</tr>
<tr>
<td>Koponen et al 2013 (qualitative, n=34)</td>
<td>Children who lived with abusive parents appeared to have more difficulties with attachment, concentration, hyperactivity and developmental delay than those adopted at birth.</td>
<td>Difficult to draw any conclusions due to study design.</td>
<td></td>
</tr>
</tbody>
</table>
Natural experiment using National Clinic data: measures used

• 4 Digit FASD analysis
• (3d Facial recognition)
• Semi structured FASD history Questionnaire*
• SCQ*
• DISCO*
• ADHD Screening Questionnaire*
• DBCL
  • Parent
  • Teacher
• Vineland II

• Short Sensory Profile*
• WAIS IV / WISC IV
• Delis Kaplan Executive Function Tests
• CELF 4 (3 initially)
• TROG
• Social Interpretation cards
• PSI
• CCC
• BRIEF

*used in this analysis
Mukherjee et al. (2019) Alcohol. 76:23-28
### Sample characteristics

Mukherjee et al. (2019) Alcohol. 76:23-28

<table>
<thead>
<tr>
<th>Age group</th>
<th>Sex</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than 10y</td>
<td>Male</td>
<td>19</td>
<td>19</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 to 14y</td>
<td>Male</td>
<td>23</td>
<td>14</td>
<td>37</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 to 19y</td>
<td>Male</td>
<td>7</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>greater than 20y</td>
<td>Male</td>
<td>8</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>57</td>
<td>39</td>
<td>96</td>
</tr>
</tbody>
</table>
Sample characteristics

Mukherjee et al. (2019) Alcohol. 76:23-28
ADHD is equally prevalent across the groups: 74%, n=96

Mukherjee et al. (2019) Alcohol. 76:23-28
Developmental outcomes: ASD

ASD/SCD is equally prevalent across the groups: 68%, n=91

Mukherjee et al. (2019) Alcohol. 76:23-28
Percent with probable/definite difference on SSP profiles, by neglect

Mukherjee et al. (2019) Alcohol. 76:23-28
Early Maltreatment on Development: study Using Vineland Adaptive Behavior Scales-II

- 57 adopted and foster children with a psychiatric diagnosis of reactive attachment disorder
- Average adaptive behaviour composite score (age equivalency) of 4.4 years
- Average chronological age 9.9 years

(Becker-Weidman 2009)
<table>
<thead>
<tr>
<th></th>
<th>No neglect</th>
<th>Neglect</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample size</td>
<td>N=37</td>
<td>N=44</td>
<td></td>
</tr>
<tr>
<td>Chronological age</td>
<td>12.1 (10-14)</td>
<td>12.1 (10.5-14)</td>
<td></td>
</tr>
<tr>
<td>Receptive language</td>
<td>3.7 (3.01-4.39)</td>
<td>3.7 (2.86-4.48)</td>
<td>0.956</td>
</tr>
<tr>
<td>Expressive language</td>
<td>5.5 (4.85-6.24)</td>
<td>6.2 (5.21-7.17)</td>
<td>0.302</td>
</tr>
<tr>
<td>Written language</td>
<td>8 (7.11-8.82)</td>
<td>8.5 (7.78-9.29)</td>
<td>0.312</td>
</tr>
<tr>
<td>Personal daily living skills</td>
<td>5.7 (4.87-6.62)</td>
<td>7 (5.65-8.29)</td>
<td>0.136</td>
</tr>
<tr>
<td>Domestic daily living skills</td>
<td>5.8 (4.84-6.78)</td>
<td>7.7 (6.38-9.06)</td>
<td>0.027</td>
</tr>
<tr>
<td>Community daily living skills</td>
<td>7.1 (6.15-8.04)</td>
<td>8.2 (7.1-9.33)</td>
<td>0.134</td>
</tr>
<tr>
<td>Interpersonal relationship</td>
<td>4.6 (3.59-5.51)</td>
<td>4.8 (3.87-5.7)</td>
<td>0.724</td>
</tr>
<tr>
<td>socialisation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Play and leisure time socialisation</td>
<td>5.1 (4.08-6.04)</td>
<td>4.9 (4.06-5.75)</td>
<td>0.808</td>
</tr>
<tr>
<td>Coping skills socialisation</td>
<td>4.9 (3.9-5.89)</td>
<td>4.9 (4.25-5.63)</td>
<td>0.934</td>
</tr>
</tbody>
</table>

Mukherjee et al. (2019) Alcohol. 76:23-28
Findings Summary

Our findings suggest 2 broad conclusions

◦ That neurodevelopmental disorders are seen independent of neglect
◦ Neglect does not appear to make the neurodevelopmental presentation any worse

Limitations

◦ Numbers not huge
◦ Does not have a group of neglect alone
◦ Does not measure the psychological impact and overlap

Mukherjee et al. (2019) Alcohol. 76:23-28
Behavioural Emotional Social Survey

Online survey advertised via social media

Completed by parents/cares of 253 children aged 4-16 with FASD from 8 countries, but mostly from UK, USA and Canada

Adverse Childhood Experiences (ACE) questionnaire
  - Abuse, neglect, witnessed domestic violence, lived with parent that was an addict, mentally ill or imprisoned, experienced divorce

Griffith Empathy Measure
  - Cognitive and affective empathy

Strengths and Difficulties Questionnaire
  - Peer problems, conduct problems, hyperactivity, emotional problems, prosocial behaviour

Price et al. (in prep)
Adverse Childhood Experiences

- Sample of children with FASD scored significantly higher than population data on all ACEs except for physical and sexual abuse.
- Physical abuse score was similar to population data and sexual abuse score was lower.
- However, these figures probably underestimate the true scores.
- Survey was completed by (mostly adoptive) parents on behalf of their children and many reported being unsure of neglect or abuse.

Price et al. (in prep)
Strengths and difficulties Questionnaire

- SDQ is standardised and gives a score of average, raised, high or very high.
- Majority of FASD sample of children were very high on every scale. Prosocial is reverse scored so a high score indicates a lack of prosocial behaviour.
- Overall, 82% of FASD children were in very high for overall behavioural difficulties.
- On empathy, FASD children in every age range had significantly lower empathy scores than normative data, with high effect sizes.

Price et al. (in prep)
Summary of ACE/PAE survey findings

• Children in this population with FASD had high levels of ACEs including maltreatment – 78% had at least one
• Low empathy, high levels of behavioural/emotional/social difficulties
• High levels of comorbid conditions
• Neurological and cognitive functioning was in normal range
• Number of ACEs not associated with empathy
• Weak positive correlation between ACE score and behavioural difficulties
• Those diagnosed age 8 or younger – fewer behavioural difficulties
• Little or no impact of trauma on cognitive and behavioural functioning identified in children with FASD

Price et al. (in prep)
Lab study – Intelligence, Executive functioning and brain function

- Lab study to assess intelligence, executive functioning and brain activity
- 3 groups – a) FASD, no trauma, b) FASD and trauma, c) typically developing controls
- Psychometric inventories, behavioural tasks and neuroimaging
- Expect to see more severe or more likely problems in ‘both’ group
- Opportunity to assess feasibility of fNIRS in FASD children

(Price et al. in prep)
Here is what the mole looks like

Wack it as fast as you can before it gets away!

Press the space bar to continue

Sometimes, an eggplant will pop up in your garden.
The eggplant looks like this.

Don’t squash the eggplant!
2 steps left
Results – IQ and executive function

- Children with just FASD (97.4) and children with both FASD and trauma (99.5) had IQ scores in normal range (85-115).
- No difference between groups in inhibitory control or working memory

<table>
<thead>
<tr>
<th></th>
<th>FASD-only (n=7)</th>
<th>FASD and trauma (n=8)</th>
<th>Control (n=8)</th>
<th>F</th>
<th>df</th>
<th>$\eta_p^2$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Go/no-go errors</td>
<td>5.69 (5.82)</td>
<td>7.58 (5.8)</td>
<td>5.40 (4.31)</td>
<td>.62</td>
<td>2, 37</td>
<td>.03</td>
<td>.54</td>
</tr>
<tr>
<td>ToH errors</td>
<td>9.15 (4.78)</td>
<td>7.92 (3.97)</td>
<td>6.27 (3.69)</td>
<td>1.71</td>
<td>2, 37</td>
<td>.09</td>
<td>.20</td>
</tr>
</tbody>
</table>

(Price et al. in prep)
What is the impact on families?

- 12 semi-structured interviews with adoptive parents of children with FASD
- Study designed to investigate impact of behavioural difficulties on stress of caregivers
- Parents talked about behavioural problems, but were more keen to talk about dealing with professionals
- Parents of children with FASD need more support – healthcare professionals, teachers etc need specific training

(Price et al. in prep)
The Child

When describing their children, parents tended to talk about the following themes:

- Feeling sorry for them
- Behavioural difficulties of child are a source of stress for parents
- Children behaved differently in school than at home
- Some behaviours were dangerous to themselves or others
- Having a child with FASD has negatively affected family life, e.g. strain on marriage, socialising, holidays
- Parents worried about the future for their children
- Having older children or other adults at home was very helpful
- Children had many strengths and parenting them can be very rewarding

(Price et al. in prep)
The Child

“She was very aggressive with other children, you know, a child would walk past, and she’d just run up and scratch them... and we found it very hard to take her anywhere, because she would attack other children.”

“If there’s any little kids around, he tries to make them laugh, and if they’re crying he wants to get involved and stop them being upset. He’s great with kids.”

(Price et al. in prep)
‘The system’ was not directly related to any question in the schedule, but difficulties with service providers was by far the most emphasised theme in these interviews

- Temporary placements became permanent
- Parents were hindered in caring for their children by a system that was not able to help
- Parents felt they were being blamed for their children’s difficulties
- Teachers, social workers, healthcare professionals, and adoption support workers did not have appropriate training or knowledge of FASD
- Parents wanted recognition of their children’s conditions – diagnosis or an EHCP
- Some service providers did have FASD training, and this made a big difference

(Price et al. in prep)
The System

“We’ve gone everywhere, that’s the point, everybody tries to pass the buck on. I mean, they literally sent us around ... we eventually got assigned our own social worker, and she sent us back to the GP”

“We wouldn’t have changed our minds either [about adopting], but what [FASD training] would have changed is how we started up... it would have been putting support in place, and trying to understand, ‘cos you completely think it’s your own parenting, don’t you?”

(Price et al. in prep)
Carers study

• Different from other Children
• Lack of information given
• Lack of knowledge
  • in professionals
  • How to manage children
• Have to fight for things
• Misunderstood and blamed
• Family stress and benefits of 1:1
• Concerns for future

Mukherjee et al. (2015)
Conclusions

- Children with FASD have significant social and behavioural difficulties.
- High levels of ACEs in our samples of those with FASD
- Impact of traumatic experiences appears negligible in these studies, but more studies needed
  - “Postnatal neglect in this group did not make the developmental outcome any worse, suggesting that prenatal alcohol influences these outcomes independently. Professionals who support families looking after a child with both FASD and a history of neglect should be aware that the behavioral difficulties are likely to be related to prenatal alcohol exposure and not necessarily reflective of parenting quality” Mukherjee et al. 2019
- Parents reported behavioural problems were stressful, but services were poor
- Children with FASD tend to be given services designed for attachment and trauma, which may not be suitable
- Families affected by FASD need recognition, early diagnosis and support
FASD Conference

University of Salford - Thursday 12th December 2019
Media City, Salford Quays

The UK has one of the highest estimated rates of Foetal Alcohol Spectrum Disorders (FASD) in the world, but these conditions are commonly misunderstood, under-recognised and under-diagnosed.

The University of Salford will be hosting a one-day FASD conference on Thursday 12th December 2019 at Media City, Salford Quays. Ideal for healthcare professionals, social workers, educators, researchers, students and families affected by FASD.

The Royal College of Paediatrics and Child Health has approved this activity for Continuing Professional Development in accordance with the current RCPCH CPD Guidelines

Confirmed speakers include:
Bill Esterson MP, Chair of APPG on FASD
Dr Larry Burd, International FASD Expert
Dr Raja Mukherjee, UK Clinic Lead

Registration £100

To register, and for full programme, go to tinyurl.com/salfordfasd

For any questions, email a.d.price2@salford.ac.uk
Thank you

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William Hogarth *Gin Lane* (1751)