

Birth Mothers Experiences

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Acknowledgement for support European Birth
Mothers Association

Learning Disabilities
Services

Declaration of interest related to FASD

Non Payment Activities

- Medical Advisor to FASD charities
- Scientific advisor to various FASD international and national conferences
- Executive member of the UK FASD professionals network

Paid Activities

- Lead Clinician National FASD Behavioural Clinic (NHS)
- Honoraria received from conference presentations from
 - Pharmaceutical Companies
 - Charities related to Adoption and Fostering
 - Private education consultancies
- No Formal ongoing contract exists with any of the above other than FASD clinic



Why

- Studies of General population, professionals and Adoptive carers completed by our team
- Only one real published study of birth mums and that was a specific sample and not necessarily representative
- Needed to understand birth mums experiences systematically



Methods

- interpretative phenomenological analytical (IPA) approach as described by Smith (Smith, Flowers & Larkin 2009).
- IPA was chosen because it offers a framework for studying lived experience which was the primary aim of the research study



What is IPA

- ▶ IPA is concerned with trying to understand lived experience and with how participants themselves make sense of their experiences. Therefore it is centrally concerned with the meanings which those experiences hold for the participants.
- ▶ IPA is phenomenological in that it wishes to explore an individual's personal perception or account of an event or state as opposed to attempting to produce an objective record of the event or state itself
- ▶ At the same time, while trying to get close to the participant's personal world, IPA considers that one cannot do this directly or completely.
- ▶ IPA is also a strongly idiographic approach concerned with detailed analysis of the case either as and end in itself or before moving to similarly detailed analyses of other cases.



Process

- Recruited through European Birth Mothers Support Network and NHS FASD behavior clinic SABP.
- Semi structured interviews with people who agreed to take part
- Recorded and then transcribed and analysed thematically.



Participants

- 12 women identified and contacted
- 5 took part aged 30-50
- All now currently not drinking
- Interviews recorded, transcribed and analysed on nivivo
- Thematic analysis completed



Themes

- Four major themes were identified:
- “to blame or not to blame?”
 - “life as a series of battles”
 - “on a crusade with a renewed sense of purpose”
 - “what helps?”



To blame or not to blame : sense of inevitability

- ▶ *In a sense if anyone was going to have a FAS baby it would have been someone like me simply because of the way...Simply because of my history you could almost see it there waiting to happen*
- ▶ Well in that X's disorder is 100% preventable. If I hadn't of drunk whilst I was pregnant he would not have FASD.

Life a series of battles

- *I think I am still at a point where I'm putting one foot in front of another to get through every day.*
- But of course I'm saying to everyone "he's got FAS or ARND". It is because I drank and they were saying oh no don't be silly. They just wouldn't have it. They just would not accept it. But I kept insisting that is what it was and I kept giving them information."
- *Yeah horrible. Umm yes it was really hard. It is one think thinking yes this is what it is and another thing being told yes you're the reason this is why your child is like this*

On a crusade : New sense of purpose

- *I was determined I would get her all the help and support I could... I started hunting round for support for help and everything like that which I've been doing ever since*
- *I must admit once I'd got sober and dealt with the guilt and thought to myself you know what I can't change what has happened but I can change what I do for her now and that is when I started hunting round for support for help and everything like that which I've been doing ever since*

What helps

- ▶ *He's lovely. He is a lovely, lovely boy. He has lots of talents*
- ▶ *If all you're doing is beating yourself up, you know so overcome by guilt, it isn't actually helping anyone you know it's done it happened. You've got to move on from that and do what you can to make it as good as you can*

Conclusions

- ▶ Particularly striking was the tension that exists for the women in considering the issue of blame. The balance between drinking in terms of choice yet what also emerges from the analysis is the women's experiences of being victims of circumstances beyond their control.
- ▶ There is a need to work through grief
- ▶ Despite this a sense of hope is present. The mothers make the best of a difficult situation which is reflected in their renewed sense of purpose to do the best they can for their child and to raise awareness.

Questions

