A Qualitative Study Investigating Barriers and Enablers to Supporting Breastfeeding for Babies with Down Syndrome (DS)

Abstract

Introduction: Down Syndrome (DS) is the most common genetic condition in the UK. Breastfeeding has immediate and lifelong benefits, yet assumptions and barriers thwart it in babies with DS. This study aimed to explore maternal experiences, investigating enablers and barriers and how they may be overcome.

Materials and Methods: This was a primary research study using a multiple case study methodology with Ethics Approval from Bristol University Health Science Student Research Ethics Committee and the support of the Down Syndrome Association. Three mothers who either breastfed or attempted to breastfeed their baby with DS participated in a semi-structured interview which was transcribed and analysed using reflexive thematic analysis.

Results: Of the three mothers interviewed, one had transitioned to formula, one was mixed feeding, and one had successfully breastfed. Two overarching themes were identified, each with three subthemes: 1. 'Professionals Attitudes are Key' with subthemes 'It's a Numbers Game', 'Luck of the Draw' and 'If they had had more Expert Knowledge' and 2. 'A Huge Emotional Upheaval' with subthemes 'Coping with Emotions Experienced', 'It's a Marathon' and 'Having Self-belief'.

Discussion: Mothers' experiences were mixed, from negative detrimental comments to highly engaged and supportive health professionals. Two mothers were experienced at breastfeeding their prior children, but despite their knowledge, found accessing specialist expertise challenging. One mother was primiparous, her experience lacking much-needed emotional support and professional knowledge. Despite World Health Organisation guidelines and the UNICEF Baby Friendly Initiative guidelines, there is a gap facilitating breastfeeding babies with DS.

Conclusion: Maternal perseverance and increased professionals' expert support are key enablers. Access to specialist knowledge at diagnosis via specific care pathways would optimise enablers and minimize barriers.

For access to the full report please contact Jenny Davies at au22655@bristol.ac.uk or Jenadavies2@hotmail.com