

Women's experiences of hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders during pregnancy, birth and beyond



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Background:

Maternity is a key transition period in a woman's life with a higher prevalence of obstetric issues affecting women with hypermobile EDS (hEDS) and Hypermobility Spectrum Disorders (HSD) than in the general population.

A recent review of the international literature highlighted current knowledge on child-bearing care considerations but found there is limited evidence (Pezaro et al, 2018). The review is in the clinical toolkit <http://www.rcgp.org.uk/EDS> (poster 50).

If the experience of hEDS/HSD remains poorly understood by the multidisciplinary team, maternity care may be significantly compromised.

Aim:

The aim was to examine the international experiences of women diagnosed with hEDS/HSD across the antenatal, intra-partum and postnatal periods

Methods:

Qualitative study using semi-structured interviews and thematic narrative analysis.

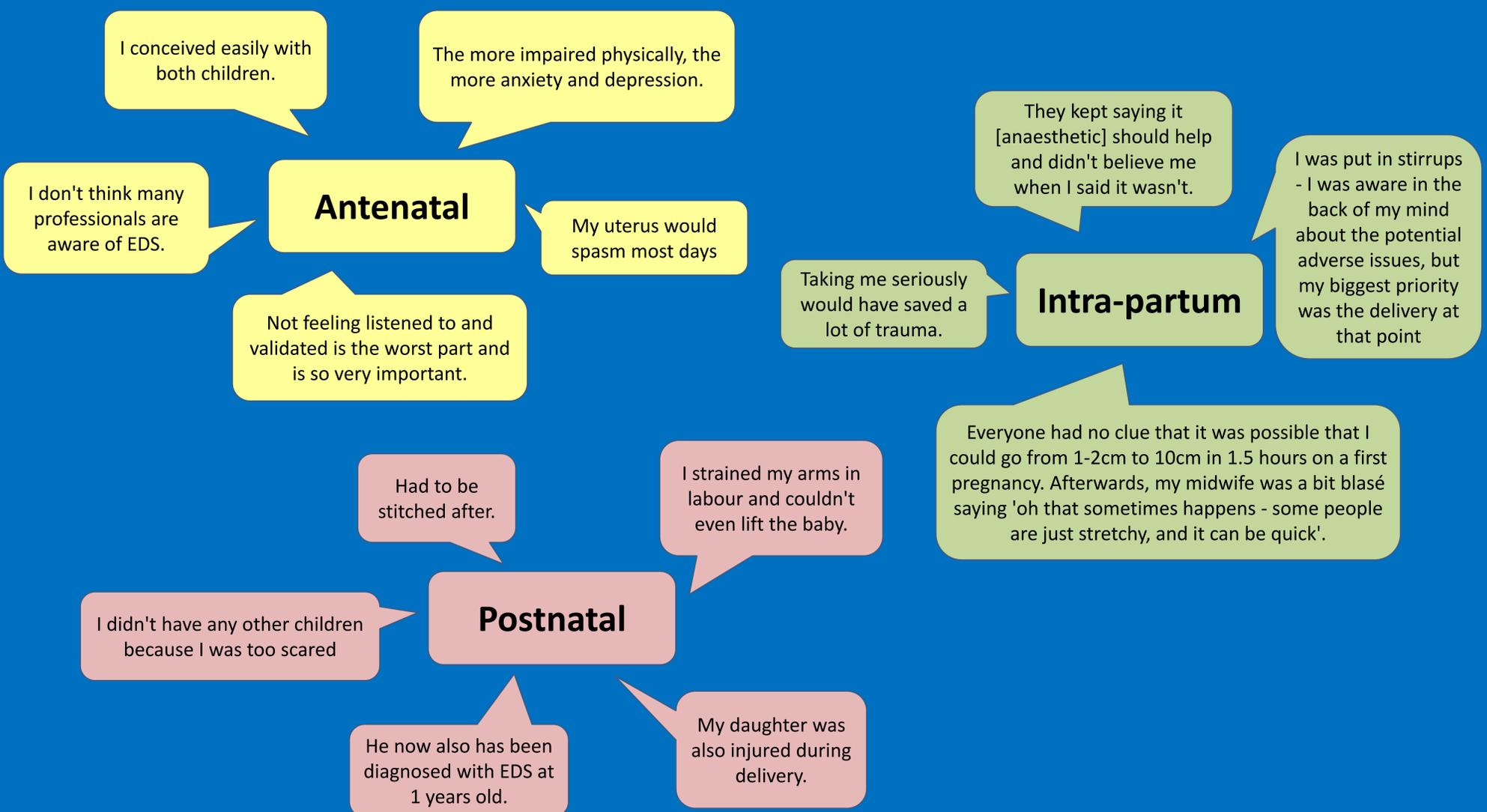
Participation criteria:

- over the age of 18
- confirmed medical diagnosis (before or after pregnancy) of either hEDS, HSD, EDS Type III, EDS Hypermobility Type (HT) or Joint Hypermobility Syndrome (JHS).
- Been pregnant and given birth

Key findings and conclusions:

- Few maternity professionals had heard of hEDS/HSD and knew the child-bearing and postnatal care considerations of these women.
- Women felt that they knew their bodies and capabilities but when telling maternity professionals, they were not listened to, with their concerns downplayed. e.g. precipitate labour /birth, increased likelihood of joint subluxations and perineal tearing, slower wound healing and the reduced effectiveness of local anaesthetics.
- Women also faced breastfeeding and positioning challenges postnatally, often requiring lots of support from the partner and family.
- This study provides access to deeper vital knowledge to raise awareness and inform care considerations, guidelines and education in maternity care.

Women's narratives



Participant Demographics (n=40; pregnancies=54, births=52)

Age	25-55 years old
Country	UK=29, USA=10, Canada=1
Year of child birth	1981-2018
Diagnosis type	hEDS=9, HSD=0, EDS Type III=11, EDS HT=16, JHS=4
No. of children inc. still births	one=28, two=10, three=2
Conception	Before diagnosis=38, After diagnosis=16
Type of birth	Vaginal=37, Caesarean=15, currently pregnant=2

Other conditions (reported by more than one person)

Postural Orthostatic Tachycardia Syndrome (n=14); Asthma (n=13); Migraine (n=10); Fibromyalgia (n=10); Allergy/intolerance (n=8); Irritable Bowel Syndrome (n=7); Arthritis (including osteoarthritis and rheumatoid arthritis) (n=6); Depression (n=7); Anxiety (n=6); Polycystic Ovary Syndrome (n=6); Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (n=5); Scoliosis (n=4); Endometriosis (n=3); Anaemia (n=3); Hypertension (n=3); Gastroesophageal conditions (n=3); Hypothyroid (n=2); Irritable bladder (n=2); Mast Cell Activation Syndrome (n=2); Spontaneous Cerebrospinal Fluid leak (n=2); Temporomandibular Disorder (n=2); Autism (n=2).

References: Pezaro, S., Pearce, G. & Reinhold, E (2018). Hypermobile Ehlers-Danlos Syndrome during Pregnancy, Birth and Beyond: A Review of Midwifery Care Considerations. *British Journal of Midwifery*, 26(4).