Exploring the experiences of women and their partners in pregnancies affected by a suspected severe fetal anomaly

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Explore views of women and partners when a severe congenital anomaly is suspected

Understand parental decision-making and subsequent choice to continue or terminate pregnancy

Best support for pregnant women / partners when a severe anomaly is suspected

Direct future policy and practice

Prevent inadvertent increase in socioeconomic inequalities in neonatal mortality

Talking about her gives a meaning to her life

I really want to share her story. It gives her a purpose

PATIENT AND PUBLIC INVOLVEMENT

Telling his story is a celebration of his life

Being able to talk about this away from the doctors, would really have helped

BACKGROUND

Around 2-3% of pregnancies are affected by a congenital anomaly. These anomalies, in turn, account for around 30% of neonatal and infant mortality in the UK. Whilst rates of detection are similar for all socio-economic groups, rates of termination for congenital anomalies are lower in more deprived socio-economic areas. This variation explains a quarter of the widening socioeconomic gap in neonatal mortality.

AIMS

This study aims to explore the decision-making processes of prospective parents faced with a decision to continue or terminate a pregnancy associated with a severe congenital anomaly. Special consideration will be given to the influence of socio-economic deprivation on this process.

METHODS

This is a qualitative study, drawing on data gathered from interviews and recording of consultation between parents and clinicians, and will be informed by a systematic examination of the available literature. Women will be recruited from two centres in the East Midlands. Purposive sampling will be used in order to ensure a heterogeneous sample including women from a range of socioeconomic and ethnic groups, gestational age at diagnosis, and diagnoses (or suspected anomalies) with poor prognostic outcomes. In addition the sample will include women who continue their pregnancy and those who terminate. All anomalies are screened for by the national Fetal Anomaly Screening Programme (FASP).

	Possibility of a definite diagnosis	Uncertain diagnosis
Well defined prognosis	* Anencephaly * Trisomy 13 * Trisomy 18 * Renal agenesis	
Uncertain but potentially lethal prognosis	* Trisomy 21 (Down's Syndrome)	* Congenital diaphragmatic hernia * Severe cardiac * Spina Bifida * Lethal skeletal dysplasia * Exomphalos
Uncertain but correctable diagnosis		* Gastroschisis * Cleft lip/palate

SAMPLE

The 9 highlighted anomalies are included. Correctable anomalies are excluded as they will have minimal impact on mortality. Trisomy 21 is excluded as there are underlying inequalities in both access and take up of screening, making comparisons difficult.

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