DIFFICULT DECISIONS: Understanding patients’ experiences and ethical dilemmas resulting from advances in fetal anomaly detection.

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Abstract: Fetal anomaly detection is a fast moving field which is in the interesting position of being both widely accepted and controversial. We are currently at the threshold of a new level of detail in prenatal testing, whole genome sequencing, which will bring with it many more opportunities to detect anomalies before birth. However the more technology advances, the more anomalies of uncertain or ambiguous significance are being detected. When this occurs, women and couples must make the decision to continue or end the pregnancy on the basis of such ambiguous information.

This thesis explores the currently established ethical justifications for prenatal screening and testing in light of these ambiguous diagnoses, using qualitative data drawn from the experiences of people who have been confronted with an ambiguous diagnosis during pregnancy as well as normative analysis. Using a reflexive balancing method this analysis examines whether the process as it stands fulfils these established ethical aims, and whether the ethical justifications themselves are appropriate. It will be argued that the aim of promoting autonomy, which is generally given as the primary ethical purpose of the fetal anomaly detection programme is not fulfilled by the process as it stands. Furthermore it will be argued that ‘promoting autonomy’ should not be the primary ethical justification for fetal anomaly detection as, at least in the three accounts of autonomy explored here, it is not a sufficiently nuanced principle to encompass the realities of prenatal decision-making in the context of an ambiguous diagnosis. Other possible justifications are then explored to contribute towards a future framework for analyzing technological developments in this field.

Methods:
- Literature review to identify ethical justifications for fetal anomaly detection in guidelines and subject literature.
- Qualitative in-depth interviews with 12 couples and 2 individual women to gain insight into lived experiences of decision making in the context of diagnostic ambiguity.
- Normative ethical analysis.
- Reflexive balancing to draw conclusions

The decision making process

Challenging the notion that fetal anomaly detection ‘Promotes Autonomy’

- Entry to the process not based on adequate understanding
- Obstacles to obtaining and understanding information
- Difficulty with imagining the future
- Significant number of constraints and outside influences

Challenging ‘Promoting Autonomy’ as an ethical justification for fetal anomaly detection

- Prenatal decisions are not seen as an opportunity for self expression
- The decision generally involves more than one person and the fetus
- Rational prenatal decision-making is an illusory concept
- The opportunity for choice is balanced by the punishment and blame associated with the choice.

Outlook from experience – participants’ views on expanding prenatal testing to include whole genome sequencing:

« If I had not gone through what I went through then I would say ‘oh gosh, it’s brilliant…’ But because we went through what we went through I’m a bit more inclined to say…maybe it’s best to leave well alone »

« I expect everybody on the planet has blemishes inside their chromosomes…If I’m looking at you and say you have some…its not a big deal…but if you hadn’t been born yet, you just don’t know how big a deal that’s going to be. Something that is nothing is absolutely massive in the embryo, psychologically, and I think you’re just better off not knowing »

Conclusions:
- The fetal anomaly detection programme does not promote autonomy.
- Promoting autonomy should not be the aim of the programme, as this principle is insufficiently nuanced to encompass the realities of decision making in the context of an ambiguous diagnosis.
- Principles which should be considered in a future framework include promoting happiness, reducing measurable suffering, protection and partnership.