

Social & Ethnic Differences in Attitudes & Consent to Prenatal Testing



University of Leeds

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Grant Holders and Researchers

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Background to the Studies

Advances in DNA technology = increase in the range of conditions where prenatal tests will be available

Obtaining separate informed consent to each... require system of obtaining broad classes of consent

Such a system needs to be build on parents' attitudes to testing

No adequate classification system available

Aims of the Studies

Compare attitudes of different social and ethnic groups to different conditions

Describe and compare reasons for these attitudes between conditions and between social and ethnic groups

Devise a classification system??

The studies: Design

Study 1a:

Quantitative questionnaire (target n=400)

Study 1b:

Qualitative semi-structured interviews with a sub-sample from study 1a
(target n=60)

Data from study 1a & 1b was supplemented with data from a sub-sample of women who had used genetic services (n=19)

The Studies: Methodology

Sample:

Pregnant Pakistani & white indigenous women attending community
Antenatal clinics, over 30 weeks gestation

Outcome measures:

Postnatal attitude towards prenatal diagnosis
Postnatal attitude towards termination of pregnancy

The questionnaire... hypothetical scenario

When answering the questions, assume that the test would be carried out:

- using routinely collected blood
- early in pregnancy
- with no risk to you or the pregnancy
- to tell you whether the baby **definitely** does or does not have the condition

The questionnaire

Please tick either 'No', 'Yes', or 'Not sure'.

Main features of the condition

Would you
want a
prenatal
test?

Would you
consider
termination if the
test showed the
baby had this
condition?



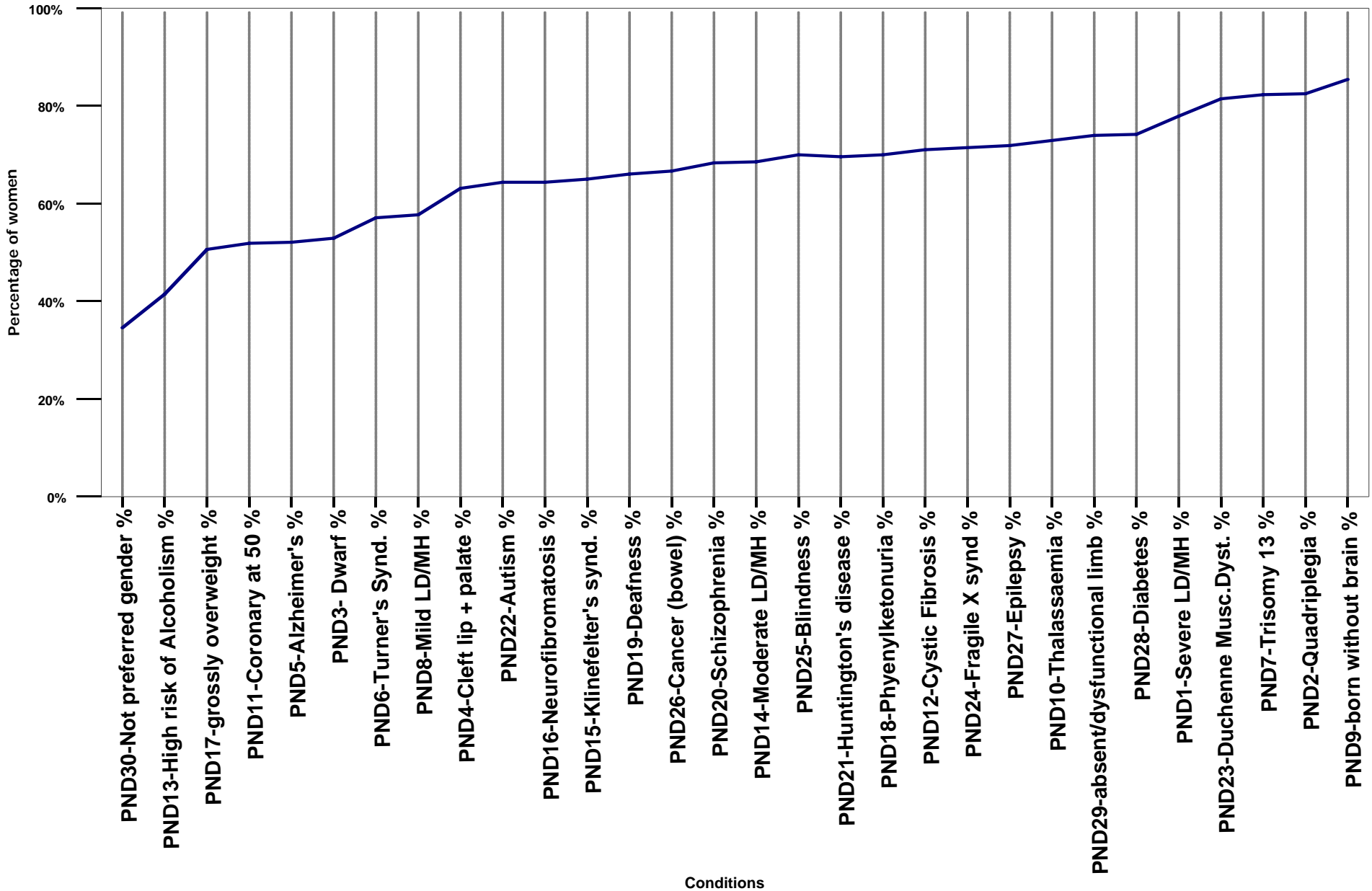
Child would have problems with lungs and digestive systems, require a lot of medical care throughout life and have a shortened lifespan (death probably before 40 years of age).	No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/>	No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/>
A male child would have a progressive muscle-wasting disease, be wheelchair-bound by 11 or 12 years and have a much-shortened lifespan (death probably before 20 years of age).	No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/>	No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/>
Child would have severe learning disabilities/mental handicap, unable to speak or understand, require a lot of looking after and have a nearly normal lifespan.	No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/>	No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/>
Child would have severe learning disabilities/mental handicap, requires a lot of looking after and die within first few months of life.	No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/>	No <input type="checkbox"/> Yes <input type="checkbox"/> Not sure <input type="checkbox"/>

Completed Questionnaires: Ethnic origin x Education

	ETHNIC ORIGIN		Total
	UK White	Pakistani	
GCSE or less	113	125	238
A Level or more	109	73	182
Total	222	198	420

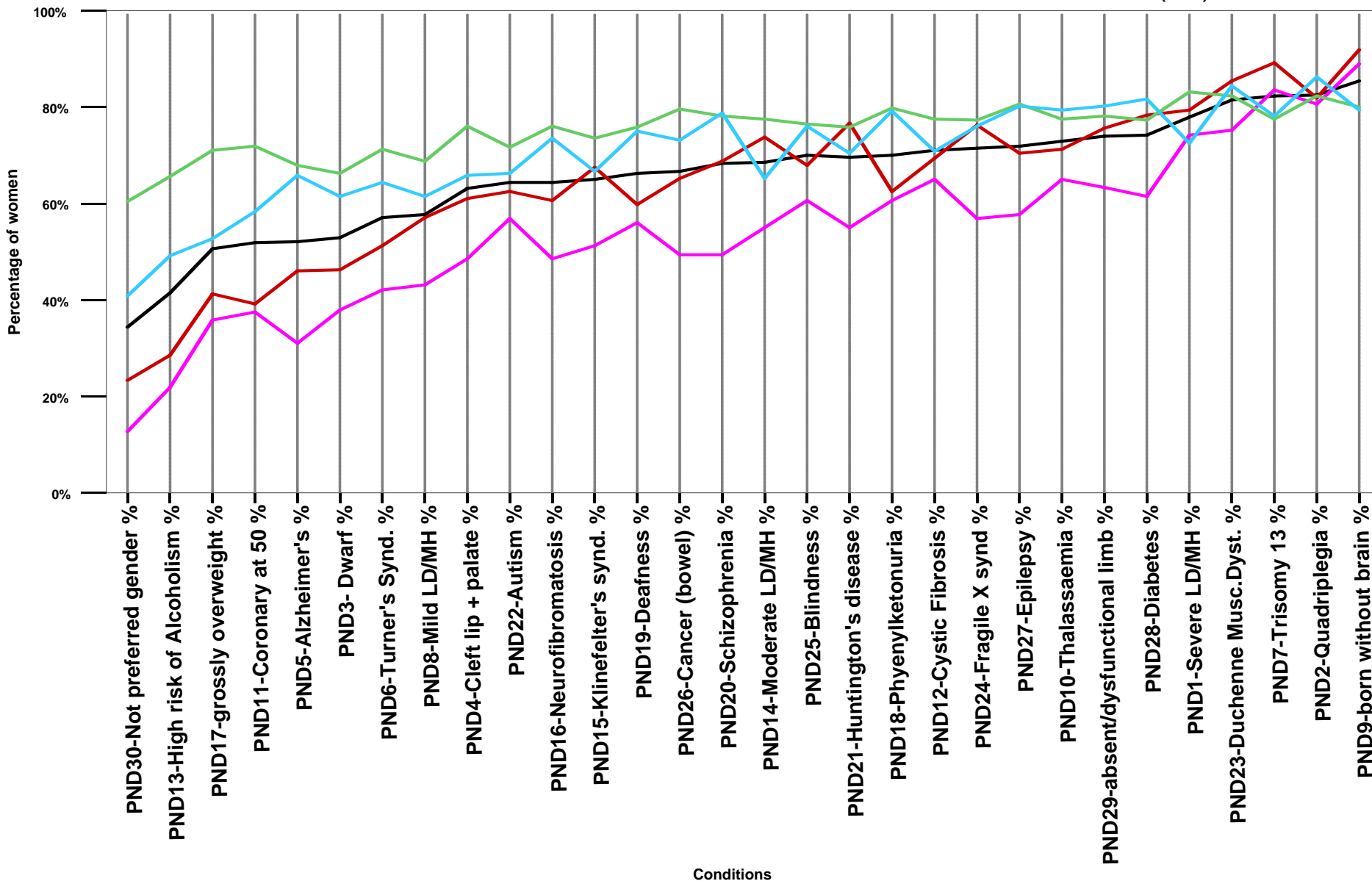
All women who said "Yes" to PND: conditions ordered by "Yes" to Prenatal Diagnosis

Groups of women
All women (n=420)



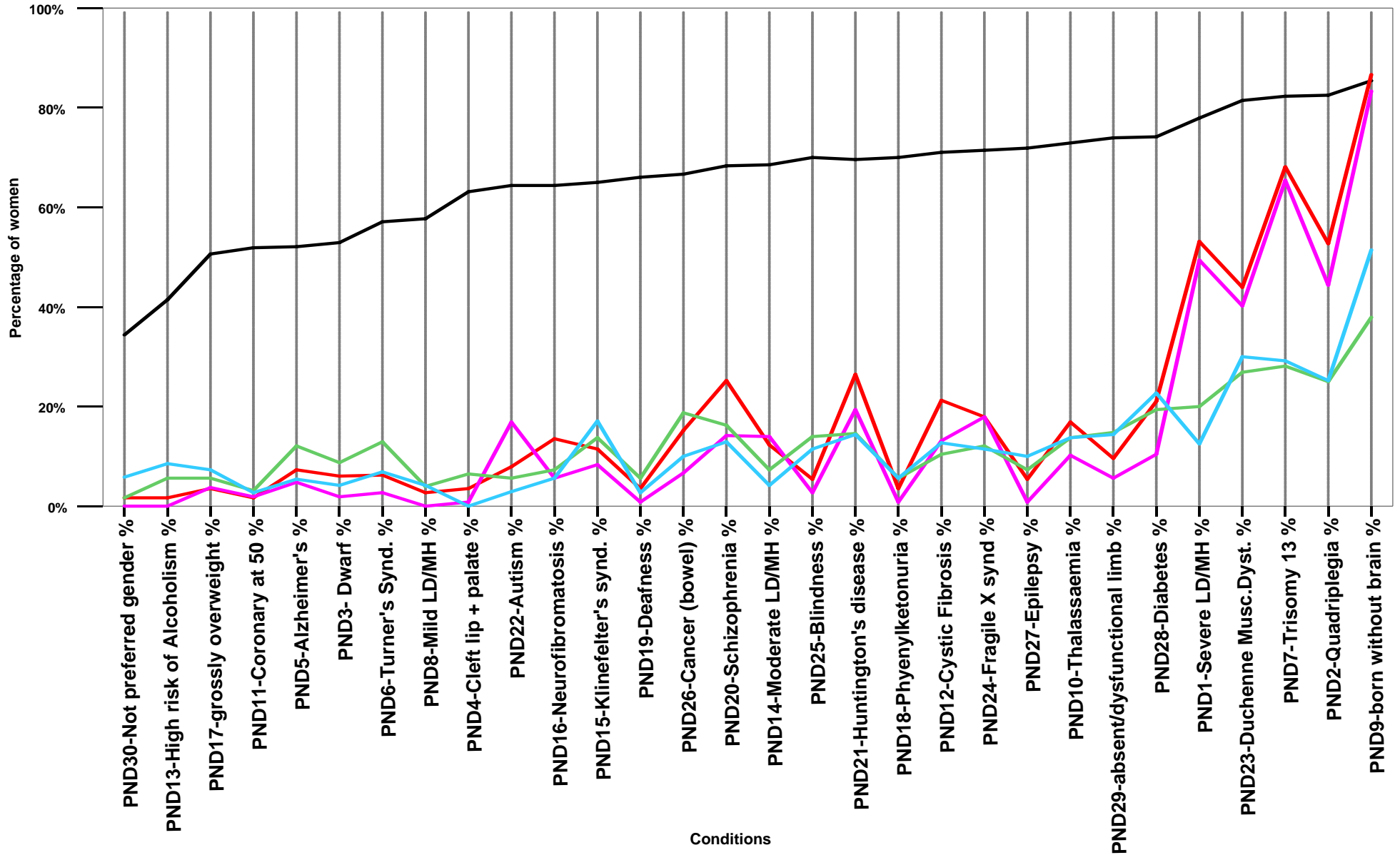
All women who said "Yes" to PND: data subdivided by women who said "Yes" to Prenatal Diagnosis from each group: conditions ordered by "Yes" to PND

- Groups of women**
- All women "YES" to PND (n=420)
 - Ind White-Low ed (n=113)
 - Ind White-Hi ed (n=109)
 - Pakistani-Low ed (n=125)
 - Pakistani-Hi ed (n=73)



**All women who said "Yes" to Prenatal Diagnosis:
data subdivided by women who said "Yes" to
Termination of Pregnancy from each group:
conditions ordered by "Yes" to PND**

- Groups of women**
- All women "YES" to PND (n=420)
 - Ind White-Low ed (n=113)
 - Ind White-Hi ed (n=109)
 - Pakistani-Low ed (n=125)
 - Pakistani-Hi ed (n=73)



A classification system??

Do individuals hold similar attitudes to different conditions?

Multivariate analysis conducted by Prof Tony Coxon of Edinburgh University

Two techniques:

- Multidimensional scaling
- Hierarchical cluster analysis

A small group of conditions, anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy, and to a lesser extent, severe learning difficulties, stood out from the rest.

No other clusters were identifiable.

Reasons?

- Women often considered it self evident that a termination would not be justified.
- In Barbara's words, a condition such as blindness, "*wouldn't bother me*".
- Problems were acknowledged, but regarded as insignificant or manageable in the overall scheme of things – there was plastic surgery, prostheses, Braille and sign language, therapy, parental reserves of understanding and patience.



Reasons why 'yes'?

Nadira: If anything happened to me, or I died, or their dad's not around...who's going to look after them? Because the way a mother looks after you, nobody else does.. they're not other people's problems and you know what people can be like out there. You gonna regret it yourself that it's suffering 'cos of me...you might as well just put an end to it before you knew it was gonna go through all that and die slowly, and that kid's gonna blame you as well.



Heather: One child can live to be one, the other can live to be 30 - you never know, and you're living with that every day, not knowing whether you're going to bury them next year, or whether they're going to carry on and grow up into adulthood. She went on: ..even though you work full time, you still sort out the physio, the medicine, the hospital visit.

Different conditions?

Rebecca thought she probably would have a termination for thalassaemia: *They're going to know that they're gonna die, and they're not going to have much of a life in and out of hospital.*

For her, facial disfigurement was not a reason for termination: *Their life is just the same really.*

Lareb disagreed: *His parents will not look at him with hatred but friends, brothers and sisters will say, “you stay away from us, your face is not good, don’t come near our friends”...they will say “don’t sit with my friends, you go out – go to your room” .*

Summary of UK Results

1. Attitudes to testing

- A high level of interest in testing
- 6% of UK Pakistani women and 4% of white indigenous women wanted no prenatal testing at all

2. Attitudes to termination

- For the great majority of conditions, fewer than a quarter of participants would consider a termination of pregnancy
- 25% of UK Pakistani women and 6% of white indigenous women would consider a termination for none of the conditions on the list

3. Conditions?

A small group of conditions, anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy, and to a lesser extent, severe learning difficulties, stand out from the rest.

The great majority of women would like prenatal tests for these conditions, and even women who on the whole rejected testing tended to make exceptions for these conditions.

Interest in termination was lower, but again, if a woman who was essentially against termination was prepared to make exceptions to that rule, these were the conditions seen to justify an exception being made.

4. “Clustering” of conditions?

Women’s views of “less serious” were much more variable than their views of “more serious”.

In focus groups, cluster approach acceptable, but only for “more serious” conditions.

Otherwise, most participants wanted to make their own choices.

Study 1a:

Quantitative questionnaire (target n=400)

Study 1b:

Qualitative semi-structured interviews with a sub-sample from study 1a (target n=40)

Sample:

Saudi fathers and mothers, with and without an affected child, attending genetic and outpatient clinics at King Faisal Hospital & Research Centre, Riyadh.

Comparison between studies: attitudes to prenatal testing

- Saudi and UK Pakistani women had very similar attitudes.
- UK white women had more favourable attitudes to prenatal testing for only two conditions: anencephaly and trisomy 13/18
- These conditions cause death at, or soon after, birth

Comparison between studies: Attitudes to Termination

- Group differences depended on condition.
- UK Pakistani women had least favourable attitudes overall.
- In Saudi Arabia, as in the UK, attitudes towards termination were most favourable in cases of anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy, and severe learning difficulties.

Why have testing: TO KNOW

“I would do the prenatal diagnosis so that I could be prepared psychologically and educate myself about the disease that the child might have, but I would never abort any kind of genetic condition unless it would affect my life...”

Lamia (28 year old Saudi female, highly educated with two children)

Why have termination of the pregnancy: Poor quality of life (Fathers)

Thamer (34 year old Saudi male, highly educated with three healthy children and two affected with PKU:

“..I have to hide my healthy children at meal time in a locked room as a jail like criminal people, because I do not want the affected daughters to be upset by looking at their brothers and sisters eating what they want to eat....”

Hussein (49 year old Saudi male, highly educated (assistant professor) with seven healthy children and one child with sickle cell anemia):

“..Any kind of condition that makes the parents busy with the disabled child and ignore the healthy children should be terminated..”

Why have termination of the pregnancy: Poor quality of life (Mothers)

Wasmih (35 year old Saudi female, low education with three healthy children and two with cystic fibrosis and one who died of the same condition)

“...When my daughter was in ICU, I prayed that God would end her pain and suffering by taking her soul. The eldest of my children is a boy who is a 1 ½ years older than my dead daughter and he also has cystic fibrosis. He has nightmares about his late sister whom he was very attached to...”

Dina (30 year old Saudi female, low education with one healthy child and one deaf child)

“..in hopeless untreated cases such as a brainless fetus or a newly born whose lifespan won't exceed a couple of months...”

Why NOT have termination of pregnancy?

RELIGION

Lama (30 year old Saudi female, highly educated with three healthy and two deaf children)

“... I would not abort in any of the survey cases because it is against Islamic law as far as I know, except for the alcoholic case because it is against Islam law”

Salwa (36 year old Saudi female, low education with four healthy children)

“I am convinced that Islam is against abortion, even if the Fatwa states differently...”

Summary of factors influencing Saudi parents' decisions about termination of pregnancy

- **Perceptions of severity of the condition**
- **Effect on family life (time, business, family relationships)**
- **Stigma (people ask questions, people criticize, future marriage concerns)**
- **Knowledge (fathers without an affected children had least favourable attitudes)**

Main Conclusions

- Perceptions of relative severity are similar across genders and cultures
- The majority of people consider that a termination of pregnancy is justified for *some* of the conditions studied
- BUT: most conditions are not seen by most people as justifying a termination
- The list of conditions considered to justify a termination varies between individual people, posing challenges for informed consent