Leeds, 22 May 2012

Raising awareness of genetics among culturally diverse communities

How families manage their risk after seeing the geneticist

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Genetic counselling

(usually) after having affected pregnancy/child;
(less often) family history

Likely recurrence risk

1 in 4, 1 in 2

Risk management

Scans, PND (if genetic test), TOP

What influences couples' responses to recurrence risk and risk-management information?

- Understanding of 'genetic' diagnosis/risk
- Availability of prenatal genetic test
- Severity of condition
- Affected child/children
- Unaffected child/children
- Attitudes to abortion

Do attitudes change over time?

- Responses contingent rather than fixed

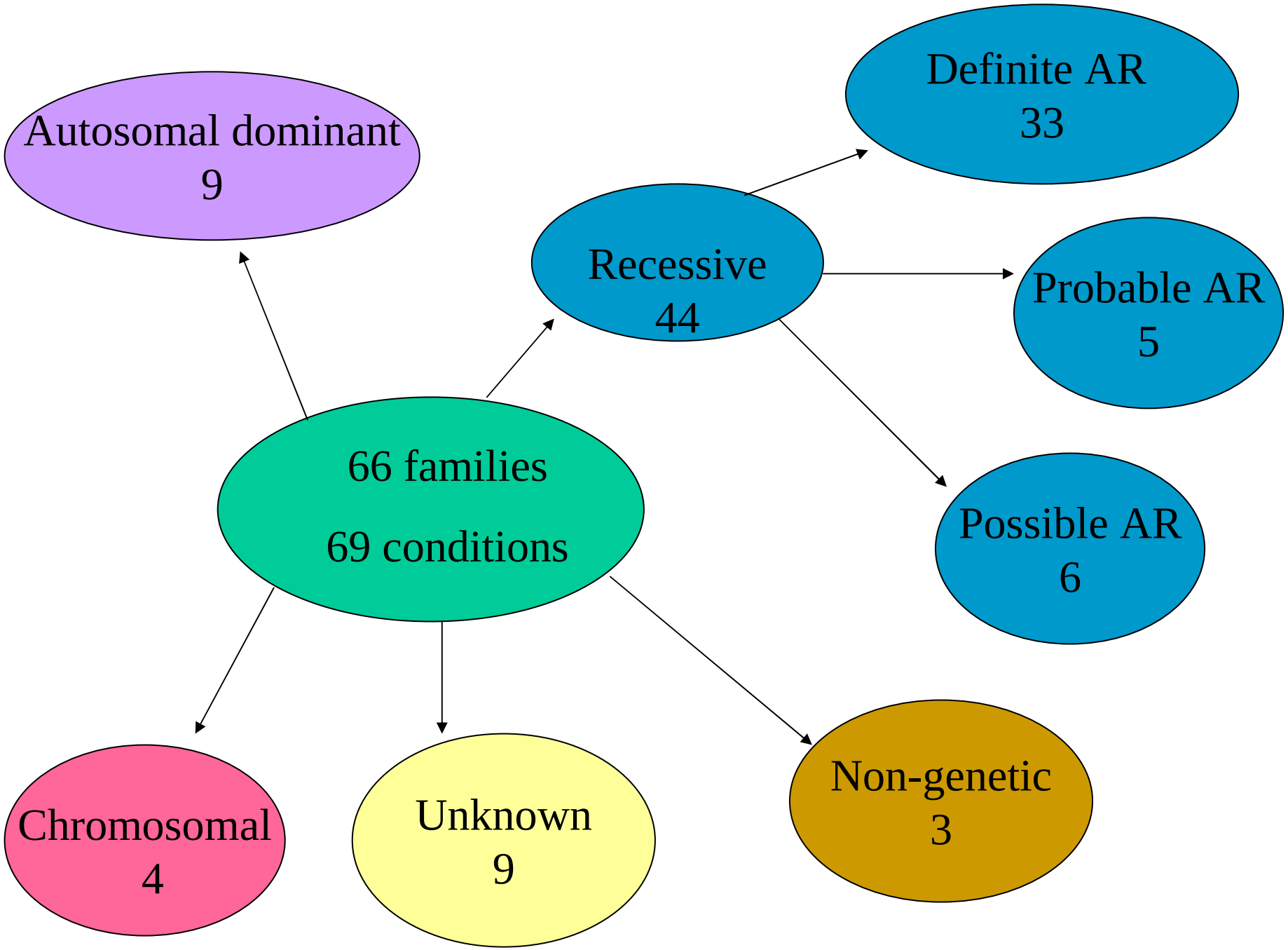
My study

66 couples of Pakistani ethnicity & Muslim religion
High Wycombe (9,703;6%)

Background:

Consanguinity debate
Stigma of public health discourse

Islam & PND/ TOP: diversity in religious rulings; research shows attitudes vary *within* faith groups


Autosomal dominant
9
Definite AR
33
Recessive
44
Probable AR
5
66 families
69 conditions
Possible AR
6
Chromosomal
4
Unknown
9
Non-genetic
3

51 couples' responses to risk information after referral (fieldwork 2001-4…+)

Methods:

Clinic observation

Semi structured interviews at home

Majority 3+ clinics and interviews

Participant observation:

Interpreting and mediation (12 families)

4 categories of risk response:

Taking the risk

or

Postponing; Managing; Exempt

Initial Responses:

24 (nearly ½) Risk Takers

10 Postponers]

6 Managers

11 Exempt

Risk takers (24/51):

Sceptical it is ‘genetic’, sceptical of risk discourse

Had unaffected children already; confident they can

Want sibling for child; to ‘fill the gap’; ‘save the marriage’

“We’ve had our bad luck”/ “affects only boys”

No prenatal genetic test

Abortion unacceptable

Postponers (10/51):

No unaffected, or caring for affected

Traumatic experiences

No prenatal test (8/10)

Managers (6/51):

2 or more unaffected children (mothers decided), or

Condition is fatal (fathers decided)

Prenatal genetic test available

Exempt (11/51):

Separation (1)

Completed families (10)

4 years later:

	Takers	Postponers	Managers	Exempt
Initial	24 (nearly ½)	10	6	11
Later	19	6	14	12

15 couples responses changed: fewer risk-takers; more risk managers

6 more fatally-affected born

2 mutations identified

1 unaffected birth, unplanned

3 Postponers become risk-takers:

2 decline management to avoid its stress,

1 confident after unexpected, unaffected baby

2 Postponers become risk managers:

Overcome initial ‘shock’, prenatal genetic test available

4 Risk-takers become managers:

Fatal or severe conditions, 3 ‘managed’ by scans if genetic test, considering TOP:

“It would be a medical decision” ; “wrong to knowingly bring such a child into the world”

4 Risk-takers become managers/postponers'other:

Repeated infant deaths;

1 genetic test to inform therapy (2 unaffected)

3 postponing while wait for mutation research,

discussed adoption, gamete donation

1 manager becomes postponer:

Childless; 3 lost pregnancies

1 manager becomes exempt:

After 4th child, completed family, sterilisation

'I did not want to take the risk again'

Conclusions

Risk responses may change over time:

Mostly risk-takers become managers (but can go either way)

Key contingencies:

Reproductive history; unaffected/affected children;
Severity of condition;
Availability of prenatal genetic test

Challenges assumptions about (static) religion/culture, or “in denial”:

Reproductive history
Severity of and experience with condition
Reflexive adults, //s with other ethnic groups

Distinguish initial from later responses

Long term versus short term responses (re. own children’s marriages)?

Reference:

Shaw, A. 2011. Risk and reproductive decisions. *Social Science and Medicine*, 73:111-120.

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