

Attitudes to prenatal testing and termination of pregnancy for fetal abnormality: a comparison of white and Pakistani women in the UK

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Objectives To compare the attitudes of women from two different ethnic backgrounds to prenatal testing for a range of conditions, and to see if “clusters” of attitudes to different conditions could be identified, for which prenatal testing might be offered as a package.

Methods Four hundred and twenty white and Pakistani women living in the UK were surveyed about their attitudes to prenatal testing and termination for 30 different fetal conditions. All participants had recently had a baby.

Results Pakistani women held more favourable attitudes to prenatal testing, but less favourable attitudes to termination than their white counterparts. Both groups were most in favour of termination for the same four conditions: anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy. The rank ordering of conditions was also similar. Only 4% of Pakistani and 2% of white women wanted no prenatal testing at all. Fewer than a quarter of participants would consider a termination of pregnancy for 85% of the conditions, but only 25% of Pakistani women and 6% of white women would consider termination for none of the conditions. More advanced statistical analyses were used to measure how closely associated the 30 conditions were in respondents’ answers. These analyses identified a principal dimension, reflecting the overall perceived seriousness of the conditions, and a cluster of severely disabling conditions—anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy, and severe learning difficulties—which stood out from the rest. Even within this cluster there remained a considerable amount of individual variation.

Conclusion Women in the study wanted to make up their own minds about the conditions that to them merited testing or termination. These findings have implications for obtaining informed consent. Copyright © 2007 John Wiley & Sons, Ltd.

KEY WORDS: attitudes; ethnicity; prenatal testing; termination of pregnancy

INTRODUCTION

All pregnant women in the United Kingdom are now offered screening for Down syndrome and screening for sickle cell disease and thalassaemia is also being introduced. However, as prenatal tests become feasible for more and more conditions, a debate has been prompted about the ethics of offering tests for ‘minor’ abnormalities (Boyle and Savulescu 2003, Scott 2005). A member of the public recently attempted to have two doctors prosecuted for authorising an abortion of a foetus with cleft lip and palate. Such cases attract media attention, but surprisingly little is otherwise known about public attitudes to prenatal testing for different conditions. A public consultation exercise conducted in 2004–5 by the UK’s Human Genetics Commission (HGC) found

broad support for expanding prenatal screening programmes, provided that the newly included conditions were ‘serious’ or ‘severe’ (The Human Genetics Commission, 2005), but problems of definition were not further explored. In the USA, an attitude survey conducted to explore ‘Reproductive Genetic Testing: What America Thinks’ (Genetics and Public Policy Center, 2004) found that, ‘a majority of Americans think that testing for health-related purposes is an appropriate use of reproductive genetic testing’, but the purposes were described only in broad terms (‘fatal childhood disease’, ‘adult onset conditions’), and as in the HGC consultation, the questions were couched in terms of tests that respondents felt should be available, rather than tests they personally thought they would use.

Research on the psychosocial aspects of prenatal testing for genetic disorders is extensive, but has been dominated by the two conditions—Down syndrome and cystic fibrosis—for which screening has been offered in the past. The majority of women hold positive attitudes to the availability of prenatal screening for

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these conditions and overall uptake rates are high (Green *et al.*, 2004). Inequalities have, however, been identified: although white and South Asian women in the UK hold similar, relatively positive, attitudes to screening for Down syndrome (Dormandy *et al.*, 2005), knowledge of Down syndrome is more limited among South Asians (Chilaka *et al.*, 2001), and in a recent systematic review, it was found that women of South Asian origin in the United Kingdom were less likely to be offered prenatal testing for Down syndrome and less likely to take up that offer (Rowe *et al.*, 2004). Prenatal carrier screening for thalassaemia is, in general, favourably regarded by UK Pakistani women (Ahmed *et al.*, 2005), but again inequalities have been identified in service provision (Atkin *et al.*, 1998; Davies *et al.*, 2000; Modell *et al.*, 2000; Rowe *et al.*, 2004). Since, for religious reasons, Pakistani women find testing and termination much more acceptable in the first trimester of pregnancy (Ahmed *et al.*, 2006), uptake rates in a service which cannot offer this have to be interpreted very cautiously. Ethnic group comparisons conducted in countries such as the USA (Kuppermann *et al.*, 2006), are not directly relevant because the minority groups in question are quite different.

Despite the expansion of prenatal testing programmes and the acknowledged importance of cultural factors (Weatherall, 2005) in their planning, little information is available on the attitudes of women from different cultural backgrounds to other kinds of prenatal genetic testing. A few studies have compared attitudes to testing and termination for different kinds of conditions, but only in special populations, such as the parents of affected children (Wertz *et al.*, 1991), or students (Milner *et al.*, 1998), or in countries with a very different demographic profile from the United Kingdom (Hietala *et al.*, 1995). The acceptability of testing and termination for specific conditions has been much more widely studied, predominantly in the context of counselling families known to be at increased risk of the disorder: cystic fibrosis (Denayer *et al.*, 1991; Lafayette *et al.*, 1999; Murray *et al.*, 1999; Henneman *et al.*, 2001), Fragile X (Murray *et al.*, 1997; Skinner *et al.*, 2003), breast cancer (Lodder *et al.*, 2000), achondroplasia (Gollust *et al.*, 2003) adrenoleukodystrophy (Costakos *et al.*, 1991), and a variety of other rare conditions have been studied in predominantly white populations. Acceptability of prenatal testing for Tay-Sachs has been studied in Jewish populations (Kronn *et al.*, 1998) in the United States and elsewhere, and haemoglobin disorders in a variety of countries including Saudi Arabia (Alkuraya and Kilani, 2001), Lebanon (Zahed and Bou-dames, 1997) and Pakistan (Ahmed *et al.*, 2000). This body of literature shows that across a range of conditions and populations, prenatal testing is acceptable to a proportion of families who already know they are at increased risk of a specific disorder. More detailed comparisons of acceptability between conditions and between ethnic groups are precluded by the 'one condition, one ethnic group' nature of the investigations. The latter kind of comparative information would, however, be valuable in the context of prenatal screening programmes offered

to the general population, such as those run in the United Kingdom by the National Screening Committee.

The nature of the condition is known to be influential in the decision to terminate a pregnancy, following the diagnosis of an abnormality (Evans *et al.*, 1996; Mansfield *et al.*, 1999; Statham, 2002; Zlotogora, 2002), but it has been acknowledged that the decision is not well understood. (Shaffer *et al.*, 2006). Religion is important, but as one factor among many, and different families make different decisions (Ahmed *et al.*, 2006).

Since attitudes towards different conditions vary between individuals, and preferences must be respected if informed consent is to be achieved. This is particularly important, but particularly difficult to achieve, when testing is being offered for multiple conditions. Some fear (Elias and Annas, 1994; Harris and Harris, 1995) that information overload may lead to 'misinformed' consent, and have recommended seeking generic consent to a battery of tests for serious conditions. This has the advantage, for some, that it enables seriousness to be decided by the medical profession, (Elias and Annas, 1994) but it would limit parents' freedom to fine-tune their screening decisions on the basis of personal values.

Little research attention has been paid to similarities and differences in the attitudes held by individual people to different conditions. Even studies which have looked at more than one condition have only compared the percentage of people who would consider a test, or a termination, for each of the conditions, rather than report, say, the percentage of people who would want a test for Down syndrome but not for cystic fibrosis (Wertz *et al.*, 1991; Evers-Kiebooms *et al.*, 1993; Hietala *et al.*, 1995; Bell and Stoneman, 2000). The present study aims to inform debate about screening for multiple conditions, by first comparing the attitudes of women from two different ethnic backgrounds to testing and to termination for a range of conditions, and then looking for any evidence of 'clusters' of attitudes to different conditions, for which prenatal testing might be offered as a package. White and Pakistani women were studied, the latter group being chosen because families of Pakistani origin comprise the largest minority ethnic group in the North of England, and also because our Institute has the necessary language and cultural resources to engage members of that community in research. Most Pakistani families living in the study catchment area have their origins in the Mirpuri region of Pakistan. Some women come to the United Kingdom on marriage, but many were born and educated here. Education is an important influence on health-related attitudes, so the white and Pakistani samples were recruited to achieve broad comparability in educational terms.

While it is acknowledged that many factors besides attitudes play a part in making real world decisions, no informed debate about generic consent can take place without an understanding of women's views, and the present study was designed to address that aim.

The focus of the study was the conditions themselves, not the way tests are presented, their accuracy or associated miscarriage risks. These factors are, of course, important influences on current test uptake, but

as considered further in the Discussion the relationships between them are complex and potentially altered by multiple testing and by other technological developments in the future. Study participants were women who had recently had a baby, because of researcher and Ethics Committee concerns about seeking women's views on tests that were not actually on offer.

MATERIALS AND METHODS

Questionnaire

A self-completion questionnaire was devised and piloted by a multidisciplinary group of clinicians and social scientists, based on the work of Wertz and colleagues (1991). It contained brief descriptions of real conditions chosen to include physical, mental and sensory disorders, and for their potential to reveal differences in attitudes towards testing and termination. The number of conditions was restricted to 30 to avoid overburdening participants and the conditions were purposely not named, to minimise the influence of preconceived ideas and because some names would be unfamiliar to participants. Participants were asked to assume that a hypothetical test carried out early in pregnancy, using routinely collected blood, would tell them definitely whether the baby had the condition in question.

For each condition, women indicated whether they would want a prenatal test and if they would consider termination should the baby be affected (Appendices 1 and 2). The questionnaires were designed to be self-completed and administered by post, but some were interviewer-assisted. A member of the research team was fluent in the relevant South Asian languages, and questionnaires were administered as appropriate, in English, Urdu, Punjabi or Mirpuri.

Sample and recruitment procedure

Women were recruited while pregnant but the questionnaires were completed about 6 weeks after delivery. Participants were selected to give approximately equal numbers from each ethnic group (defined in terms of family origins in the United Kingdom for the white group and family origins in Pakistan for the Pakistani group), and educated or not beyond General Certificate of Secondary Education (GCSE) or equivalent level. Clinic staff asked potential participants at routine antenatal appointments if they would agree to being approached by a researcher. If so, a researcher explained the project in the woman's preferred language, and sought informed consent to participate. The study was approved by the appropriate Local Research Ethics Committees.

Statistical analysis

Data management and simple statistical comparisons were conducted using SPSS Version 10.0 (SPSS Inc, 1999). A hierarchical clustering analysis (Johnson, 1962)

was conducted to identify any distinct clusters of conditions. The data were analysed in parallel using multidimensional scaling (Coxon, 1982) to examine the relation between attitudes to the different conditions: a measure of similarity was first calculated between each pair of conditions and the resulting information was represented as a map or spatial configuration. Separate analyses were conducted for the test and termination data.

RESULTS

Sample characteristics

Of those women who agreed to talk to a researcher, 83% agreed to participate, and 78% of the latter (65% of those who agreed to be approached) went on to complete questionnaires. The final sample consisted of 420 women: 222 white (109 educated above GCSE level) and 198 of Pakistani background (73 educated above GCSE level). Table 1 presents demographic data for these four subgroups.

Attitudes to prenatal testing and to termination of pregnancy for individual conditions

Figures 1 and 2 show the percentages of UK white and Pakistani women of differing educational levels answering 'yes' to the questions about testing and termination respectively. To facilitate comparisons, conditions are ranked in both figures in order of the percentage of the total sample who would consider testing, and summary information about testing is reproduced in Figure 2 to provide context for the termination data. For brevity, the names of conditions rather than the scenario descriptions are used from here on in presenting the results, and in the discussion to follow.

Figure 1 shows a high level of interest in prenatal testing: for most conditions, more than half the sample wanted testing. Attitudes converged at the 'more serious' end of the spectrum, where around four-fifths of women wanted prenatal testing for anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy, and severe learning difficulties.

Cochran's Q tests for the differences between correlated proportions (the proportion replying 'yes' for each condition) confirmed what was clear from the graph, namely, that in four subgroups interest in prenatal tests for different conditions varied significantly ($p < 0.001$ in each case).

Figure 2 shows that women from all four subgroups were most in favour of termination for the same four conditions (anencephaly, trisomy 13 or 18, quadriplegia, and Duchenne muscular dystrophy). From the graph it can be seen that attitudes to termination for severe learning difficulties—the condition which ranked fifth overall—were also relatively favourable

Table 1—Demographic characteristics of study participants

		White		Pakistani	
		Up to GCSE level	Above GCSE level	Up to GCSE level	Above GCSE level
		<i>N</i> = 113	<i>N</i> = 109	<i>N</i> = 125	<i>N</i> = 73
		<i>N</i> (%)	<i>N</i> (%)	<i>N</i> (%)	<i>N</i> (%)
Place of birth (missing data on 1 case)	UK	112 (99)	108 (99)	45 (36)	37 (51)
	Pakistan	0	0	79 (64)	34 (48)
	Other	1 (1)	1 (1)	0	1 (1)
Religion	None	40 (35)	33 (30)		
	Catholic	15 (13)	15 (14)		
	Other Christian	57 (50)	60 (55)		
	Islam	1 (1)	0	125 (100)	73 (100)
	Other	0	1 (1)		
How well do you speak English? (only asked of Pakistani participants)	Very well			54 (43)	56 (77)
	Fairly well			7 (6)	1 (1)
	Just a little			27 (22)	11 (15)
	Not at all			37 (30)	5 (7)
Preferred spoken language (only asked of Pakistani participants)	English			55 (44)	53 (73)
	Hindi			9 (7)	2 (3)
	Mirpuri			44 (35)	4 (5)
	Punjabi			7 (6)	5 (7)
	Pushto			3 (2)	0
	Urdu			7 (6)	9 (12)
Regional origin in Pakistan (missing data on 1 case)	Attock Dist.			26 (21)	4 (5)
	Mirpur Dist.			76 (61)	32 (44)
	Nowsera/Peshawar Dists.			2 (2)	0
	Punjab			17 (14)	35 (48)
	Sindh			3 (2)	2 (3)
First pregnancy?	Yes	43 (38)	58 (53)	31 (25)	34 (47)
	No	70 (62)	51 (47)	94 (75)	39 (53)
Age in years	Mean (SD)	28 (6.0)	30 (4.3)	26 (5.2)	25 (3.8)

in white women, but this feature was less apparent in Pakistanis. For the remaining 25 conditions, fewer than a quarter of participants from any of the subgroups said they would consider a termination of pregnancy.

Cochran's Q tests again confirmed that all four subgroups were much more likely to consider termination of pregnancy for some conditions than for others ($p < 0.001$ in each case).

Figure 3 shows the scattergram obtained by plotting the percentage of the Pakistani sample who wanted prenatal testing for each of the 30 conditions against the equivalent percentage from the white sample. Agreement was very high: the rank order correlation (ρ) between the two sets of values was 0.87. Figure 4 presents the data for attitudes to termination of pregnancy. Again, the correlation was very high: $\rho = 0.83$. These figures suggest that, despite differences between groups in the absolute levels of support for testing or for termination, the perception of *relative* severity was strongly shared.

Individual women's attitudes to prenatal testing, and to termination of pregnancy, for the 30 conditions

To avoid multiple comparisons, it was necessary to summarise attitudes across conditions. Each woman could say No, Not sure, or Yes to prenatal testing for each of the 30 conditions. Scoring these alternatives as 0, 1 and 2 respectively and adding the scores across conditions gave a measure with a minimum value of 0 (would not want testing for any of the 30 conditions) and a maximum of 60 (would want testing for all of the 30 conditions). This measure (Cronbach's $\alpha = 0.96$), revealed substantial variation in attitudes in both the white and Pakistani groups (Figure 5).

Non-parametric Mann-Whitney tests showed that Pakistani women had significantly higher scores than white women, in both the more ($z = -3.6$, $p < 0.001$) and less ($z = -4.6$, $p < 0.001$) educated subgroups.

A total score reflecting attitudes to termination for fetal abnormality ($\alpha = 0.94$) also revealed

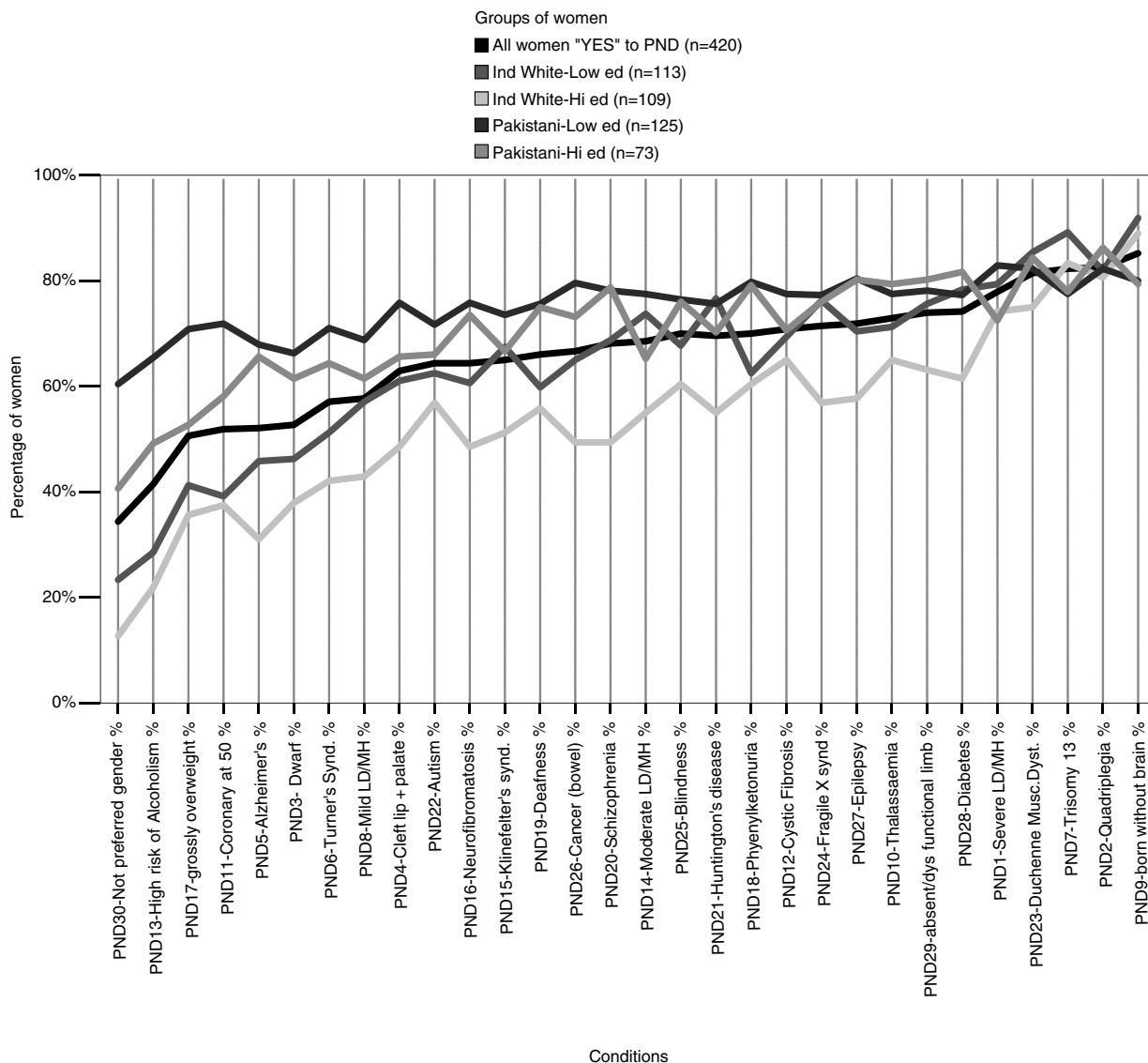


Figure 1—Women who said ‘Yes’ to PND in each group, and in full sample. Conditions are ordered by percentage in full sample saying ‘Yes’ to PND. 1SEVLD, Severe learning difficulty/mental handicap; 2QUADRI, Quadriplegia; 3DWARF, Dwarf; 4CLEFT, Cleft lip and palate; 5ALZHEI, Alzheimer’s; 6TURNER, Turner’s syndrome; 7TRI13, Trisomy 13; 8MILDLD, Mild learning difficulty/mental handicap; 9BRAIN, Born without brain; 10THAL, Thalassaemia; 11CORON, Coronary at 50; 12CF, Cystic fibrosis; 13ALCOH, High risk of alcoholism; 14MODLD, Moderate learning difficulty/mental handicap; 15KLINE, Klinefelter’s syndrome; 16NFIBR, Neurofibromatosis; 17OVERW, Grossly overweight; 18PHENY, Phenylketonuria; 19DEAF, Deafness; 20SCHIZ, Schizophrenia; 21HUNTI, Huntington’s disease; 22AUTIS, Autism; 23DUCHE, Duchenne muscular dystrophy; 24FRAGX, Fragile X syndrome; 25BLIND, Blindness; 26CANCER, Cancer (bowel); 27EPILE, Epilepsy; 28DIABE, Diabetes; 29LIMB, Absent/dysfunctional limb; 30SEX, Not preferred gender

considerable variability (Figure 6) but less favourable attitudes than towards testing.

Less educated Pakistani women had significantly lower scores than corresponding white women ($z = 3.37, p = 0.001$), but within the group of more educated women, the trend was much weaker and did not reach statistical significance ($z = 1.90, p = 0.057$).

The attitude summary scores computed to facilitate group comparisons had very skewed distributions (Figures 5 and 6), so statistical analyses were limited to the above nonparametric comparisons, and the predictive power of other demographic variables was not examined. However, as a check on the conclusions drawn from the main group comparisons, attitude summary scores were

again inspected, this time subdividing the Pakistani sample by place of birth: the pattern of attitude differences was as previously reported, whether the comparison with white women was made using information from Pakistani women born in the United Kingdom or born in Pakistan.

‘Clustering’ of responses to the 30 conditions

No differential clustering was evident in women’s attitudes to testing, but rather a single rather dense cluster of serious conditions was identified, with a succession

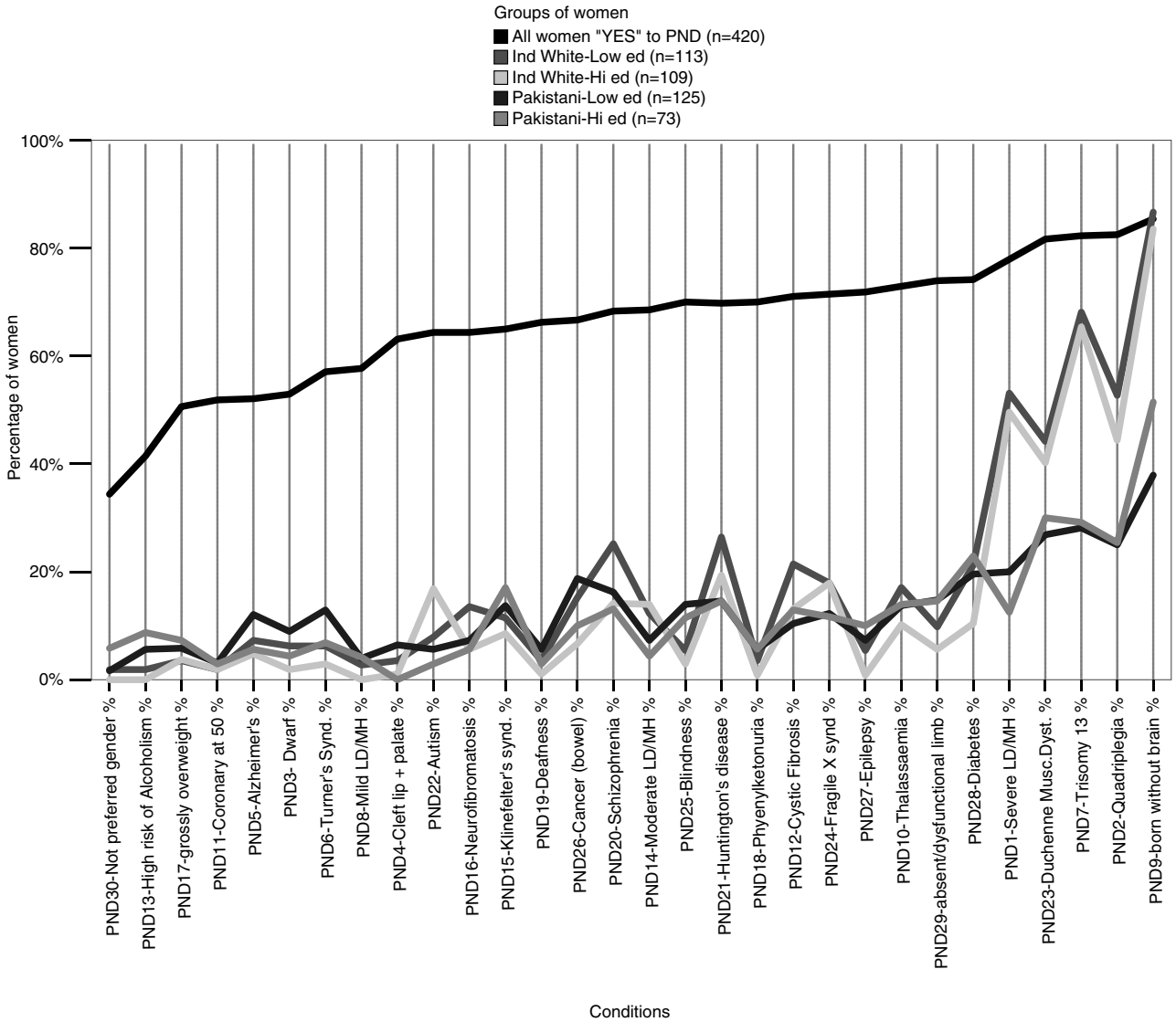


Figure 2—Women who said 'Yes' to TOP in each group. For purposes of comparison with Figure 1, conditions are still ordered by percentage in full sample saying 'Yes' to PND, and those percentages are given again. (For abbreviations see legend of Figure 1)

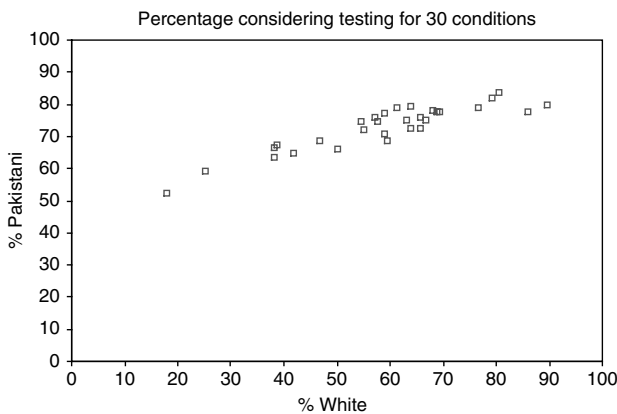


Figure 3—Percentage considering testing for 30 conditions

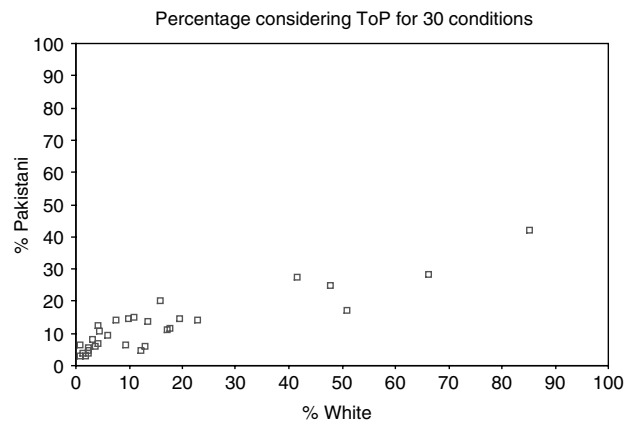


Figure 4—Percentage considering ToP for 30 conditions

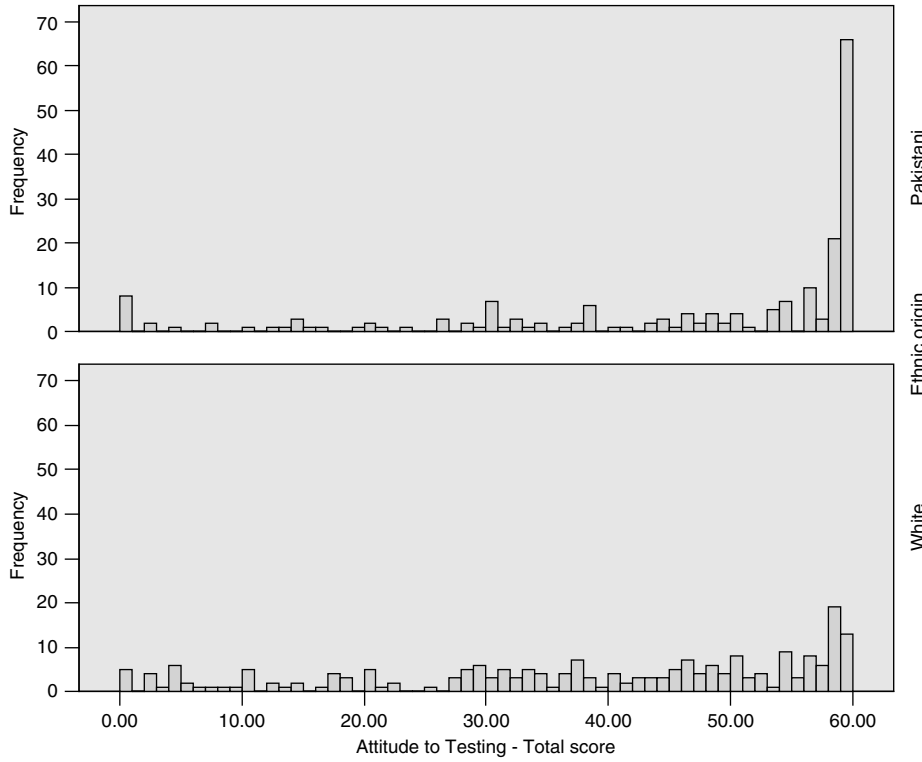


Figure 5—Pakistani and white women’s attitudes to prenatal testing

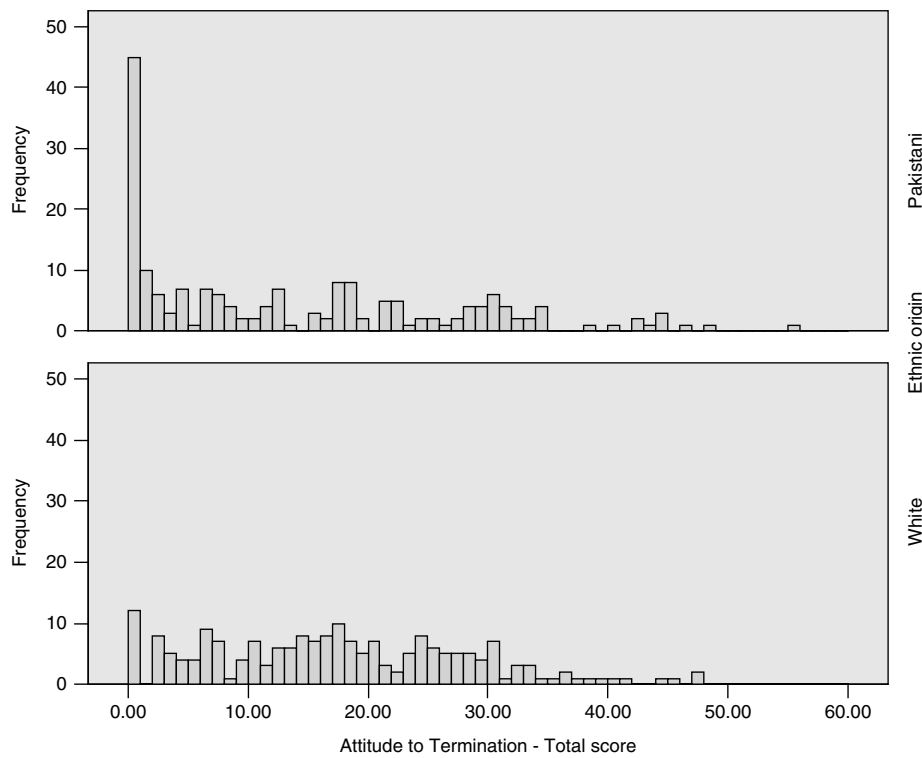


Figure 6—Pakistani and white women’s attitudes to termination of pregnancy

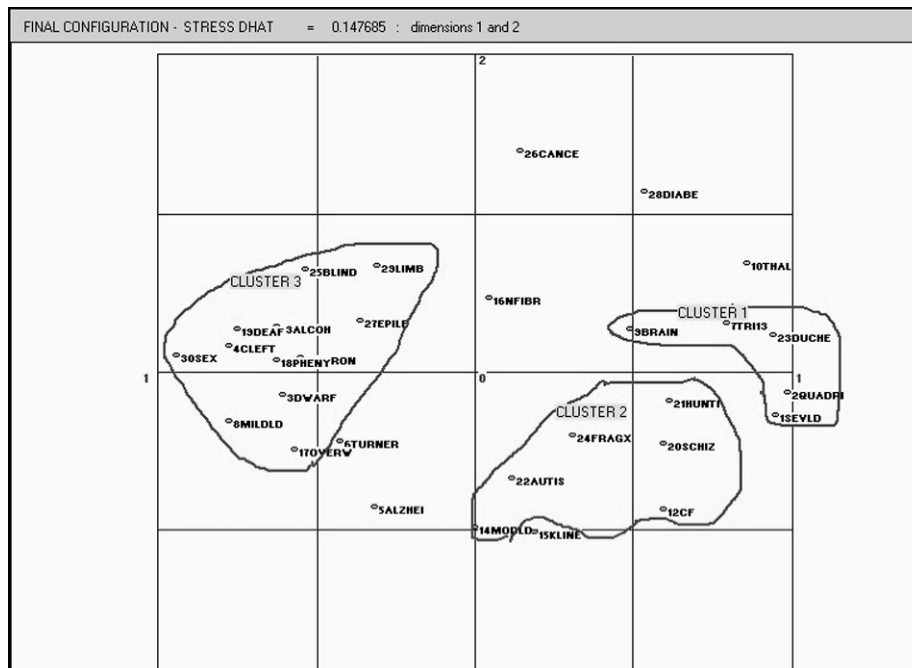


Figure 7—Termination 3 main clusters embedded in 2D configuration. Horizontal axis: Dimension 1, 'seriousness' Vertical axis: Dimension 2, uncertain interpretation. (For abbreviations see legend of Figure 1)

of waves of decreasingly serious conditions augmenting the core. The configuration arising from the multidimensional scaling analysis of these data had a two-dimensional structure, dominated by a first dimension which reflected the seriousness of the conditions (data not shown).

Attitudes to termination appeared to be more structured than attitudes to testing. Hierarchical clustering analysis revealed a 3-group solution: a central core of severely disabling conditions, a second cluster of serious conditions (ultimately merged), contrasted with a large third group of relatively less serious conditions. There was a 2D multidimensional scaling solution (Figure 7), again dominated by a first 'seriousness' dimension (plotted on the horizontal axis), but accommodating the three groups of conditions well. The second dimension (vertical axis) appears from inspection to have no simple interpretation, but retaining it permits a clearer representation of the results.

When separate analyses were conducted for each subgroup, the distinction between a cluster of more severe conditions and the rest could be seen even more clearly. The only exception to this was in the analyses of Pakistani women's attitudes towards prenatal testing, where attitudes were so favourable overall that no clear distinction could be made between clusters of more and less severe conditions.

DISCUSSION

We have shown that overall Pakistani women hold more favourable attitudes to prenatal testing, but less favourable attitudes to termination than their white

counterparts. Most women in both groups wanted some prenatal testing, and most would consider a termination for some conditions. However, less than a quarter of participants would consider a termination of pregnancy for the great majority of conditions studied. Many women, particularly in the Pakistani group, wanted prenatal testing for some conditions for which they would not consider a termination.

Anencephaly, trisomy 13 or 18, quadriplegia, Duchenne muscular dystrophy, and to a lesser extent, severe learning difficulties stood out from the rest. Even women who on the whole rejected testing or termination tended to make exceptions for these conditions. It could be argued that these were the conditions women regarded as the most 'serious' in the context of prenatal decision making.

The results of the study were of course obtained by asking hypothetical questions of women who had recently had a healthy baby. As discussed further below, pregnant women facing real decisions might make different choices, not least because of the miscarriage risk attendant on current procedures for diagnostic testing. In addition, the questionnaire's scenarios describing the various conditions had to be kept short, and their language simple. Different wording might have produced different results, and of course women facing a decision about having a diagnostic test today would be given much more information than we provided. The study was designed some years ago, and with hindsight we would have included sickle cell disease—now the subject of a National Screening Committee programme—in our list. This omission would clearly need rectifying if a similar study were to be conducted on other minority ethnic groups in the United Kingdom.

Recognising the limitations in the data, we remain unconvinced that evidence of 'clusters' in attitudes to different conditions could be used as the basis for a generic consent process for prenatal testing. Data aggregated across women can help policy makers gauge where demand lies and appreciate how similarities and differences between conditions are perceived overall. However, even within the four most serious conditions there remain substantive differences in the attitudes of individual women. Women who distinguish between particular conditions should have their views respected, even if most women's attitudes to those conditions tend to be similar. The distinction between aggregate and individual views may first be illustrated using two conditions, Duchenne muscular dystrophy and quadriplegia, both of which belonged to the cluster of 'serious' conditions. Attitudes towards them were strongly associated: 77% of the sample wanted testing for both conditions. However, 11% (44 women) only wanted testing for one of the two conditions (24 for quadriplegia and 20 for Duchenne). To take a second example: 68% of the sample wanted testing for both Duchenne and Huntington's, but another 15% (63 women) only wanted testing for one of these, 56 for Duchenne and 7 for Huntington's. In other words, although overall more people wanted testing for Duchenne than for Huntington's, a small minority took a different view. Many more such examples could be given, each showing a positive association overall between attitudes to the two conditions—which is the reason why the internal-consistency reliability (alpha coefficient) of the total score is so high—but also suggesting that an indivisible 'package' of prenatal tests would not be acceptable to women, except perhaps those who prefer to avoid 'information overload'.

Extrapolating to a multiple-test future from a single-test evidence base is also problematical for other reasons. We acknowledge fully that the results of our study are not directly generalisable to prenatal testing today, in large part because the miscarriage risk associated with CVS or amniocentesis constrains test uptake. However, a woman who has already undergone invasive testing for Down syndrome (or CF, or thalassaemia) incurs no extra risk to learn about other conditions. The possibility of extra information might also increase the uptake of diagnostic tests in these groups.

At present, miscarriage risk constrains the *offer* as well as the uptake of diagnostic testing, but there is some evidence (Caughey *et al.*, 2004) that 'a substantial proportion' of low risk women would be interested in invasive prenatal diagnosis for Down syndrome if it were offered. If the invasive procedure could also diagnose some of the other 30 conditions studied here, it seems likely that uptake in this group would also increase.

A technical breakthrough (e.g. obtaining fetal cells from maternal blood) would be required before women could fully act upon the testing preferences revealed in the present study. However, debates that are essentially about multiple testing, and what women prefer, have arisen already in the context of ultrasound scanning, and in the context of diagnostic testing following a CVS

or amniocentesis for Down syndrome, and this trend is likely to continue.

Advances in technology may make it easier for women to act upon their testing preferences, but termination decisions are likely to remain complex, and attitudes may be a poorer guide to behaviour. A meta-analysis of data on termination rates (Mansfield *et al.*, 1999) found big differences between conditions, similar to those found here, but closer comparisons are not possible because of sampling differences between the various studies. Age, parity, gestation, experience with different conditions, family circumstances, and the information and counselling provided are amongst the factors likely to be influential in decision making, and their role and interaction require further study (Shaffer *et al.*, 2006).

The results of the present study challenge a number of stereotypes about cultural differences, but they do not support the argument that 'consumer eugenics is a very real prospect' (Human Genetics Alert, 2000) in public attitudes to reproductive technology.

A recent review (Green *et al.*, 2004) concluded that informed consent was often not achieved even for Down syndrome screening, and even in special projects. The challenge posed by offering tests for multiple conditions, on a routine basis and in a manner perceived as 'balanced' by the majority, should not be underestimated, but must be addressed if the public are fully to realise the benefits of scientific and technological advances.

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Professor Bob Mueller of the Department of Clinical Genetics, St James's Hospital, contributed to the conception and design of the study. Professor Tony Coxon conducted the Multidimensional Scaling and Hierarchical Clustering Analyses.

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Competing interests: HC is a director of Leeds Prenatal Screening Service Ltd and Logical Medical Systems Ltd.


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Appendix 1—Extract from questionnaire

Please tick either 'Yes', 'No', 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?	
	No	<input type="checkbox"/>	No	<input type="checkbox"/>
	Yes	<input type="checkbox"/>	Yes	<input type="checkbox"/>
	Not sure	<input type="checkbox"/>	Not sure	<input type="checkbox"/>
1. 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"/>	No	<input type="checkbox"/>
	Yes	<input type="checkbox"/>	Yes	<input type="checkbox"/>
	Not sure	<input type="checkbox"/>	Not sure	<input type="checkbox"/>
2. Child would be unable to move from the neck down, require a lot of looking after and have a normal lifespan.	No	<input type="checkbox"/>	No	<input type="checkbox"/>
	Yes	<input type="checkbox"/>	Yes	<input type="checkbox"/>
	Not sure	<input type="checkbox"/>	Not sure	<input type="checkbox"/>
3. Child would have a normal lifespan and be extremely short.	No	<input type="checkbox"/>	No	<input type="checkbox"/>
	Yes	<input type="checkbox"/>	Yes	<input type="checkbox"/>
	Not sure	<input type="checkbox"/>	Not sure	<input type="checkbox"/>
4. Child would have a treatable cleft lip or palate, require medical interventions throughout childhood and have a normal lifespan.	No	<input type="checkbox"/>	No	<input type="checkbox"/>
	Yes	<input type="checkbox"/>	Yes	<input type="checkbox"/>
	Not sure	<input type="checkbox"/>	Not sure	<input type="checkbox"/>

Appendix 2—All 30 conditions in the order they appeared in the IHT questionnaire

1. 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.
2. Child would be unable to move from the neck down, require a lot of looking after and have a normal lifespan.
3. Child would have a normal lifespan and be extremely short.
4. Child would have a treatable cleft lip or palate, require medical interventions throughout childhood and have a normal lifespan.
5. Child would develop a degenerative mental condition by age 60, require a lot of looking after and possibly have a shortened lifespan.
6. Child would be a very short female who might have some medical problems, a normal lifespan and would not be able to have children.
7. Child would have severe learning disabilities/mental handicap, requires a lot of looking after and die within first few months of life.
8. Child would have mild learning disabilities/mental handicap, able to work and live independently and have a normal lifespan.
9. Child would be born without a brain and die before or soon after birth.
10. Child would have a blood condition, require blood transfusions and medical treatment throughout life and have a shortened lifespan.
11. Child would be at high risk of heart attack (before age 50).
12. 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).
13. Child would be at high risk of becoming alcoholic and have a potentially shortened lifespan.
14. Child would have moderate learning disabilities/mental handicap, could communicate, have a normal lifespan and require a lot of looking after.
15. A male child would have mild learning disabilities/mental handicap or behaviour problems, unusually tall and not very masculine appearing, need some looking after, be unable to father a child and have a normal lifespan.
16. Child might have disfiguring large lumps on head and face, which are noticeable from a distance, have a normal lifespan and might need medical care in childhood.
17. Child would be grossly overweight and have a potentially shortened lifespan.
18. Child would have a blood condition that could cause mental problems if left untreated, have a normal lifespan and have strict diet restrictions throughout life.
19. Child would be deaf from birth and have a normal lifespan.
20. Child would have a normal lifespan and a high risk of developing mental illness in adulthood, need some looking after and long-term medication, be unable to work or relate to others.

(continued overleaf)

Appendix 2—(Continued)

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21. Child would develop an incurable condition by age 40, which has both severe mental and physical deterioration, require constant looking after and medical help and have a shortened lifespan.
 22. Child would have severe behavioural and communication problems, have a normal lifespan and require looking after.
 23. 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).
 24. Child would have a normal lifespan, behavioural and communication problems, have moderate learning disabilities/mental handicap and require looking after.
 25. Child would be blind from birth and have a normal lifespan.
 26. Child would develop bowel cancer in early adulthood, require surgery and medication and have a potentially shortened lifespan.
 27. Child would have a neurological condition that causes fits/convulsions from early life, have a normal lifespan and require long-term medication.
 28. Child would have a physical illness requiring daily injections, there might be possible complications such as heart and kidney disease, blindness, would have limitations on diet throughout life and have a potentially shortened lifespan.
 29. Child would have a normal lifespan and be born without an arm or a leg, or have an arm or a leg that does not function.
 30. Child is not the sex desired by the parents.
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