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Author(s): Helen Lloyd, Pratima Singh, Rowena Merritt, Adarsh Shetty, Jenny Yiend, Swaran Singh, and Tom Burns

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**A Comparison of Levels of Burden in Indian & White Parents with a Son or
Daughter with Schizophrenia**

RUNNING TITLE: Ethnicity And Parental Burden In Schizophrenia

Authors:

Helen Lloyd*, Pratima Singh, Rowena Merritt, Adarsh Shetty, Jenny Yiend, Swaran
Singh and Tom Burns

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*Corresponding Author

Dr Helen Lloyd, BA (hons), MSc, D.Phil

Department of Social Psychiatry

University of Oxford

Warneford Hospital

Oxford OX3 7JX

Tel:+ 44 (0)1865 223635

Fax:+ 44 (0)1865 793101

helen.lloyd@psych.ox.ac.uk

Dr Lloyd was responsible for the conception and design of the study along with Professor Burns, but was solely responsible for analysis and interpretation of the data and for drafting this article. The contributions, affiliations and qualifications of co-authors are detailed on the final page.

ABSTRACT

Background:

Caregiver burden in mental illness is believed to differ between ethnic groups, but few studies have examined this in schizophrenia in the UK.

Aim:

To measure burden in British North Indian Sikh and White British parents with a son or daughter with established schizophrenia managed in outpatient care.

Method:

A cross-cultural cohort study measuring family factors, patient psychopathology and levels of burden and distress.

Results:

Overall levels of burden were low with no significant differences between the groups. Burden subscale scores showed Indian parents were more affected by psychotic behaviours than White parents. The groups also differed on several socio-demographic variables.

Conclusion:

In stabilised community patients the overall extent of burden experienced by both Indian and White parents is low and comparable. However, Indian parents were more burdened by psychotic behaviours. This may be a result of co-residence as Indian patients are more likely to live with their families. Social and economic factors in the country of residence and levels of acculturation may also influence levels of burden and the illness behaviours found most bothersome by parents.

Declaration of Interest:

None.

Keywords:

Parental Burden, Schizophrenia, Ethnic Differences, Outpatients, Family.

INTRODUCTION

Inconsistent approaches to conceptualising and measuring caregiver burden generate considerable heterogeneity in research findings. This is further complicated by varied samples of both patients (e.g. in-patients, outpatients, newly diagnosed and chronic patients) and caregivers (e.g. parents, spouses and siblings). Studies of burden in caregivers of in-patients (Moller-Leimkuhler, 2005) and recently discharged patients (Lauber et al, 2003), have all reported higher levels of burden than those in stabilised community samples (Foldemo et al, 2005).

Few studies outside North America have examined levels of caregiver burden across different ethnic groups. White American caregivers report more negative consequences and burden than Black American caregivers (Horwitz & Reinhard, 1995), even though the former were less likely to reside with their ill son or daughter (Guarnaccia & Parra, 1996). No previous studies have directly examined differences in burden among carers from Indian and White families in the UK. Expressed emotion studies find higher EE scores for White than Indian carers (Wig et al, 1987) raising the possibility that caregiver burden may be higher in UK Whites than in UK Indians.

MATERIAL AND METHODS

Setting and Samples

The sample comprised two groups of patients diagnosed with schizophrenia and their primary carers (parent with the most contact): British North Indian Sikh (Indian) dyads (n. 23) and White British (White) dyads (n. 16). The Indian group were recruited from Southall, Middlesex, which is home to a large homogenous North Indian population, and the White group were recruited from areas adjacent to Southall and from East Oxford. Indian parents were all born and raised in North India and migrated as adults to the UK. Indian patients were either born and raised in the UK or migrated here before the age of 11. Local ethical approval was obtained from West London Mental Health Trust and Oxfordshire Mental Health Trust.

The sample was obtained by an extensive and systematic review of community mental health team caseloads in Southall, Northolt and East Oxford. Key-workers and care coordinators approached patients about the study or gave approval for their patients to be contacted. Patients who agreed to take part were interviewed and asked to nominate their primary parental carer. Nominated parents were contacted and interviewed by a researcher blind to that patient's symptoms and functioning. Eligible patients were: aged 18-50 years, White British or British North Indian Ethnicity (born in UK or arrived before age 11yrs), diagnosis of schizophrenia or schizoaffective disorder, 2-15 years duration of illness, living with, or in weekly contact with a parental carer, in regular contact with community mental health services and able to provide written informed consent.

Instruments

All instruments used for the study were well known and well validated. We obtained a Hindi version of the General Health Questionnaire (GHQ-12) for use with the Indian parents, but SS, a native Punjabi speaker translated the Perceived Family Burden Scale (PFBS) for the purposes of this study with the help of a Hindi speaking research assistant.

All parents completed the PFBS, which was designed (Levene et al,1996) to investigate family interaction predictors of early relapse in schizophrenia. It distinguishes between objective and subjective components of family burden by asking first if symptom behaviours are present and second if they are bothersome. Each of the 24 items is rated on a 4-point Likert scale covering 'not at all', 'a little', 'considerably' or 'a great deal'. Behaviours form the following four clusters: anxiety-depression (looks fearful, looks sad, mopes, threatens suicide, acts suspicious and self harms), uncritical (talks loudly, yells, talks nonsense, laughs frequently, uses abusive language, paces), passivity (stays in bed, hardly talks, looks messy) and aggression (refuses medicines, refuses help, threatens violence, throws things, harasses others, blames others).

Parents also completed the GHQ-12, which is used to measure distress and to screen for psychiatric morbidity in the general population and has good levels of validity and reliability (Goldberg & Williams, 1998). The 12-item version is quick and easy to administer and can be scored using a Likert scale (1-2-3-4) or as a screening instrument using bimodal scoring (0-0-1-1). It has been validated (Jacob, et al, 1997) in Indian women living in Southall with an optimal threshold for caseness of 2/3.

Social and demographic characteristics were collected from both parents and patients. Indian parents were interviewed with a translated version of the parent interview by Hindi/Punjabi speaking researchers (PS and AS), and White British researchers (RM and KK) interviewed White parents. Parents were interviewed at home within 4 weeks of their son or daughter's interview.

Patient diagnosis was confirmed by the International Classification of Diseases (ICD-10) diagnostic criteria for research (DCR) (World Health Organisation, 1992). Patient psychopathology was measured by Positive and Negative Symptom Scale (PANSS) (Kay, Fishbein et al, 1987). All patient interviews were conducted by HL.

Statistical Analyses

This study had 77 % power at 5 % significance level to detect medium to large effects according to Cohen's guidelines (Cohen, 1992). Group differences were investigated using ANOVA (with group as a between participants variable and subscale as a within participant variable), independent *t*-tests or Mann-Whitney *U*-tests (where the data did not meet the assumptions required for parametric tests). Chi-squared tests (χ^2) were used to analyse categorical variables in both the patient and parent groups. Fisher's exact test (*FET*) was used to analyse categorical data where expected cell values in the contingency table were less than 5.

RESULTS

The case notes of 1849 patients were screened in four community mental health teams (see figure 1). Of these 1728 were excluded on the basis of diagnosis, duration of illness, ethnicity, age or because they did not have a parental carer. Of the 121 patients eligible and approached to take part, 60 were White and 61 were Indian. Sixteen of the White sample agreed to participate. Of the 44 White refusals 27 were from parents and 17 from patients. Twenty-three of the Indian sample agreed to participate. Of the 38 Indian refusals 21 were from parents and 17 from patients. In total 82 dyads declined participation. Patients refused to participate because they were “too ill” (n.15) or because “taking part would cause distress for themselves or their families” (n.19). Parents were either too busy (n. 20), or reluctant to talk about their son or daughter for the purposes of the interview (n. 28). **There were no differences between the groups in reasons for refusing study entry, and a comparison of participants and non-participants in terms of age, sex, diagnosis and duration of illness were also performed and revealed no differences between the groups. The slight difference in participation rates between the two groups may be explained by the more positive attitudes towards the psychiatric profession held by Indian families.** The small sample sizes were a consequence of high refusal rates, which are common problems in studies of individuals with schizophrenia (Lester & Wilson, 1999), but in this study were also exacerbated by the addition of parental refusal rates, a problem which has been acknowledged by other studies recruiting both patients and carers (Jenkins & Schumacher, 1993; Szmukler et al, 1998).

<Figure 1 here>

Socio-demographic characteristics

Table 1 shows the socio-demographic characteristics of the samples at baseline. Two-thirds of Indian and three-quarters of the White parents were female. Three quarters of White parents were educated to A-Level standard or equivalent compared to just over a quarter of Indian parents. However, none of the White parents progressed beyond A-level, whereas just

under a fifth of Indian parents attained tertiary level education. None of the White parents were 'unemployed' at baseline compared to over one third of the Indian parents. The majority of Indian parents lived with family compared to just over half of White parents, and the former were 3.6 times more likely to live with their son or daughter than their White counterparts. Indian households were also larger than White households. There was no difference between the groups in the proportion of parents who owned and rented properties.

Just under a quarter of Indian patients were married compared to just one White patient. Indian patients were 4.7 times more likely to live with their families than White patients. Indian patients had higher PANSS negative symptom scores than White patients, but did not differ significantly from the White patient group in duration of illness or other symptoms.

<Table 1 here>

Perceived burden scores

The overall scores for objective and subjective burden were low, and there were no statistically significant differences between the two groups of parents (Table 2). In addition, the mean GHQ scores of parents did not meet the threshold scores for caseness (distress or serious psychological morbidity) and there were no differences between the groups. Analysed in accordance with the binomial scoring system (i.e. 0-0-1-1) just over a third of the Indian parents, and one fifth of the White parents showed evidence of mild distress. A smaller number in each group (Indian: 3, White: 2) scored higher indicating moderate to severe psychological morbidity. There were no statistically significant difference Indian and White parents in GHQ caseness.

<Table 2 here>

Table 3 shows the PFBS cluster scores for both Indian and White parents. A 2 x 4 ANOVA with between participant factor Group (Indian, White) and within participant factor Subscale

(anxiety/depression, passivity, uncritical, aggressive) was conducted for objective and subjective scores separately. This approach appropriately controls for Familywise error rates where a scale comprises several separate subscales which are to be considered separately (Howell, 2007). Main effects of Group were not significant ($F_s < 1$) indicating no overall group differences in burden scores. Main effects of subscale reflected generally lower ratings on the aggressive cluster compared to others ($F_s > 4.5$, p 's $< .005$). There was a significant Group x Subscale interaction on objective ($F(3,111) = 6.22$, $p = .001$, partial $\eta^2 = .14$) and subjective ($F(3,111) = 7.32$, $p < .001$, partial $\eta^2 = .17$) burden measures. Bonferroni corrected follow up t -tests were conducted to elucidate the nature of this interaction. These revealed significant group differences on the uncritical cluster alone (yells, laughs frequently *etc.*), for objective ($t(36.4) = 2.83$, $p < .01$) and subjective ($t(36.4) = 2.74$, $p < .01$) burden (Figures 2 & 3).

<Table 3 here>

<Figures 2 & 3 here>

DISCUSSION

Parents social and demographic & baseline characteristics

There were some striking differences between the two groups of parents. Indian parents achieved a higher level of education despite a greater proportion of White parents receiving foundation level education. These findings appear to reflect national patterns where a greater proportion of British Indians achieve above average education levels (Department for Education and Skills, 2006) and have greater participation rates in higher education than Whites in the UK (Connor, 2003). These differences may reflect gender and social norms in the country of origin or, alternatively, may be a consequence of interrupted schooling caused by migration to Britain. At interview more White parents were employed than Indian parents. In the UK, British Indians have slightly higher unemployment rates than their White British counterparts (7% Vs 5%), while unemployment in other minority groups is substantially

higher (Smith, 2000). There were no differences in the number of Indian and White parents who were retired or considered their main role as a housewife.

The majority of Indian parents lived with other family members, who nearly always included their ill offspring, whereas White parents lived alone or with a spouse. Similar patterns of residence have been reported by other studies comparing White families with other ethnic groups (Bulger et al, 1993). Indian households were larger than White households, a finding which also seems to reflect national patterns (Office National Statistics, 2002). The high rates of home ownership in both groups also reflect UK patterns with British Indians and White Britons having higher rates (76 % and 69 % respectively) than other ethnic groups (Office of National Statistics, 2005).

Patients social and demographic baseline characteristics

Indian and White patients were similar in many respects. They were comparable in age and time in general education but more Indian patients were educated to degree level. Given the age of onset of schizophrenia it is striking that over one third of the Indian patient sample was educated to this level. This may reflect the considerable emphasis placed on the value of education and business success by the North Indian British community, and the support provided by Indian families in their co-resident patterns.

The most dramatic difference was the number of Indian patients who were married. Clearly this reflects the importance of marriage and family in Indian community and Dharmic religions. In addition, Indian family cultural norms and kin involvement may also significantly increase marriage opportunities for mentally ill relatives.

The high rates of home ownership and educational achievement of UK Indians suggests that they are relatively well acculturated compared to other ethnic groups in the UK. However, patterns of kin residence and the importance of marriage suggest the maintenance of strong cultural traditions from the country of origin.

Patient clinical characteristics

Clinically the samples were very similar apart from Indian patients having higher negative symptoms scores. Our patients were mild to moderately ill with symptoms scores ranging from average to below average for medicated community patients (Kay et al, 1987).

Levels of burden & psychiatric morbidity in parents

Generally both Indian and White parents experienced low levels of burden, a finding reported in other studies (Foldemo et al, 2005; Moller-Leimkuhler, 2005) and there were no differences between the groups. Low objective burden scores suggest that parents experienced few bothersome behaviours in their offspring, and the low subjective burden scores suggest that the behaviours they reported gave them little cause for concern. These burden levels reflect the mild/moderate symptom profile of the patients.

High levels of burden have been consistently associated with high psychological distress in caregivers (Barrowclough & Parle, 1997; Provencher et al, 2003) but the direction of causality is unclear. Therefore it was not a surprise when levels of parental distress were generally low with no differences between the groups. Only one third of the Indian sample and one fifth of the White sample experienced mild distress measured with the GHQ. This proportion of distressed Indian parents was lower than some caregiver burden studies in mental illness (Bibou-Nakou et al, 1997) and comparable with others (Magliano et al, 1999). The proportion of distressed White parents was unusually low when compared to GHQ case levels of 29-60 % reported by other studies (Winefield & Harvey, 1993). Indeed the proportion of White parents reporting distress in this study was just above that reported for community samples (Goldberg et al, 1976). These low levels of distress suggest that the burden levels we recorded are accurate and not an underestimation due to small sample sizes.

Indian parents were significantly more burdened than their White counterparts by positive psychotic behaviours (uncritical cluster). Several studies of caregiver burden and schizophrenia have demonstrated that the strongest predictors of burden are patient symptoms (Lowyck et al, 2004; Madianos et al, 2004; Provencher & Mueser, 1997). Pai & Kapur (1982) also found a significant correlation between patient symptoms and family burden in India. In our study, Indian patients had higher negative symptom scores than White patients and as such one might expect Indian parents to report more concern with symptoms in the passivity cluster. However, this does not appear to be the case, and the data suggests that Indian parents may be more tolerant of passivity behaviours and more sensitive to positive psychotic behaviours. This may, possibly, be a consequence of living with their ill offspring.

Co-residence

Other studies have also found that co-residence was associated with burden in parents (Jenkins & Schumacher, 1999; Thornicroft et al, 2004). Pai and Kapur (1981) found that the behaviours most burdensome to family members in India were those which disrupted family routines and induced stress in other family members. In our Indian sample yelling and using abusive language are those that impact most on family members, and are therefore most burdensome, particularly in larger and more crowded households. However, these findings differ from those reported by Gopinath & Chaturvedi (1981), where relatives of patients with schizophrenia in India found behaviours related to inactivity and poor self care more distressing. Why this difference exists is unclear; one explanation might be that relatives in India are more likely to rely on ill family members economically and are therefore more distressed by work inactivity (Gopinath & Chaturvedi, 1992). None of Indian parents in our study were financially dependent on their ill offspring.

The limitations of this study were the small sample sizes and a possible selection bias (patients agreeing to take part being less ill or in more harmonious relationships with their parents), both of which may have increased the possibility of finding false negatives. In

addition the samples were deliberately restricted to control for confounding variables (e.g., kin relationship, severity of illness), which may obscure potential relationships between ethnicity and burden. Furthermore, restricting the study to patients with an established illness resulted in a relatively stable sample with mild-moderate illnesses; this narrowed the range of observed burden scores.

The findings from this study suggest that the extent of parental burden in UK Indians and UK Whites may be comparable, while some of the behaviours that influence it may differ. Also, UK Indians may also share some similarities with carers in India, as co-resident living patterns and notions of familial respect are highly valued core cultural elements that are retained despite migration. The interaction of local socio-economic and patient clinical factors (e.g. the relative affluence of this North Indian Punjabi Sikh population and stabilised patients) may explain the similarities between the two UK groups, while cultural patterns of co-residence explain the similarities with non-migrant Indians. **An investigation of the socio-demographic, clinical and service use determinants of burden in these samples was performed and will shortly be reported in a linked paper (Lloyd et al, in prep).**

This is the first study to examine burden in a roughly matched sample of British Indians and White British parents caring for a son or daughter with schizophrenia. As such the findings are preliminary and require further investigation. Nevertheless, these results challenge the prevalent notion that Indian families cope markedly better and require less support than White British Carers. Therefore clinicians may wish to consider the potential sensitivity to psychotic behaviours among Indian carers. In addition, those responsible for allocating or organising funding and resources may also wish to consider that Indian carers require the same support as White British carers.

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DISCLOSURE

The preliminary results of this study were presented at the European Network for Mental Health Service Evaluation (ENMESH 2006).

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Figure 1 Consort Diagram of Study Sample

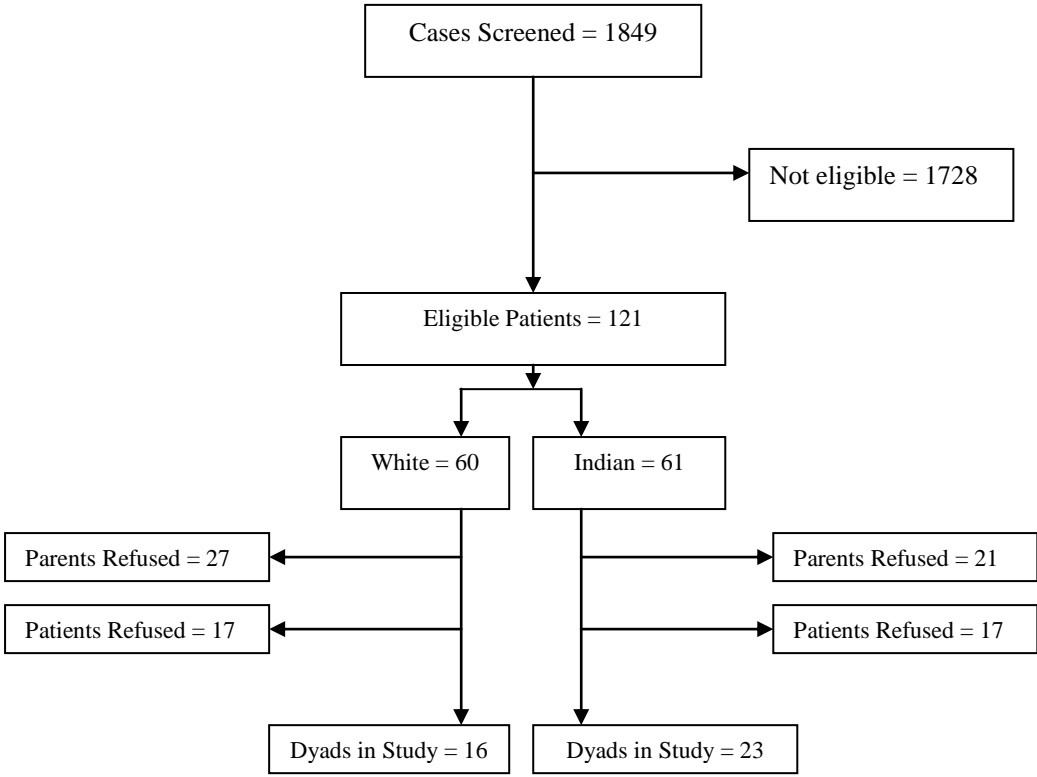


Table 1 Characteristics Of Parents And Patients

	INDIAN (n = 23) %		WHITE (n = 16) %		Stats
Parents					
Gender, female	14	61 %	12	75 %	
Age, years: mean (s.d.)	58.9	(9.96)	60.4	(11.9)	
Years in General Education: mean (s.d.)	9.82	(5.33)	11.5	(1.82)	
Highest Level of Education:					
Primary or less	14	61 %	4	25 %	
Secondary (incl. A levels)	5	22 %	12	75 %**	** p= 0.01
Tertiary (Degree or higher)	4	17 %	0	0 %*	* p=<0.05
Occupational Status:					
Employed	6	26 %	9	56 %	
Not Employed	8	35 %	0	0 %**	** p=<0.01
House W/H or Retired	9	39 %	7	44 %*	* p=<0.05
Marital Status:					
Married	12	52 %	7	44 %	
Separated/divorced	3	13 %	6	37 %	
Widowed	8	35 %	3	19 %	
Usual Living Situation:					
Alone or with Spouse	2	9 %	6	37.5 %	
With Family	21	91 %	10	62.5 %*	* p=<0.05
Living with Patient:					
Yes	17	74 %	7	44 %*	* p=<0.05
No	6	26 %	9	56 %	
Size of Household: No. of Adults (Lower quartile, Upper quartile)	3.00	2.00-4.00	2.00	1.00-3.00*	* p=<0.03
Type of Accommodation:					
Owned	19	83 %	13	81 %	
Rented	4	17 %	3	19 %	
Patients					
Gender, female	7	30.4%	6	37.5 %	
Age, years: mean (s.d.)	31.5	5.96	34.0	7.68	
Years in General Education: mean (s.d.)	12.5	1.07	12.3	1.85	
Highest Level of Education:					
Primary or less	2	8.7 %	1	6.3%	
Secondary (incl. A levels)	12	52.2 %	12	75.0%	
Tertiary (incl. Degree)	9	39.1 %	3	18.7%	
Occupational Status:					
Sick leave/Unemployed	12	52.2 %	11	68.7%	
Protected work/study	6	26.1 %	4	25 %	
Paid employment	5	21.7 %	1	6.3%	
Marital Status:					
Single	18	78.3 %	15	93.7%*	* p=<0.05
Married	5	21.7 %	1	6.3%	
Usual Living Situation:					
With Family	18	78.3 %	8	50 %*	*p=<0.05
Not With Family	5	21.7 %	8	50 %	
Size of Household:					
No. of Adults: mean (s.d.)	3.5	2.7	2.4	1.7	
Type of Accommodation:					
Privately Owned	11	47.8 %	5	31.3 %	
Rented private/council	12	52.2 %	11	68.7%	
PANSS score: mean (s.d.)	69.9	16.7	59.9	14.6	
Negative symptom score: mean (s.d.)	19.2	5.89	15.6	4.84*	*p=<0.05
Positive symptom score: mean (s.d.)	17.1	6.39	14.8	6.05	
Duration of illness, years mean: (s.d.)	8.12	3.89	9.53	3.77	

Table 2 Burden and General Health of Parents

	INDIAN (n = 23)		WHITE (n = 16)		95 % CI of Difference	
					Lower	Upper
Perceived Family Burden Scale (PFBS):						
Objective Burden (report of behaviours): mean (s.d.)	7.13	(4.79)	5.50	(4.66)	-1.49	4.75
Subjective Burden (appraisal of behaviours): mean (s.d.)	21.7	(17.5)	16.0	(16.0)	-6.07	16.3
General Health Questionnaire-12 (GHQ-12): mean (s.d.)	12.6	(4.98)	12.5	(6.93)	-3.81	3.90

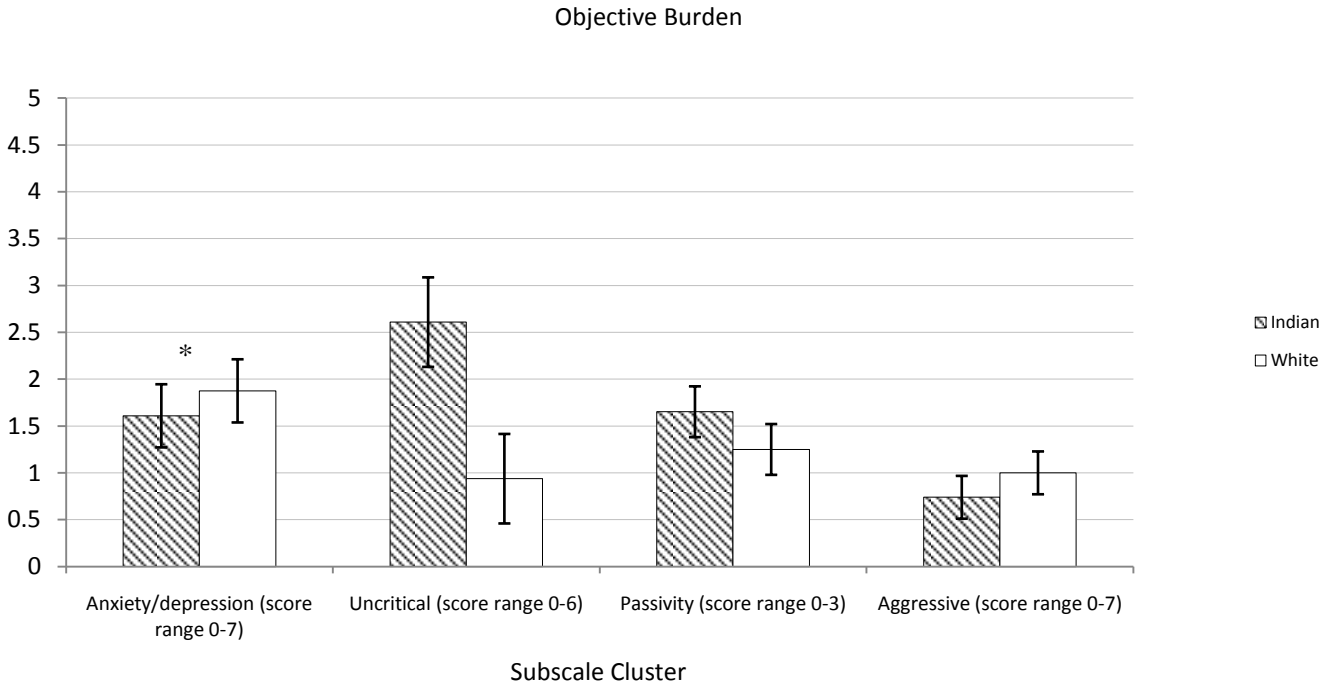
* $p < 0.05$, ** $p = 0.01$

Table 3 Perceived Family Burden Scale Cluster Scores

		INDIAN (n = 23)		WHITE (n = 16)		95 % CI of Difference	
						Lower	Upper
Anxiety/depression mean (s.d.):	OB	1.60	(1.51)	1.87	(1.25)	-1.20	.668
	SUB	4.86	(5.47)	5.62	(4.66)	-4.16	2.65
Uncritical mean (s.d.):	OB	2.60	(2.29)	0.93	(1.38)**	.473	2.86
	SUB	7.34	(7.65)	2.18	(3.97)*	1.34	8.97
Passivity mean (s.d.):	OB	1.65	(1.30)	1.25	(1.06)	-.396	1.20
	SUB	4.78	(4.84)	3.06	(2.86)	-.789	4.22
Aggressive mean (s.d.):	OB	0.79	(1.09)	1.00	(1.67)	-1.15	.636
	SUB	2.04	(3.85)	3.18	(5.69)	-4.23	1.94

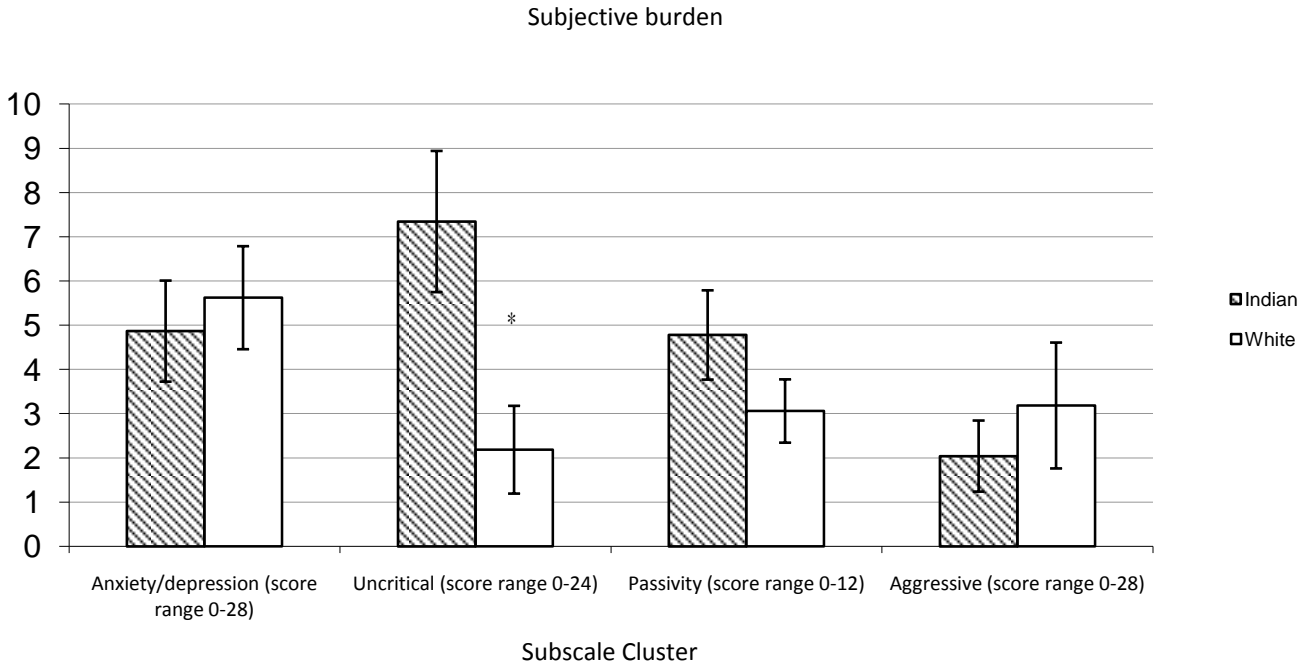
* $p < 0.05$, ** $p = 0.01$

Figure 2 Mean Objective Burden Cluster Scores



* group contrast significant at $p < .01$

Figure 3 Mean Subjective Burden Cluster Scores



* group contrast significant at $p < .01$

Contributions, affiliations and qualifications of co-authors:

Dr Pratima Singh MBBS, MRCPsych

Specialist Registrar General Adult Psychiatry

University of Oxford

Current: Oxleas NHS Foundation trust.

Dr Singh made a substantial contribution to data collection and commented on manuscript draft.

Dr Rowena Merritt BSc (hons) D.Phil

Research Assistant

Department of Psychiatry

University of Oxford

Dr Merritt made a substantial contribution to data collection and commented on manuscript draft.

Dr Adarsh Shetty MBBS, MRCPsych

Specialist Registrar

University of Oxford

Current: Nottinghamshire Healthcare NHS Trust

Dr Shetty contributed to data collection and commented on manuscript drafts.

Dr Jenny Yiend D.Phil

Department of Psychiatry

University of Oxford

Dr Yiend contributed statistical advice and analyses and commented on drafts of the manuscript.

Professor Swaran Singh MBBS, MD, MRCPsych

Honorary Consultant Psychiatrist,

East Birmingham Early Intervention Service

Professor of Social & Community Psychiatry

Warwick University

Professor Singh contributed to the design of the study and commented on drafts of the manuscript.

Professor Tom Burns CBE, DSc, FRCPsych

Professor of Social Psychiatry

University of Oxford

Department of Psychiatry

Professor Burns contributed to the design of the study, supervised Dr Lloyd and made substantial contributions to the manuscript.