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Family burden of schizophrenia and depressive illness

Specifying the effects of ethnicity, gender and social ecology

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Background The burdens experienced by relatives of mentally ill persons are substantial.

Aims To study the relationship between family burden and sociocultural context.

Method A comparative study of Euro-Americans and Latinos ascertained whether dimensions of family response are (a) non-specific to diagnostic groups; and/or (b) variable across cultural settings.

Results Regardless of diagnosis or ethnicity, patient misery was found most burdensome and distressing. However, considerable difference in shades of meaning and nuance across groups appears in relation to what is classed similarly as 'misery'. Only gender was significantly associated with social performance (males reported to have greater deficits). A complex cultural-ecological effect was observed among the Latino-schizophrenia group.

Conclusions Findings suggest similarities and differences in levels of family burden in relation to socio-cultural factors across cultural and diagnostic groups. The specificity of results by objective and subjective measures, types of burden, gender, ethnicity, diagnosis, and living situation confirm the importance of context and heterogeneity in understanding family burden and distress.

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The specific issues we examine in this paper originate with the question of whether persistent mental disorder affects families from different cultures in similar or different ways. This inquiry is relevant to both the clinical status of the patient and the well-being of the family. The clinical relevance of familial 'expressed emotion' has been established empirically as significantly associated with a patient's course of illness across a wide variety of cultural settings (Jenkins & Karno, 1992; Bebbington & Kuipers, 1994) and psychiatric conditions (Butzlaff & Hooley, 1998). However, specification of additional psychosocial factors which may be associated with a patient's course of illness is required, particularly in light of recent findings that have established a correlation between 'expressed emotion' and 'family burden' (Scazufca & Kuipers, 1996). There is ample documentation of the profound and pervasive effects of an identified case of mental disorder on other family members (Fadden *et al*, 1987; Schene *et al*, 1994). Research on family burden is critical to the conceptual and empirical expansion of what constitutes a 'case' of psychiatric disorder, that is, the scope of the social domain in which the illness is lived and managed. Cross-culturally, the most immediately relevant of social settings is the family or kin group, among whom mental disorder may reconstitute or ravage personal and social relations (Hatfield & Lefley, 1987; Ali & Bhatti, 1988). The aim of this paper is to investigate and compare the perceived family burden associated with mental disorder across culturally and clinically distinct groups.

LITERATURE REVIEW

In psychiatric research, the topic of 'family burden' continues to challenge empirical investigation, due to the various conceptual, measurement, and methodological difficulties associated with the concept

(Falloon *et al*, 1984). Historically, systematic attention to the notion of family burden began in earnest only with the advent of widespread policies of deinstitutionalisation. Relevant research during this early period included work by Grad & Sainsbury (1968) and Pasamanick *et al* (1967) who studied in-patient hospital treatment *versus* out-patient home care of mentally ill patients. A critical distinction between 'objective' and 'subjective' burden was introduced during this period: "Objective burden had effects on the household and subjective burden was the informant's own perception of whether the household had suffered some degree of burden" (Hoenig & Hamilton, 1967).

Platt and colleagues (1980) were one of the first research teams to introduce a discrete multi-dimensionality to the concept of family burden, with the Social Behaviour Assessment Schedule (SBAS; Platt *et al*, 1980), which consists of three dimensions: (a) disturbed behaviour; (b) social performance; and (c) adverse effects on others. Biegel & Milligan (1992) acknowledge efforts to dimensionalise family burden by observing that the stresses of caring within the family are multiple and pervasive for all families and diagnoses, which suggests the presence of distinct multiple dimensions. Schene (1990) refines the concept of 'objective burden' by specifying it concretely to cover tasks that the caregiver and his/her family carries out (e.g., helping, supervising, controlling, and paying) and activities they are themselves unable to perform (e.g., work, hobbies, clubs) because of their caregiving task. In contrast, 'subjective burden' is determined by how a family member experiences, or responds to, potentially distressing types of behaviour or situations (Schene, 1990). Hatfield & Lefley (1987) have usefully proposed three sets of factors for researchers to examine: (a) the meaning of the diagnosis of mental illness to the family, including its aetiology; (b) the living arrangement and caregiving responsibility; and (c) the type of support, understanding, and compassion provided by the community. To date, little empirical analysis of the relationships between these or other variables of relevance has been completed.

Specifying the context of family burden: ethnicity and class, gender, type of psychiatric disorder, and living arrangement

We shall now briefly cite available research on family burden involving the socio-

cultural variables of: (a) ethnicity and class; (b) gender; (c) diagnosis; and (d) type of living arrangement. Overall, the evidence of the socio-cultural characteristics of patients and the burden on the family caregiver is conflicting. Biegel & Milligan (1992) have suggested that there is little empirically convincing evidence available to support the relationship between family burden, and socio-demographic characteristics of patients, such as age, education, gender, ethnicity or social class. However, this conclusion has been challenged by recent trends which do support the relationship of socio-cultural variables to family burden.

Ethnicity and social class have received sparse attention in the literature in relation to family burden (Guarnaccia & Parra, 1996). The primary line of ethnicity-related research has examined the differential rates of mental health hospitalisation for ethnic groups (Lefley, 1994). In relation to family burden, Jenkins (1988) suggests that Hispanic families may conceptualise mental illness on a continuum, and that their ideas permit both acceptance of current disability and hope for the future; these cultural orientations may mediate the subjective dimensions of family burden. Tessler *et al* (1990) report that, when controlling for education, African-Americans seemed to be less tolerant of disruptive and psychotic behaviour, while Euro-Americans appeared to be less tolerant of patients who made no work-related contributions to the household.

Turning to the association of the gender of the patient and the family burden, 30 years ago Grad & Sainsbury (1968) reported no significant relationship. However, Mors *et al* (1992) report that if the patient is male, family stress levels are likely to be significantly higher. Chaves *et al* (1993) found that male patients fare worse than female patients on a family disability assessment scale. Further support for this finding comes from Scazufca & Kuipers (1996), who note that relatives of male patients with schizophrenia report more social deficits for male patients than for female patients. A critical point to bear in mind here is that not only the patient's gender but also the caregiver's gender must be considered. For example, the concept of family burden is often an implicitly 'gendered' notion, since the lion's share of primary caretaking is often provided by mothers, daughters, wives, sisters and other female kin.

Regarding types of psychiatric disorders, we find that most research into family burden thus far has concerned patients diagnosed as having schizophrenia. Mors *et al* (1992) reported on a comparative study that examined levels of family burden in families of subjects diagnosed as having schizophrenia, and in families with patients with other diagnoses. Investigators reported no differences in levels of family distress between the non-organic psychotic disorders, mood disorders, and anxiety disorders. Other studies report a pattern of differences in family burden, particularly when rating positive or negative symptoms (Mueser *et al*, 1997; Provencher & Mueser, 1997).

Commenting on living situations, George Brown *et al* (1962) long ago observed that the type of household in which patients reside was important to rehospitalisation: patients who had been hospitalised for schizophrenia who were discharged to live with kin fared worse than did their counterparts who settled into lodgings outside their family setting. The living situation or social ecology of the home environment may be expected to mediate the clinical course of illness and the type of family burden.

The foregoing review suggests the need for additional systematic research on the family burden of psychiatric disorders. Although a number of socio-cultural variables have been associated with levels of objective and subjective burden, more empirical research is needed to draw more informed conclusions. The large numbers of variables involved in family burden research suggests that a multivariate analysis strategy should be used to attempt to account for some of the many contradictions currently found. The present study was designed to take these factors into account by investigating the perceived family burden associated with mental disorder across culturally and clinically distinct groups.

METHODS

The study reported upon here is drawn from a five-year National Institute of Mental Health-sponsored study conducted in home and out-patient clinical settings. The general aim of the research was to investigate the relationships between psychosocial and cultural aspects of the experience of persistent mental disorder across different

ethnic and diagnostic groups (Jenkins, 1997; Coelho *et al*, 1998; Jenkins & Cofresi, 1998; further details available from the authors upon request). The study design called for a two-by-two comparative sample of 80 subjects divided into four groups of 20 by ethnicity (Latino and Euro-American) and diagnosis (schizophrenia and depression). An explicitly comparative design for the study of these questions can help to ascertain whether socio-behavioural features of family response are (a) non-specific to particular disorders, and/or (b) variable across cultural settings.

Participants were recruited from the out-patient facilities of northeastern Ohio in the United States. The research diagnostic criteria for schizophrenia or unipolar (non-psychotic) depression were the DSM-III-R criteria, based on a Schedule for Affective Disorder and Schizophrenia (SADS; Spitzer & Endicott, 1978) interview conducted by trained mental health professionals. The onset of all patients' illness had occurred at least two years before our research contact. Patients were all between 20 and 55 years old, were currently being treated in out-patient psychiatric facilities, and residing with, or in regular weekly contact with, family member(s). Patients with clinically significant substance abuse or organic conditions were excluded. As with any community sample of out-patients, these subjects exhibited a heterogeneous course of illness in terms of recovery and sustained illnesses, while remaining consistent with DSM-III-R criteria. Also recruited to the study was a key relative of each patient (family member with the most face-to-face contact and primary caretaking role), who was interviewed using a standardised family burden instrument (SBAS, described below). 'Latino' designates Spanish-speaking ethnic groups within the USA. 'Euro-American' refers to a group of ethnically heterogeneous English-speaking American residents of European heritage.

Table 1 summarises the socio-demographic and clinical characteristics of the sample of patients. Since data were missing for the key relative of one depressed Latino woman, there were only 79 patients in the sample. The majority of patients in the depressed group are female and in the schizophrenia group, male. At the time of the study, the mean length of illness for the group overall was 17 years since onset of psychotic or depressive symptoms. Many in the schizophrenia sample also suffered

from depression (33%). Overall, patients in the sample had high levels (over 85%) of prescribed medication and medication compliance at the time of entry into the study. Nearly all (95%) of the Latino patients are Puerto Rican (80% born on the island), with one Cuban and one Honduran. The majority (73%) of the Latinos are primarily or only Spanish-speaking and relatively unacculturated, with a mean score of 1.95 (s.d.=0.78) on our adapted five-point scale (initially formulated by Cueller *et al.*, 1980). The vast majority of the Euro-American families had resided in the US for at least four generations and all have English as their first language.

The socio-demographic and clinical characteristics of the key relatives are presented in Table 2. The vast majority (88%) of relatives caring for the schizophrenia group are women. Additional socio-demographic data indicate that most (60%) are mothers. This differs from the depressive group, where there was a greater representation of male relatives, many of whom were husbands. Thus the difference in relatives' gender can be accounted for by there being more married couples in this group.

'Family burden' can be defined as behavioural difficulties, social disruption, and adverse effects of illness on family (or significant others). The instrument we employed to measure this construct is the SBAS, developed in England by Stephen Platt and his colleagues (Platt *et al.*, 1980). This instrument has the advantage of measuring both objective and subjective degrees of burden in three separate domains: (a) patient's disturbed behaviour; (b) social performance; and (c) adverse effects on others. For each of these three domains, the key relative is interviewed to ascertain the objective presence of burden, assessed on a three-point scale (0=abstention; 1=present to moderate degree; 2=present to an extreme or severe degree). For example, in the case of the variable 'misery', 0=no or little misery; 1=crying or obviously miserable for part of the time; and 2=rarely cheerful or does not respond to attempts to cheer him/her up. If a particular type of behaviour is reported as present (either moderately or severely), then relatives are questioned further about the extent to which they find such comportment subjectively distressing (rated on the same three-point scale as the objective presence of the behaviour). The interviewer seeks to concentrate on the three-month period prior to interview.

Table 1 Socio-demographic and clinical characteristics of patients

	Latino		Euro-American	
	Schizophrenia (%)	Depression (%)	Schizophrenia (%)	Depression (%)
Mean age (s.d.)	37.5 (9.1)	42.9 (9.4)	34.0 (7.7)	39.8 (8.6)
Gender				
Female	35	75	35	70
Male	65	25	65	30
Education (years)	8.4	7.2	11.4	13.3
Household type				
Parental head	55	5.3	30	5
Married	10	47.4	15	65
Relative	30	36.8	10	10
Non-relative	0	5.3	30	5
Other	5	5.3	15	15
Marital status				
Single	70	30	50	25
Married/partner	15	55	15	65
Divorced/widowed	15	15	35	10
Social class (median)	5	5	5	3
Mean age at onset (s.d.)	20.8 (7.9)	23.7 (9.9)	21.4 (5.0)	21.2 (9.1)
Mean years illness (s.d.)	16.8 (7.3)	19.3 (9.5)	12.6 (5.9)	18.6 (9.7)
Mean admissions (s.d.)	4.2 (2.8)	1.1 (1.6)	4.8 (2.1)	1.9 (2.8)
Ever been hospitalised (% n)	84 (16)	45 (9)	95 (19)	50 (10)
Out-patient treatment				
<1 year	5	15	5	30
1-5 years	30	40	40	30
>5 years	65	45	55	40
Recent medication				
Yes	95	90	100	100
No	5	10	0	0
Adherence to recent medication				
Regular	80	65	80	95
Somewhat irregular	15	20	15	0
Very irregular	0	5	5	5
Not applicable	5	10	0	0

The SBAS interview was translated into local colloquial Spanish usage, via an iterative process of pilot testing and translation back and forth, to refine and clarify the instrument in the eyes of the local Hispanic community. At the conclusion of this process, neither the interviewers nor pilot respondents expressed any significant confusion about the nature of these clinically-oriented survey questions. Initial pilot use of the instrument revealed that the notion of 'burden' in relation to mental illness is culturally valid among Latinos, for whom statements of family burden may be expressed as *un gran carga* (a great burden/responsibility), *un gran peso* (a great

weight), or *un gran cruz* (a great cross) that *me causa mucho sufrimiento* (may cause one much suffering). Reliability between raters for the SBAS raw scores resulted in intra-class correlation coefficients of 0.85 or better for all six sub-scales, and a weighted κ statistic for reliability of the individual items was acceptable (80% or above) for all items.

RESULTS

Each of the global sub-scales (for disturbed behaviour, social performance, and adverse

Table 2 Socio-demographic characteristics by key relatives

	Latino		Euro-American	
	Schizophrenia (%)	Depression (%)	Schizophrenia (%)	Depression (%)
Mean age (s.d.)	50.6 (18.4)	38.5 (14.5)	49.7 (14.2)	39.6 (12.1)
Gender				
Female	85	36.8	90	55
Male	15	63.2	10	45
Education (years)	6.8	8.6	11.4	13.3
Marital status				
Single	20	21.1	10	10
Married/partner	35	53.1	65	70
Divorced/widowed	45	15.8	25	20
Living with patient				
Yes	85	84.2	40	60
No	15	15.8	60	40

effects on others) was analysed by stepwise multiple regressions.

Patient's disturbed behaviour: objective and subjective

Analyses of variance revealed no significant differences in the mean scores across groups. Only a slight trend for an interactive diagnostic-ethnicity effect was observed ($P=0.01$), with the Latino schizophrenia group scoring highest. Stepwise multiple regression proved uninformative with respect to socio-demographic and clinical characteristics (such as number of years ill, age, socio-economic status, gender, and severity of symptom scores as reported through the BSI-53 (Derogatis, 1993)). A similar non-significant finding was observed for subjectively assessed disturbed behaviour by the patient. To account for the similarity of response across these four groups, a further analysis was conducted of the individual items which comprise the sub-scale for 'disturbed behaviour'.

Specific analysis of the 22 separate items that comprise this sub-scale revealed a striking uniformity of response across both ethnic and diagnostic groups. The top-rated (or tied for top) item across all four groups (for objective scores) was the patient's 'misery'. That is, independently of whether patients were diagnosed as having schizophrenia or depression, were Latino or Euro-American, their relatives reported that the most frequently observed 'disturbed behaviour' was 'misery', as opposed to other symptoms such as 'odd

ideas' or 'somatic complaints'. This finding for misery was similar, but somewhat less consistent, for subjective distress scores.

Since the prominence of this individual factor could contribute to the appearance of cross-cultural and cross-diagnostic uniformity, masking differences reported for other kinds of disturbed behaviour and the distress they cause, we further analysed the individual items of this sub-scale and in Tables 3–6 the top 10 items are ranked in order.

Consider all items reported for at least 50% of respondents across the four groups. This analysis showed that for depressed Euro-Americans, after 'misery', only 'worrying'; and 'withdrawal' are reported to occur, and both of these types of behaviours are

subjectively perceived as highly distressing. For Latinos with depression, worrying, forgetfulness, and withdrawal are frequently reported. For the Euro-American schizophrenia group, worrying and withdrawal were mentioned frequently, but worrying is not often of great concern, and neither are of as much concern as underactivity, among six other common items of disturbed behaviour. Relatives of Latinos with schizophrenia are much less concerned with worrying and withdrawal than with odd ideas, underactivity, forgetfulness, irritability, and indecisiveness. Irritability is more often of greater concern in the Latino schizophrenia group than any other behaviour type; it is mentioned by only 37% of the Euro-American relatives of patients with depression.

Social performance: objective and subjective

Our initial analysis of relatives' reports of the objective existence of deficits in social performance showed a main effect by diagnosis, with patients with schizophrenia having poorer social performance than depressed. This is a result we might expect; however, further analysis revealed that variance between groups is almost entirely accounted for by gender ($P>0.001$). Relatives of male patients reported the presence of significantly higher deficits in social performance than did relatives of female patients. Thus gender turned out to be the only predictive variable for this sub-scale, overriding both ethnicity and diagnosis. Only a trend for an ethnicity-by-diagnosis interaction ($P=0.07$) was observed, with

Table 3 Euro-American patients with depression: disturbed behaviour ($n=20$)

Item	Objective Problem reported <i>n</i> (%)	Subjective Distress when problem present <i>n</i> (%)
Misery	16 (84)	13 (81)
Worrying	13 (68)	11 (85)
Withdrawal	11 (58)	9 (82)
Somatic complaints	9 (47)	6 (67)
Fearfulness	8 (42)	5 (63)
Underactivity	8 (42)	7 (88)
Forgetfulness	7 (37)	4 (57)
Indecisiveness	7 (37)	6 (86)
Irritability	7 (37)	7 (100)
Obsessional behaviour	6 (32)	3 (50)

Table 4 Latino patients with depression: disturbed behaviour ($n=19$)

Item	Objective Problem reported n (%)	Subjective Distress when problem present n (%)
Misery	15 (79)	11 (73)
Worrying	15 (79)	10 (67)
Forgetfulness	15 (79)	9 (60)
Withdrawal	14 (74)	5 (36)
Slowness	12 (63)	6 (50)
Overdependence	11 (58)	4 (36)
Irritability	10 (53)	9 (90)
Underactivity	10 (53)	6 (60)
Odd ideas	9 (47)	8 (89)
Somatic complaints	9 (47)	4 (44)

Table 5 Euro-American patients with schizophrenia: disturbed behaviour ($n=20$)

Item	Objective Problem reported n (%)	Subjective Distress when problem present n (%)
Misery	16 (80)	11 (69)
Underactivity	15 (75)	8 (53)
Withdrawal	13 (65)	8 (62)
Worrying	12 (60)	3 (25)
Forgetfulness	11 (55)	8 (73)
Irritability	10 (50)	8 (80)
Odd ideas	10 (50)	6 (60)
Self-neglect	10 (50)	10 (100)
Somatic complaints	10 (50)	3 (30)
Fearfulness	8 (40)	4 (50)

Table 6 Latino patients with schizophrenia: disturbed behaviour ($n=20$)

Item	Objective Problem reported n (%)	Subjective Distress when problem present n (%)
Misery	13 (65)	11 (85)
Odd ideas	13 (65)	7 (54)
Underactivity	13 (65)	8 (62)
Forgetfulness	12 (60)	9 (75)
Irritability	12 (60)	11 (92)
Indecisiveness	11 (55)	10 (91)
Withdrawal	11 (55)	7 (64)
Worrying	9 (45)	5 (54)
Fearfulness	8 (40)	6 (75)
Overdependence	8 (40)	5 (63)

the Euro-American and Latino schizophrenia groups scoring higher than the depressed groups.

For relatives' subjective perceptions of deficits in social performance, a main effect for diagnosis was observed ($P>0.01$), with the schizophrenia group overall (independent of ethnicity) scoring higher. No effects were observed for gender or any other socio-demographic or clinical variables here. Thus in the domain of social performance, female patients are reported to objectively carry out these behaviour types and activities significantly more than men, but relatives' subjective distress over such deficits were observed most significantly for the schizophrenia group.

Adverse effects on others: objective and subjective

For relatives' report of the objective presence of adverse effects on others, the most significant finding is for an interactive effect ($P<0.001$) for diagnosis and 'living status', defined here as key relatives living with their ill family member. Relatives living with a family member suffering from schizophrenia rated highest. The opposite is true for the depressed group, in which we observed a true cross-over interaction.

When 'adverse effects on others' is considered in terms of relatives' associated subjective distress, there are two primary findings. First, there was a significant living-status-by-diagnostic effect ($P<0.001$), with the schizophrenia group scoring higher (just as for the objective measure of this sub-scale). The reason why the Latino schizophrenia group scores highest here, may lie in the fact (seen in Table 2) that, for the schizophrenia group, most key relatives are women, and most of those are mothers; this was observed for both ethnic groups. Given this socio-demographic context, we decided to investigate more closely whether the type of informant might account for these findings. An analysis of types of kin informants ('mother' versus all other types) was only possible for the schizophrenia portion of the sample, because most of the key relatives of the Euro-American depressed group were spouses.

Through this analysis we see a significant 'type-of-informant' by-ethnicity interaction, with Latino mothers scoring significantly higher than Euro-American mothers ($P<0.05$). Is this to be accounted for by the fact that Latino mothers were

more likely to live with their affected relative? According to the data, this is apparently not the case, because the relationship occurs independently of living status: Latino mothers are no more likely to live with their relatives than Latino 'others' (all other Latino relative types). Thus the highest adverse effects are reported by mother-patient dyads in the Latino schizophrenia group. Nevertheless, ethnicity and living status do appear to be related: χ^2 analysis of ethnicity and living status ($\chi^2=10.7$, $P<0.001$) showed that, in this sample, these are not independent variables. More specifically, the Latino group is more likely to be living with their ill family member than their Euro-American counterparts (85 *v.* 50%).

DISCUSSION

For the first domain of burden assessed by the SBAS, that of disturbed behaviour, the non-significant findings for objective and subjective levels of burden across the groups may seem contrary to what might be expected from the cultural variation in perceptions of the symptoms and meaning of psychiatric disorder. One might also expect that schizophrenia would be perceived as objectively and subjectively more severe in nature than depression, but in fact no significant differences were observed. The similarity of scores could be taken as evidence that, from the family perspective, the socio-behavioural characteristics of schizophrenia and depression are perceived similarly as sources of distress. Of course, the high levels of compliance with medication in this sample may explain some of the similarity in ratings of burden. However, it was striking to find that, independent of psychiatric disorder or ethnicity, relatives agreed that the most frequent and most distressing symptom is the patient's misery. Perhaps among a medicated sample such as this, it is not surprising that distinct ethnic groups react to persistent major mental disorder in similar ways. Or perhaps this finding for the commonality of the objective existence of, and subjective distress associated with, 'misery' can be taken as confirmation of the research imperative to factor-in human suffering in our understanding of the social course of major mental disorder (Kleinman, 1995).

In sum, these data show that (a) there appears to be substantial similarity in relatives' reports of, and responses to,

symptom-related types of behaviour, showing that the behavioural impact of persistent mental disorder can be similar across diagnostic and ethnic groups; and (b) these observations also suggest considerable difference in nuance in the interpersonal behavioural and affective environment across these groups – that is, perhaps in the meaning of what they all gloss as 'misery', on the one hand, and the variation in the frequency of the individual symptom items across the four groups on the other (Tables 3–6).

For the second domain of burden assessed by the SBAS, that of social performance, findings were different for the objective and subjective measures. In relatives' reports of patients' actual performance of socially-related activities, no ethnic or diagnostic differences were observed. Instead, a main effect for gender was observed, with male patients reported to have significantly greater deficits in this domain. Given that this sub-scale taps a variety of tasks which might be considered gender-related (e.g., household tasks, management, emotional support), this might not be regarded as surprising. However, we suggest that it is very important because, like their 'normal' counterparts, women with serious, persistent mental disorder are reported to carry out a variety of tasks despite serious psychiatric symptoms. This is significant, and we can suggest two reasons why these might be mediated among women in relation to individual variability: (a) performance of these tasks could pose a gender-specific extra burden (or vulnerability) on these women (as compared with men); or (b) performance of these social roles and tasks may be experienced positively by some women as engaging and meaningful activities which help to structure their psychological and social experience. From other sources of data (observational and in-depth interviews) collected for this study, there is evidence to support each of these hypotheses, depending upon the individual. Certainly the literature on schizophrenia consistently reports overall better social performance of women relative to men, with better pre-morbid functioning, social adjustment, treatment response, and possibly course of illness among women (Seeman, 1995).

However, this was not so in the domain of relatives' subjective distress over social performance; here a main effect only for diagnosis was observed, with the schizophrenia group generating the greatest

subjective distress among relatives. Thus for these data it appears that distress over social performance is not significantly related to either gender or ethnicity but rather to the type of psychiatric disturbance.

For the third domain of burden assessed by the SBAS, that of adverse effects on others, findings were similar for the objective and subjective measures, with the Latino schizophrenia group scoring highest. We interpret this to mean that while 'living status may be a stronger immediate cause of adverse effects, ethnicity is a substantial factor in the likelihood of living with an ill family member. In analysing these scores further, recall that: more of the patients in the schizophrenia group are male; of the individual items in the profiles of disturbed behaviour, irritability was more frequently a concern among the Latino schizophrenia group; and most of the key relatives are female, often mothers. Taken together, this may add up to a particularly difficult social ecology in which Latino mothers (nearly all Puerto Rican in this case) experience high degrees of stress in their often heroic management of schizophrenia illness in family settings. This is made all the more difficult by adverse social conditions, scarce financial resources, and single parenthood, an altogether common but sociopolitically unacceptable situation among this group. Why should there be a different substantive finding among the depressed group, where relatives *not* residing with their ill family member report greater adverse effects? We might speculate that while actually living in the throes of depressive illness in a particular household, the adverse effects appear less significant than they do from a distance. Further comparative empirical study will be required to shed light on this, and the results from this study will in future be subjected to more refined qualitative corroboration, in order to formulate hypotheses for further examination.

CONCLUSION

These results suggest the need for additional examination of subtle variations in cultural patterns and psycho-social dynamics of living situations and across diagnostic and ethnic groups. The relation between the variables is like that between Chinese boxes: the relevant feature of ethnicity for this analysis is specified by living situation, and the relevant feature of living situation is living with mother. This

is quite distinct from the analysis of objective social performance, where the variable that accounted for the effect was truly a distinct, independent one – gender is distinct from ethnicity or diagnosis.

We found a surprising amount of similarity in certain socio-cultural factors associated with persistent mental disorder, as observed among the sub-scale scores for disturbed behaviour. On the other hand, fine-grained analyses revealed a great deal of specificity in the individual items. Gender emerged as significantly related to scores for *objective* social performance, with males reported to have greater deficits, whereas the *subjective* distress associated with such deficits appears diagnostic-specific (schizophrenia engendering more).

These findings lead to the conclusion that it may be an error to regard any diagnostic category such as schizophrenia or depression, let alone any ethnic group such as Latino or Euro-American, as a monolithic entity that cannot be broken down into component variables. The specificity of our results by objective and subjective measures, by domains of specific types of burden, by gender, ethnicity, diagnosis, living situation, and type of relative, is impressive. Finally, we observe that culture appears to be selective: in some ways the impact of persistent major mental disorder appears quite similar, and in others it is very culturally specific. As is becoming ever more apparent in biogenetic research, the social and cultural context of mental disorder appears to contribute to substantial heterogeneity and specificity of processes in psychiatric illness.

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REFERENCES

- Ali, R. M. & Bhatti, R. S. (1988)** Social support system and family burden due to chronic schizophrenia in rural and urban background. *Indian Journal of Psychiatry*, **30**, 349–353.
- Bebbington, P. & Kuipers, L. (1994)** The predictive utility of expressed emotion in schizophrenia: An aggregate analysis. *Psychological Medicine*, **24**, 1–11.
- Biegel, D. & Milligan, S. (1992)** *The Role of Race in Family Caregiving With Persons With Mental Illness: Burden, Support Systems and the Use of Self Help*. Cleveland, OH: Mandell School of Applied Social Sciences.
- Brown, G. W., Monck, E. M., Carstairs, G. M., et al (1962)** Influences of family life on the course of schizophrenia illness. *British Journal of Preventative Social Medicine*, **16**, 241–263.
- Butzlaff, R. L. & Hooley, J. M. (1998)** Expressed emotion and psychiatric relapse: A meta-analysis. *Archives of General Psychiatry*, **55**, 547–552.
- Chaves, A., Seeman, M., Mari, J., et al (1993)** Schizophrenia: Impact of positive symptoms on gender social role. *Schizophrenia Research*, **11**, 41–45.
- Coelho, V., Strauss, M. & Jenkins, J. (1998)** Expressions of symptomatic distress by Latino and Euro-American patients with depression and schizophrenia. *Journal of Nervous and Mental Disorders*, **186**, 477–483.
- Cuellar, I., Harris, L. C. & Jasso, R. (1980)** An acculturation scale for Mexican-American normal and clinical populations. *Hispanic Journal of Behavioural Science*, **2**, 199–217.
- Derogatis, L. R. (1993)** *Brief Symptom Inventory Administration Scoring and Procedures Manual* (3rd edn). Minneapolis, MN: National Computer Systems.
- Fadden, G., Bebbington, P. K. L. & Kuipers, L. (1987)** The burden of care: The impact of functional psychiatric illness of the patient's family. *British Journal of Psychiatry*, **150**, 285–292.
- Falloon, I., Boyd, J. & McGill, C. (1984)** *Family Care of Schizophrenia*. New York: Guilford Press.
- Grad, J. & Sainsbury, P. (1968)** The effects that patients have on their families in community care. *British Journal of Psychiatry*, **114**, 265–278.
- Guarnaccia, P. & Parra, P. (1996)** Ethnicity, social status, and families' experience of caring for a mentally ill family member. *Community Mental Health Journal*, **32**, 243–260.

CLINICAL IMPLICATIONS

- Since patient misery was considered the most distressing feature of the illness (regardless of diagnosis or ethnicity), it is important to bear in mind the generalised and pervasive human suffering among families who live with persistent mental disorder.
- Women with serious, persistent mental disorder carry out a variety of gender role-related tasks despite high levels of psychiatric symptomatology. Depending upon the individual and her situation, these activities could pose a gender-specific extra burden or be experienced as engaging and meaningful activities that help to structure social and psychological experience.
- The nature and extent of family burden and distress may vary considerably in relation to specific domains of sociocultural context, to include living situation, social relations and activities, gender and ethnicity.

LIMITATIONS

- The research construct of 'family burden' is not a monolithic entity but rather an area of human suffering that is more usefully decomposed into a variety of domains of specific types of burden and distress.
- The findings reported here are derived from a sample of 80 patients and their families and results are reported primarily at the group level of analysis. More qualitatively nuanced portraits of family distress are required to capture the human qualities of this subjective experience.
- The social and cultural context of mental disorder can contribute to substantial heterogeneity and specificity of psychiatric illness processes.

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- Hatfield, A. & Lefley, H. (1987)** *Families of the Mentally Ill: Coping and Adaptation*. New York: Guilford Press.
- Hoenig, J. & Hamilton, M. W. (1967)** The burden on the household in an extramural psychiatric service. In *New Aspects in the Mental Health Services* (ed. H. Freeman), pp. 612–635. London: Pergamon.
- Jenkins, J. (1988)** Ethnopsychiatric conceptions of schizophrenia illness: The problem of nervios within Mexican-American families. *Culture, Medicine and Psychiatry*, **12**, 303–331.
- (1997) Subjective experiences of persistent schizophrenia and depression among US Latinos and Euro-Americans. *British Journal of Psychiatry*, **171**, 20–25.
- & **Karno, M. (1992)** The meaning of "expressed emotion": Theoretical issues raised by cross cultural research. *American Journal of Psychiatry*, **149**, 9–21.
- & **Cofresi, N. (1998)** The sociosomatic course of depression trauma: A cultural analysis of suffering and resilience in the life of a Puerto Rican woman. *Psychosomatic Medicine*, **60**, 439–447.
- Kleinman, A. (1995)** *Writing at the Margins: Discourse Between Anthropology and Medicine*. Berkeley, CA: University of California Press.
- Kuipers, L. & Bebbington, P. (1988)** Expressed emotion research in schizophrenia: Theoretical and clinical implications. *Psychological Medicine*, **18**, 893–909.
- Lefley, H. P. (1994)** Service needs of culturally diverse patients and families. In *Helping Families Cope with Mental Illness* (eds H. Lefley & M. Wasow). New York: Harwood Academic.
- Mors, O., Sorensen, L. V. & Therkildsen, M. L. (1992)** Distress in the relatives of psychiatric patients admitted for the first time. *Acta Psychiatrica Scandinavica*, **85**, 337–344.
- Mueser, K., Webb, C., Pfeiffer, M., et al (1997)** Family burden of schizophrenia and bipolar disorder: Perceptions of relatives and professionals. *Psychiatric Services*, **47**, 507–511.
- Pasamanick, B., Scarpetti, F. & Dinitz, S. (1967)** *Schizophrenias in the Community: An Experimental Study in the Prevention of Rehospitalization*. New York: Appleton-Century-Crofts.
- Platt, S., Weymann, A., Hirsch, S., et al (1980)** The social behaviour assessment schedule (SBAS): Rationale, contents, scoring, and reliability of a new interview schedule. *Social Psychiatry*, **15**, 43–55.
- Provencher, H. & Meuser, K. (1997)** Positive and negative symptom behaviours and caregiver burden in the relatives of persons with schizophrenia. *Schizophrenia Research*, **26**, 71–80.
- Sczufca, M. & Kuipers, E. (1996)** Links between expressed emotion and burden of care in relatives of patients with schizophrenia. *British Journal of Psychiatry*, **168**, 580–587.
- Schene, A. H. (1990)** Objective and subjective dimensions of family burden: Toward an integrative framework. *Social Psychiatry and Psychiatric Epidemiology*, **25**, 289–297.
- , **Tessler, R. C. & Gamache, G. M. (1994)** Instruments for measuring family or caregiver burden in severe mental illness. *Social Psychiatry and Psychiatric Epidemiology*, **29**, 228–240.
- Seeman, M. V. (1995)** Gender differences in treatment response in schizophrenia. In *Gender and Psychopathology* (ed. M. Seeman). Washington, DC: American Psychiatric Association.
- Spitzer, R. L. & Endicott, J. (1978)** A diagnostic interview: The schedule for affective disorders and schizophrenia. *Archives of General Psychiatry*, **35**, 837–844.
- Tessler, R. C., Fisher, G. A. & Gamache, G. M. (1990)** *Dilemmas of Kinship: Mental Illness and the Modern American Family*. Amherst, MA: Amherst Social and Demographic Research Institute, University of Massachusetts.