The burden experienced by Brazilian family members affected by their relatives' alcohol or drug misuse

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Abstract

There is a virtual absence of previous research about the experiences of people affected by the presence of a substance misuser in the family in Brazil. A diverse sample of 3158 (80.6% female) affected family members (AFMs) was recruited in the largest cities in all five Brazilian regions. A Brazilian Portuguese translation of a set of standard measures for the assessment of AFM stress, strain, coping, hopefulness and total family burden, based on the stress-strain-coping-support (SSCS) model, was employed. Mothers and wives reported the greatest burden. Burden was also related to a number of other demographic and background variables, notably being higher for AFMs of lower socio-economic status and for those whose substance misusing relatives were currently receiving hospital treatment. A tentative hypothesis, based on suggested regional differences in beliefs about family structure and dynamics was mostly not confirmed. Examining the role of coping in the relationship between stress and strain, results offer some support for additive and moderation hypotheses, suggesting that greater engaged and tolerant-inactive coping add to stressful impact in the prediction of symptoms, and that lower engaged and tolerant-inactive coping in the face of relatively high stressful impact may be particularly useful in reducing symptom levels. This is the first national sample of AFMs to be studied in Brazil and the largest to have been reported from any country. The results should help build an emerging picture of how AFMs are affected and assist in planning services for AFMs.

INTRODUCTION

In line with many other developing countries, in the last decade Brazil has experienced an increase in the number of people using licit and illicit substances (Bastos *et al.,* 2008; Madruga *et al.,* 2012; UNOCD, 2012) with one study suggesting that as many as 5.7% of the Brazilian population (approximately 8 million people) are dependent on alcohol, cannabis and/or cocaine (Laranjeira *et al.,* 2012). The broader problems associated with substance misuse are multiple, including harms to those who care for or live with the substance user (Casswell *et al*., 2011; Copello *et al.,* 2009). The estimate is that over 28 million Brazilians may be living with a person suffering from some form of substance dependence (Laranjeira *et al.,* 2012). Despite this significant number, there is no previous research conducted across the country exploring the population of affected family members (AFMs). A recent study conducted with AFMs in the city of São Paulo seeking social support in mutual help groups, found there to be great uncertainty about where families might find support to deal with the problems associated with substance misuse in the family (Sakiyama *et al.,* 2014). In that sample it had taken AFMs an average of nearly three years to seek assistance after discovering that the relative was misusing substances. The belief that the relative's substance misuse was a transient problem, and that families could cope with the problem by themselves, were the reasons most often reported for delay in seeking help.

Although it remains small, there is an international literature on the experiences of AFMs. The present research followed the lead set by earlier research in Mexico, England, Italy and Australia which has been informed by the stress-strain-coping-support (SSCS) model of the experiences of AFMs (Orford *et al*., 2005a, 2017; Arcidiacono *et al*., 2010). That research has established the high levels of stress and strain experienced by family members in all countries, and has provided detailed knowledge of the coping dilemmas which family members face, and the difficulties they have in obtaining good quality social support, either

informally or from professionals. Although the conclusion is that there is a 'common core' to that AFM experience globally, research has also suggested ways in which the experience may be modified by factors such as the family member's sex and relationship to the substance misusing relative (partner, parent, sibling, etc.) as well as by socio-cultural differences (Orford, 2017). In such research the two largest groups of AFMs taking part are usually partners and parents and in several samples differences between those two groups have been found, for example reports of greater coping efforts by spouses/partners (Orford, 2017; Orford *et al*., 1992, 2005b; Velleman *et al*., 1993). The differences are not large, however, and have been absent in some samples (Arcidiacono *et al*., 2010; Velleman *et al*., 2011). Some evidence has also been produced, from inter-country or inter-regional comparisons, that the way AFMs cope shows some understandable variation by cultural group. For example: AFMs in Mexico City showed less withdrawal coping than AFMs in south-west England; those in the south of Italy reported higher levels of all kinds of coping than those in the centre and north of the country (Arcidiacono *et al*., 2010); and Sikh wives in England obtained higher tolerant-inactive coping scores than white English wives (Ahuja *et al.*, 2003).

None of those effects are more than quite weak. There is stronger evidence for the importance of the severity of the stress that AFMs are under. Measures of stress severity have regularly been found to be positively correlated (in the region of 0.3 to 0.5) with both engaged and tolerant-inactive coping and with the level of AFMs' symptoms (Orford, 2017; Orford *et al*., 2005b; Arcidiacono *et al*, 2010; Velleman *et al*, 2011; Howells & Orford, 2006; Petra, 2014). Although sample sizes have generally been small, they have sometimes been sufficient (in the region of 100) to test whether coping plays a mediating or moderating role in the relationship between stress and strain (symptoms). The provisional conclusion has been that the evidence mostly supports an additive role for certain kinds of coping (engaged and tolerant-inactive) whereby coping adds to stress in models regressing strain on other variables (Orford, 2017;

Orford *et al*., 2005b), although studies have mostly been cross-sectional and the direction of causality therefore remains unclear.

Aims of the present research

As the first such study to be carried out across Brazil, an objective was to recruit as diverse a sample of AFMs as possible in terms of such variables as regional distribution and other demographic and background variables. The aims were descriptive, correlational, and model testing.

First, we wanted to know the characteristics of the AFMs successfully recruited to the sample: their sexes and ages, relationships (partner, parent sibling, etc.) with their substance using relatives (SURs), ethnicity, and socioeconomic status. We also wanted to know the sexes and ages, and preferred substances, of the SURs, as well as for how long the AFMs had known about the SURs' substance misuse, and how they had first learned about it.

The second aim was to study Brazilian AFMs' stress, strain and coping using Portuguese translations of the same questionnaire methods used in studies of AFMs in several other countries. We also included a measure of hopefulness-hopelessness which has been included in some of those studies. This would enable us to examine how the levels of AFMs' stress, strain, coping and hopefulness related to a number of social, background and substance misuse-related variables. On the basis of findings in other countries (Benishek *et al*., 2006; Orford, 2017), we hypothesised that higher stressful impact, higher engaged and tolerant-inactive coping, higher symptoms (strain), and lower hopefulness, would each be positively correlated with AFM female sex, with AFM being a spouse/partner, and with SUR preference for cocaine or crack-cocaine, and negatively correlated with white ethnicity and socio-economic status. Although we know of no previous findings regarding the length of time the AFM has known about the SUR's substance misuse, we predicted that this variable would be

positively correlated with AFM withdrawal coping. Since the sample would be drawn from across the diverse regions of the country we would also explore differences by region. A tentative hypothesis, based on differences in history, culture and current socio-economic position, and suggested differences in beliefs about family structure and dynamics (Burdick, 2013; Goldani, 1994; IBGE, 2014), was that stressful impact, higher engaged and tolerant-inactive coping, higher symptoms, and lower withdrawal coping and hopefulness, would be found in the north and north-east compared to the south and south-east. We would examine the significance of whether SURs were reported to be currently admitted for treatment, or had ever been admitted, but we had no pre-existing hypothesis about this. It would also be possible to compare the levels of AFMs' stress, strain, coping and hopefulness in Brazil with those found in samples recruited in other countries.

We would also use the data to test whether there is evidence for a mediating, moderating or additive role of coping in the relationship between stress and strain. On the basis of earlier findings from other countries (Orford *et al*., 2001; Velleman *et al*., 2008), we predicted that the data would be most supportive of an additive model. This is important because it bears on questions about maintenance and change of AFMs' mental health and well-being, such as whether certain kinds of AFM coping can mitigate the effects of substance misuse in the family, and if so how.

We anticipated that the results as a whole would help build an emerging picture of how AFMs are affected by substance misuse in Brazil and assist in planning national services for AFMs, while at the same time contributing to the global picture of how substance misuse affects family members.

METHOD

A questionnaire pack was assembled containing demographic and background questions about the AFM participant, the SUR and his or her substance use, and a Brazilian Portuguese version of the following set of standard measures for the assessment of AFM stress, coping, strain and hopefulness which have been used regularly in previous research. With the exception of the SRT as a measure of strain, these measures were each developed by Orford *et al*. (2005b) specifically for completion by family members affected by substance problems.

Family member impact (FMI)

FMI is a 16-item questionnaire designed to assess the extent and type of harmful impact (stress) on the family member or on the family as a whole that a family member perceives the relative's drinking or drug-taking has been having recently (in the last 3 months). Items reflect two different aspects of impact: worrying behaviour (WB) – for example worry about the SUR's health or ability to work or study; and active disturbance (AD) – for example experience of quarrels, threats or upset family occasions. Response options for each item are: not at all, once or twice, sometimes, often – scored 0, 1, 2, 3. Items are summed to produce a Total impact score (FMI). Separate WB and AD scores are sometimes calculated but because in the present data they were strongly correlated (0.62), only the total FMI score is reported here.

Symptom rating test (SRT) (Kellner and Sheffield, 1973)

SRT has been used to assess the element of strain in the SSCS model. It is one of a number of questionnaires that are available for assessing the extent of mild to moderate physical and psychological ill-health in the general population. Respondents are asked to indicate whether they have experienced each of 30 symptoms recently (in the last 3 months). Response

options are never, sometimes, often − scored 0, 1, 2. The SRT can be scored by summing all items to produce a total symptom score (Symptoms) or, by calculating two sub-scales scores: 1) Psychological symptoms (Psych) – for example feelings of exhaustion or irritability; 2) Physical symptoms (Phys) – for example sleep disturbance or feelings of bodily weakness. Because Psych and Phys were highly correlated in the present data (0.77), only total Symptoms is reported here.

Coping questionnaire (CQ)

The aim of the CQ is to obtain family members' responses to a number of standard questions about the ways in which they have coped with their relatives' problem drinking or drug-taking recently (in the last 3 months). Respondents are given four response options for each item: no, once or twice, sometimes, often − scored 0, 1, 2, 3. It is scored by calculating three sub-scale scores corresponding to the three main ways of coping which have been identified in earlier research (Orford *et al.*, 2005b, 2010): standing up to the problem, or Engaged coping (Cop-Eng) – for example being assertive about the substance misuse or trying to control it; 2) putting up with it, or Tolerant-inactive coping (Cop-Tol) –for example sacrificing one's owns interests or being too fearful to take action; 3) withdrawing and gaining independence, or Withdrawal coping (Cop-With[1]) – for example putting oneself or other family members' interests first or keeping out of the SUR's way.

Hopefulness-hopelessness scale (HOPE)

HOPE has been used to assess how hopeful an AFM currently feels about the future of the substance misuse problem. It consists of 10 items, half positively worded and half negatively, presented in Likert-style format (strongly agree to strongly disagree, scored 5, 4, 3, 2 and 1 for positively worded items and the reverse for negative items). Some items focus on the

AFM's own feelings – for example feeling more positive about things; others on perceptions of the SUR – for example fear that the SUR is not getting on well.

The English version of the questionnaires was adapted to Brazilian Portuguese using a translation/back-translation procedure. The adapted version was successfully tested with a pilot sample of 30 participants.

Internal reliability coefficients (alpha) based on the present data are good for most of the scales (from 0.82 for HOPE to 0.94 for Symptoms), and satisfactory for Cop-Tol (0.74), but less than satisfactory (0.57) for Cop-With.

Total family burden (TFB)

Substantial correlations between FMI, Cop-Eng, and Cop-Tol (between 0.62 and 0.73), and between each of those three variables and Symptoms (between 0.33 and 0.43) supports the calculation of a composite variable, Total Family Burden (TFB), which is the sum of FMI, Cop-Eng, Cop-Tol and Symptoms. Additional support for the calculation of TFB comes from a principal components analysis of the present data in which all the sub-scales were entered. The two FMI sub-scales (WB and AD), Cop-Eng, Cop-Tol and the two Symptoms sub-scales (Psych and Phys) each had substantial positive loadings (0.63 to 0.81) on the first of three rotated factors. We provisionally interpret TFB as a summary measure of the degree of burden falling on an AFM due to the effects of a SUR's substance misuse.

Procedure

A group of researchers from the Alcohol and Drugs Research Unit (UNIAD) at the Federal University of São Paulo tracked down substance misuse services in the largest cities in each of the five Brazilian regions (north, north-east, central-west, south-east, south). Following an

informal telephone invitation and an official letter of invitation, a consent form was signed by those service coordinators who agreed to have the data collected with the family members of their service users. The type of services that agreed to take part in this study included: therapeutic communities, self-help groups *Amor Exigente* (a network group spread across the country that offers psychological support to families that have SURs), pastoral groups *Sobriedade* (a pastoral care movement from the Catholic Church in Brazil focused on the social problems of exclusion, poverty and violence related to drug addiction), narcotics anonymous, alcoholic anonymous, and residential rehabilitation clinics. Apart from the last of those, all were not-for-profit associations. A convenience sample of AFM's participants were recruited. Participants recruited from residential/rehabilitation clinics were initially approached by the researchers in the waiting room of the service during visits to the SUR. In self-help groups, researchers orally invited and distributed a participant information sheet to family members during group sessions. There was no participation restriction in terms of sex, age, relationship with the SUR, or frequency with which AFMs attended the centres/institutions/groups.

A third party company specialising in data collection (SPHINX BRASIL) was hired for interviewer training, gathering the data across the five regions of Brazil, and data entry and cleaning. The initial plan was for interviewers to complete an online version of the questionnaire with each participant individually, but due to difficulties with internet access in some places the majority of questionnaires were completed by the interviewer using a paper-and-pen version and transferred to the online database afterwards. Interviews took approximately 40 minutes on average. Interviews conducted in hospitals and therapeutic communities were scheduled during the family visiting time, and during group sessions in the case of self-help groups. Data collection took place between June 2012 and July 2013.

Approval to undertake the study was granted by the *Comitê de Etica da Faculdade de Medicina da Universidade Federal de São Paulo*.

Analysis

Analyses of variance, t-tests and correlations are used as appropriate. Because multiple tests of significance were calculated (70 tests in the case of the analyses reported in Table 4), we report only those results significant beyond the 0.001 level. Because with large numbers conventional significance tests, even with p set at < 0.001 for significance, can produce apparently significant results when the effect is in fact a small one, where appropriate effect sizes have also been calculated. Partial correlations are used to test for mediation. Multiple regression modelling is used to test for the independent contribution of predictor variables and when testing the coping moderation model. Median splitting of the sample on key variables is used to further explore coping moderation effects.

RESULTS

Descriptive

Table 1 provides information about AFM sex and relationship to the SUR and Table 2 provides further information about the sample. Four-fifths of all respondents were female. The largest group of respondents (60%) were parents of the SURs. Also represented were substantial numbers of both spouses/partners and siblings; about 12% of the whole sample in each case. A large range of other relationships were also represented in smaller numbers, notably aunts/uncles, daughters/sons and grandmothers/grandfathers. Also notable is the relative lack of husbands/male partners compared to wives/female partners, and the same is

true of boyfriends relative to girlfriends. In both those cases male AFMs were outnumbered

by female by 40 to 1, whereas in all other categories (parents, siblings, aunts/uncles, etc.)

male AFMs were outnumbered by only approximately 4 to 1. The modal age group for

respondents was 45-54. Respondents' educational level varied widely from nearly one in five

who had not completed basic education to nearly one in 10 who had obtained a postgraduate

qualification. Just over two-thirds described themselves as white/Caucasian. Participants

were recruited from the five geographic regions of Brazil, the largest numbers from the

south-east and north-east regions. In terms of indices of socio-economic status, two-thirds

lived in households which had a car, and just over half lived in accommodation that had more

than one bathroom, and just over one in eight had a housemaid. Since those three variables

and educational level were significantly intercorrelated (0.29 to 0.53), a single SES variable

was created by summing each of those four variables (each scored 0, 1 or 2) to create a

variable with range 0 to 8 and an alpha internal reliability coefficient of 0.71.

Nearly all (94.1%) the SURs they were concerned about were male. SURs' ages ranged from

teenage (4.8% under 18) to 55 or over (5.0%), the modal age group being 25-34. The median

length of time AFMs had known about their SURs' substance misuse was six years but this

varied widely from around a quarter of respondents who had known about the substance

misuse for 13 months or less to another approximately a quarter who had known about it for

12 years or more. Asked how long ago they thought their relatives had begun to use

substances, the median estimate was 11 years, again with much variation, nearly a quarter of

all respondents believing substance use had begun at least 20 years previously.

The most frequently mentioned way in which the substance misuse had come to light was a

change in the SUR's behaviour, for example becoming more aggressive, indifferent or

alienated (mentioned by over 40%). Also commonly mentioned (by just over 20%) were

signs at home that the relative was taking substances, for example witnessing it, smelling it,

or the AFMs finding the drugs themselves. Six percent mentioned the SUR being drunk or looking haggard at home and 6% mentioned the SUR using substances outside the home. Of sources outside the family who might have mentioned it to the AFM or helped bring it to light in some way, neighbours and friends were much more often thought to have done so (nearly 1 in 5), compared to which the law/police and school and the workplace (between 1 and 3% each) were much less frequently endorsed. Ten percent said the SUR had come for help him/herself. Health problems were mentioned as important in only 2% of cases.

According to the AFM respondents, of the four drug types most popular among SURs, marijuana was thought to be used regularly by 68.4% of SURs, alcohol by 62.1%, cocaine by 61.0%, and crack by 41.7%. When AFMs were asked about SURs' preferred drug, the order was different: crack 25.5%, cocaine 23.1%, marijuana 20.4%, alcohol 18.6% (12.4% stated there was no single preference or cited another substance). Just over half the SURs (52.2%) were reported by AFMs to be currently admitted for treatment, with 31.3% having been admitted previously but not currently, leaving 16.5% who had never been admitted.

Tests of association between stress, strain, coping, hopefulness and other variables

Table 3 provides means and standard deviations for impact, coping, symptoms, hopefulness and total burden for the present sample alongside the range of comparative scores on the same variables found in earlier studies from other countries. This shows that the present scores are mostly comparatively low, the exception being the comparatively high score for HOPE. Table 4 shows significant relationships (p < 0.001) between demographic and background variables and stress, strain, coping, hopefulness and total AFM burden. As expected, TFB was higher for women than men, and was negatively correlated with SES. There was also a significant negative correlation between TFB and the AFM's age, and a positive correlation with family size. TFB also varied significantly with the relationship

between AFM and SUR. Amongst those groups well represented in the sample, TFB scores were highest for wives and mothers, were moderately high for sisters and daughters and were lower for fathers and brothers. Scores were particularly high for the small groups of husbands and ex-wives, and notably lower for the small groups of brothers-in-law and male cousins.

There was, as predicted, a significant relationship between mean TFB scores and the region from which participants were recruited. However, the direction of these differences was not as predicted. The higher mean scores were obtained from those in the south-east and north-east regions although it had been predicted that south-east scores would be amongst the lowest. Scores from the north region were amongst the lower ones although it had been predicted that they would be amongst the highest. Lowest scores were from the central-west region.

There was a significant negative correlation between TFB and the length of time family members had known about their relatives' substance misuse. There was also a significant association between TFB and the SUR's history of admission for substance misuse treatment. Scores were significantly higher when the SUR was said to be currently admitted than when there had been a previous, but not a current, admission.

Cop-Eng displayed the same pattern of relationships with demographic and background variables as did TFB. The same was true for the other constituents of TFB (Impact, Cop-Tol and Symptoms), although as Table 4 shows not all the relationships met the $p < 0.001$ level of significance.

Although it was not significantly associated with TFB, the SUR's preferred drug was associated with Cop-Eng and Symptoms. In both those cases the biggest contrast was between the lower mean scores of those whose SURs were thought to prefer alcohol compared to those whose relatives preferred one of the three main illicit drugs.

HOPE showed relatively few significant results. It was negatively associated with the length of time AFM had known about SUR's substance misuse and was also significantly associated with SUR admission history (lower Hope associated with SUR never having been admitted).

Table 4 also shows a number of significant associations between Cop-With and demographic and background variables. There was an association with relationship, with the lowest scores for grandmothers, mothers, fathers, and daughters (as well as the small groups of husbands and female cousins), and highest scores for the small groups of ex-wives and brothers-in-law, sons and girl-friends. Cop-With was positively correlated with SES and was the only sub-scale to be associated with ethnicity, with higher scores for those of white/Caucasian heritage. Cop-With was also higher for those who gave longer estimates of the length of time AFMs had known about their SURs' substance misuse There was also a significant relationship of Cop-With with SUR's drug preference although the only significant contrasts involved SUR preference for some drug other than marijuana, cocaine, crack or alcohol, which was associated with lower scores. Cop-With was also associated with region and here the ordering of regions was more in line with expectations: mean scores were highest in the south and lowest in the north, a significant contrast equivalent to approximately two-thirds of a standard deviation. The relationship with SUR's admission history was also significant, Cop-With being significantly lower when SUR was currently admitted.

Although, therefore, a number of statistically significant associations were found, few were other than small to moderate effects in terms of size. The largest involved the AFM-SUR relationship: the higher mean scores of mothers, wives, ex-wives and husbands on Cop-Eng, Symptoms and TFB compared to those of other male and more distantly related AFMs being large sized effects, equivalent to between three-quarters and one standard deviation.

Since there was inevitably some co-variation between demographic and background variables (for example, the length of time AFM had known about SUR's substance misuse was significantly associated with both AFM age and SUR's preferred substance), two regression analyses were conducted, with Symptoms and TFB as the dependent variables respectively. Eight independent variables were included in each case. Of those variables shown in Table 4, excluded were: sex, excluded because of its association with AFM-SUR relationship; and ethnicity, excluded because of its lack of association with dependent variables. The results are summarised in Table 5. In both cases the result is highly significant but the multiple correlation coefficient is modest. The AFM-SUR relationship emerged as the single most important variable in both cases, with SUR's admission history appearing at an early stage in both stepwise analyses, with AFM's SES an important contributor to Symptoms.

Multiple regression analysis with Cop-With as the dependent variable produced a significant but small multiple correlation (R = 0.27, F = 22.3, p < 0.001), with SUR's admission history as the first entered variable in a stepwise routine, and region, AFM-SUR relationship, time AFM had known about SUR's substance misuse, and age following in that order on subsequent steps.

Tests of mediation, moderation and additive hypotheses for explaining the relationships between Impact, Coping and Symptoms.

As predicted, FMI as well as both Cop-Eng and Cop-Tol were correlated with Symptoms (r = 0.40, 0.33, 0.43 respectively). Furthermore there were substantial correlations between FMI and each of those two coping factors (0.66, 0.62). It is relevant, therefore, to explore whether coping of either of those two forms (which were themselves highly correlated, r = 0.73) mediates or moderates the relationship between FMI and Symptoms or simply adds to the influence of FMI on Symptoms. The analysis provided some support for possible mediation:

partialling out Cop-Eng reduced the correlation between FMI and Symptoms by 36% (from 0.40 to 0.25) and partialling out Cop-Tol reduced the correlation between FMI and Symptoms by 54% (from 0.40 to 0.18). However, in neither case was the FMI-Symptoms correlation reduced to a significance level greater than 0.001. More damaging to the mediation hypothesis, a control analysis in which the roles of FMI and coping were reversed, found that there were equally strong effects of partialling out FMI on the correlation between coping and Symptoms (from 0.33 to 0.10 in the case of Cop-Eng and Symptoms; from 0.43 to 0.26 in the case of Cop-Tol and Symptoms, again both partial correlations p < 0.001).

The results of the regression analyses of possible moderation are shown in Table 6. They offer some support for a moderation effect of AFM coping. When an Impact-Coping interaction term is added to the regression, it slightly increases the regression coefficient (R) from 0.40 to 0.44 when Cop-Eng is the coping variable, and from 0.46 to 0.47 when Cop-Tol is the coping variable), with the interaction term becoming the term with the largest t value and the one entered first in a stepwise regression. The results are illustrated in Figure 1. The moderation hypothesis is supported by the finding that the difference (d) in symptom scores for those high or low on FMI is greater when coping is relatively high (d = 10.96, t = 9.85, p < 0.001 in the case of Cop-Eng and d = 8.46, t = 9.68, p < 0.001 in the case of Cop-Tol) than when coping is relatively low (d = 4.70, t = 8.90, p < 0.001 in the case of Cop-Eng and d = 2.71, t = 4.57, p < 0.001 in the case of Cop-Tol).

DISCUSSION

To our knowledge the findings presented in this paper are based on the largest sample ever to be reported of family members affected by their relatives' alcohol or drug problems. The sample is diverse in terms of the regions of Brazil from which it was recruited, in terms of

demographic and background variables, and in terms of family members' reports of the relative's preferred substance, as well as in terms of the family relationship between respondent and relative. Such diversity is typical of samples of affected family members recruited via substance misuse treatment sources (Orford *et al*., 2005a; Arcidiacono *et al*, 2010; Velleman *et al*, 2011). The relative absence of husbands/male partners and boyfriends, although more extreme than is the case for samples recruited in the UK and Italy for example (Copello *et al*., 2000; Arcidiacono *et al*, 2010), has also been found in Mexico (Natera *et al*., 2011; Orford *et al*., 2001) and is likely to be typical of parts of the world where there are greater gender differences in family roles and substance use.

The sample was also very diverse in terms of the length of time substance use was thought to have been occurring and the length of time since the family member had known about it as a problem. Again such diversity is typical. An additional question was asked about how the problem had come to the family member's attention, revealing a number of points of interest. One is that it was change in the relative's general behaviour which had most commonly alerted the family member. That is consistent with the general finding, in studies of family members coping with their relatives' health or social difficulties, that it is changes in personality and general behaviour that are the most noticeable and concerning to affected family members (Orford, 1987). Another finding of interest was the frequency with which friends and other family had been influential in alerting the family member, coupled with the rarity with which the workplace, educational establishment or law enforcement had helped bring the relative's substance problem to the family member's attention. We interpret this pattern as being a reflection of how the experience of substance misuse problems for family members is something that operates largely in the informal sphere, with family members dependent on their own resources and the informal support of family and friends (Toner & Velleman, 2010).

A number of the findings, notably the high scores obtained by wives and mothers on a number of the scales, and negative correlations with the summed measure of socio-economic status, are in line with predictions and provide further support for the validity of the family member questionnaires employed, and for the success of their translation into Brazilian Portuguese. The withdrawal subscale has been an anomaly in previous studies. Unlike the engaged and tolerant-inactive subscales which are strongly positively correlated and which show significant reductions in before-after intervention studies, withdrawal scores are not correlated with either of the other two coping sub-scales and either show no change or significant increase in before-after studies (Orford *et al.*, 2005b). The conceptualisation of the withdrawal score has also been questioned on the grounds that it confuses withdrawal in the sense of avoiding the substance-using relative as much as possible, which is generally seen negatively by family members, and withdrawal in the sense of achieving some independence from the user and the user's problem (Copello, 2002). The internal reliability of the withdrawal coping subscale was unsatisfactory and results should be considered with caution. Nevertheless, a number of the findings suggest that the withdrawal coping sub-scale had some validity; for example, the lower withdrawal amongst parents and grandparents, those whose SURs were currently admitted, and those living in the more traditional north of the country, and the higher withdrawal scores of those who had known about the SUR's substance misuse for longer.

As predicted, total family burden, and each of its constituents, varied by the relationship between AFM and SUR, providing evidence that the closeness of the relationship is positively related to family burden. Mothers and wives experienced the greatest burden. More distant family members, of whom male cousins and male in-laws are examples, showed the least burden. Ex-wives were also high on burden. This is the clearest evidence to date that those AFMs in different relationships to the misusing relative are affected to different degrees

(Orford, 2017). A simple differentiation of partners and parents does not tell the whole story. However, the variation is high within each category, effect sizes are small, and only the contrast between the most extreme groups are significant.

A number of other hypotheses were confirmed including positive relationships between burden and lower socio-economic position, lower family member age, and a larger family size. Burden was lower the longer the estimated length of time since the family member had known about the relative's substance problem. Burden was also lower when the relative's preferred substance use was alcohol rather than marijuana, cocaine or crack. However, again variations were high and effect sizes low.

Our hypothesis about regional differences was mostly not confirmed. Although there were some differences between regions, these were mostly not in the direction predicted. Only in the case of withdrawal coping were the results at all consistent with the prediction that family members towards the north of the country would report more overall burden and find it more difficult to withdraw from engaging personally in trying to cope with their relatives' substance misuse than those living towards the south of the country. Hence there is only tentative support in these data for the idea of cultural differences in the experiences of affected family members. It might be that demographic characteristics associated with the regions play a more important role than cultural differences. For example, the higher TFB scores found in the south-east area might be related to the fact that, compared to the other areas, the south-east is the most urbanized, with highest population density, cost of living and social inequality (Menezes & Possamai, 2015). In addition, evidence suggests that availability of illicit drugs is higher in the south-east cities than the rest of the country (Abdalla *et al*., 2014; Pinsky *et al*., 2010). Thus, coupled with the easy access to drugs, the stresses and pressures associated with the living conditions of south-east cities might place AFMs from this area at greater risk of experiencing higher levels of burden.

We found a significant correlation between the SUR's treatment admission history and all scale scores, and in particular significantly lower scores for those AFMs whose SURs had previously been admitted but were not currently admitted. The latter group constituted about a third of the whole sample, and it may be assumed that a large proportion of the relatives of family members in that group who volunteered to take part in the study had been successfully treated for their substance misuse, That may go some way towards explaining the lower impact, coping, symptoms and total burden scores, and higher HOPE scores, found in the present Brazilian sample compared to those obtained in previous studies in other countries (Arcidiacono *et al*., 2010; Copello *et al*., 2009; Ibanga, unpublished; Lee *et al*., 2011; Orford *et al*., 2005b; Petra, 2014; Templeton, unpublished,). On the other hand admission history cannot provide the whole explanation for the low Brazilian impact, coping and symptom scores since even those for the currently admitted group were substantially lower than those from other countries. We can only speculate about the reasons for these differences from previous findings from other countries. It seems unlikely to be due to difficulties in translation of questionnaire items since care was taken in translation, other results suggest their validity, and the differences compared to other samples are in a consistent direction. Nor does it seem likely that these differences have a cultural explanation since the comparison samples are culturally diverse and the Brazilian means for all five regions, although showing some difference, all diverge from the earlier findings from other countries. We think the most reasonable explanation is that family members were recruited from treatment sources irrespective of the stage of their relatives' treatment and whether they or their relatives had benefitted from treatment. It is possible, therefore, that, unlike in the comparison studies, the sample includes relatively large numbers of family members whose relatives were now free of substance misuse and perhaps had been for some time. That was a factor found, as expected, to be related to lower family burden in a Portuguese sample containing a high

proportion of AFMs whose SURs had been abstinent for varying periods of time (Soares *et al.*, 2016). Another possibly important difference from earlier samples is the fact that the majority of SURs received treatment as inpatients (over 50% currently and 17% in the past) which might bring relief for AFMs, for example through knowing the location of the SURs who otherwise would often disappear leaving the family without information of their whereabouts. A further possible difference is that a large number of participants in the present sample were recruited via self-help groups where AFMs share and hear experiences from other AFMs, which might also have contributed to reduced feelings of burden and increased hope for their SURs. The substances used by SURs, notably the very few using heroin or methamphetamine, could also have been a factor.

Finally, the relatively large size of the sample allowed a clear test of different hypotheses concerning the way in which AFM coping influences the relationship between the stressful impact of living with a SUR and AFM strain as indexed by common symptoms of ill-health. We found only limited support for the mediation hypothesis, but some findings consistent with the moderation hypothesis suggesting that lower engaged and tolerant-inactive coping in the face of relatively high stressful impact may be particularly useful in reducing symptom levels. On balance, however, we believe the present results are most parsimoniously interpreted as supporting an additive hypotheses whereby greater engaged and tolerant-inactive coping add to stressful impact in the prediction of symptoms.

Compared to national figures (IBGE, 2010), the relatively small proportion of non-white family members participating in the current research, along with the relatively large proportion of households with a car and more than one bathroom, may suggest that the sample, although clearly diverse in terms of participants' socio-economic status, may have been somewhat biased towards the relatively well-off. This may be an indication that substance misuse self-help and treatment services, which provided the sources from which

participants were recruited, are currently being less successful in reaching those of lower socio-economic standing.

Some of the findings add to what we already know about the unsupported position in which affected family members find themselves. Although the sample was highly diverse in these respects, many family members had been living with their relatives' substance misuse problems for many years and those problems had mostly come to light because of changes in the relative's behaviour in the home and without the support of outside agencies such as those of law, education and health. Furthermore, although symptoms scores were on average lower than those found in samples of AFMs elsewhere, they are nevertheless much higher than those obtained by normative samples, indicating the negative health effects experienced by those in the family affected by someone else's substance misuse (Orford *et al*., 2005b). This study therefore strengthens the growing international literature which has reported the negative impact of substance misuse on the family and which suggests that the impact of dealing with such problems in the family is similar across countries (Arcidiacono *et al*., 2010; Orford *et al*., 2005a). At the same time, whilst acknowledging the commonality of the experiences that all AFMs face, the present findings draw attention to the importance of considering variation in terms of social factors such as gender roles, family structural relationships and socio-economic status.

There are also specific implications for treatment, prevention and research in Brazil. Currently, there is much misinformation, confusion and lack of assistance to the AFM population in Brazil (Sakiyama et al., 2014). The absence of an official organ/committee that provides guidance for drug treatments has contributed to AFMs being neglected in the public health agenda. Our findings provide the first national evidence of the profile and the stresses and strains faced by AFMs in Brazil. Therefore, they offer the evidence-based information that could support the development of a national standardised framework to meet the needs of

AFMs. Furthermore, ssubstance misuse treatment services in Brazil should ensure that the strains experienced by AFMs are assessed and the integration of treatment for both substance misuse and family adversities considered. Lastly, there remains an urgent need to develop and test interventions to improve the quality of life of AFMs. Our findings offer evidence that could support the design of trials aimed at examining the effectiveness of such interventions. Interventions such as the Five-Step Method have provided promising outcomes such as changed coping and reduced strain amongst AFMs in a number of countries and a recent Brazilian controlled trial of a tele-intervention for AFMs has produced positive results in terms of changed coping (Borges Bortolon et al., 2016).

[1]It should be noted that Cop-With, as scored for the present analysis, unlike in earlier reports (Orford *et al.*, 2005b), is based only on six positively worded items, excluding two reversed-scored items.

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Declaration of Interest

The authors report no conflicts of interest

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Table 1. Affected Family Member (AFM) sex and relationship to Substance Using Relative (SUR) (N = 3126, information missing in 32 cases)

Relationship of AFM to SUR	AFM female	AFM male
Parent	1468 (46.6%)	418 (13.3%)
Spouse/partner	368 (11.7%)	8 (0.3%)
Ex-spouse	23 (0.7%)	0 (0.0%)
Sibling	326 (10.3%)	24 (2.3%)
Daughter/son	65 (2.1%)	27 (0.9%)
Uncle/aunt	94 (3.0%)	21 (0.7%)
Grandparent	44 (1.4%)	8 (0.3%)
Sibling-in-law	24 (0.8%)	21 (0.7%)
Girl/boyfriend	41 (1.3%)	1 (0.0%)
Other[*]	88 (2.8%)	57 (1.8%)

*In descending order of group size: cousins (31), god-parents (28), nephew/neice (24), ex-spouse (23), 'others' (12), engaged (10), friends (10), parents-in-law (7)

Table 2. Other AFM sample information (N = 3115-3158)

Demographic	N (%)
Age	
17 or younger	18 (0.6%)
18-24	118 (3.7%)
25-34	332 (10.5%)
35-44	512 (16.2%)
45-54	963 (30.5%)
55-64	822 (26.1%)
65 or older	377 (11.9%)
Marital status	
Single	565 (17.9%)
Married/stable union	1831 (58.0%)
Divorced/separated	460 (14.6%)
Widowed	268 (8.5%)
Other	12 (0.4%)
Educational level	
No schooling/left school without qualifications	557 (17.7%)
Primary school only	407 (12.9%)
Secondary school only	1138 (36.1%)
Higher education diploma	786 (24.9%)
Postgraduate diploma	265 (8.4%)
Ethnic group	
Black	303 (9.6%)
White/Caucasian	2165 (68.9%)
Mixed/indigenous	666 (21.2%)
Other	9 (0.2%)
Family car ownership	
Yes	2031 (66.4%)
No	1028 (33.6%)
Number of bathrooms in the home	
None	
One	1339 (43.9%)
Two	965 (31.7%)
Three or more	744 (24.4%)
Number of housemaids	
None	2690 (85.2%)
One	419 (13.3%)
Two or more	49 (1.6%)
Region in Brazil	
North	277 (8.8)
North-East	772 (24.8)
Central-West	379 (12.2)
South-East	1303 (41.8)
South	384 (12.3)

Table 3. Mean and standard deviation scale scores and comparisons with samples of AFMs in other countries

	Impact	Cop-Eng	Cop-Tol	Cop-With[*]	Hope[**]	Symptoms	TFB
Brazil *(present results)*	33.5 (11.5)	30.0 (11.8)	14.7 (5.3)	9.0 (4.2)	36.4 (5.4)	49.3 (12.5)	127.5 (32.7)
Other Countries *(previous results)*	39.2 – 47.0 (10.1 –11.5)	34.6 – 42.3 (7.3 – 11.8)	18.3 – 23.5 (4.5 – 6.1)	8.1 –12.9 (3.7 – 5.6)	21.0 –26.2 (5.4 – 6.9)	50.3 – 63.4 (9.5 –12.5)	148.8 -174.8 (31.7 – 32.7)
Comparison countries	2,3,6,7,8	1,2,3,4,5,6,7,8	1,2,3,4,5,6,7,8	1,2,3,4,5,6,7,8	2,6	1,2,3,4,5, 6	2,3,6

[1] Mexico (Orford et al., 2005b N = 129) [2] Italy (Arcidiacono et al., 2010 N = 113) [3] Nigeria (Ibanga et al. N =) [4] England (Orford et al., 2005b N = 121) [5] England (Copello et al., 2009 N = 143) [6] England (Templeton, unpublished data N = 46) [7] Singapore (Lee et al., 2011 N = 100) [8] USA (Petra, 2014 N = 208, included AFMs affected by gambling problems)

*Brazil scoring adjusted to match scoring in other countries

**Brazil scoring slightly different from scoring in other countries

Table 4. Relationships between scale scores and demographic and background variables (only those relationships significant beyond p < 0.001 are shown)

		Impact N=3025-40	Cop-Eng N=3111-27	Cop-Tol N=3129-45	Cop-With N=3123-39	Hope N=3037-53	Syms N=3019-34	TFB N=2948-62
AFM age	r	-0.08	-0.08	-0.11	-	-	-	-0.09
AFM sex	t	-	-4.05	-6.88	-	-	-13.61	-9.02
Family size	r	-	0.07	0.09	-	-	-	0.07
SES	r	-	-0.06	-0.08	0.09	-	-0.21	-0.14
AFM ethnicity (white/other)	t	-	-	-	3.72	-	-	-
Region (5 groups)	F	16.84	20.86	18.96	21.15	-	7.81	17.89
Relationship with SUR (16 groups)	F	-	3.10	3.04	2.52	-	8.71	4.55
Time since discovered SUR's drug use	r	-	-0.10	-	0.08	-0.08	-0.07	-0.07
SUR's preferred drug (5 groups)	F	-	5.45	-	6.66	-	7.69	-
SUR treatment admission (3 groups)	F	33.96	19.02	23.37	44.82	8.72	22.28	30.62

Table 5. Stepwise multiple regression 1) Symptoms as dependent variable 2) TFB as dependent variable

Step	Symptoms	R^v	TFB	R^v
1	Relationship with SUR (3 groups[i])	0.25[a]	Relationship with SUR (3 groups)	0.18[a]
2	SES	0.31[a]	SMR admission history (2 groups)	0.24[a]
3	SMR admission history (2 groups[ii])	0.33[a]	Region (2 groups)	0.27[a]
4	Region (2 groups[iii])	0.34[a]	AFM age	0.29[a]
5	Family size	0.35[a]	SES	0.30[a]
6	SMR's preferred drug (2 groups[iv])	0.35[b]	Family size	0.30[a]
7	Time since AFM discovered substance misuse	0.36[c]	SMR's preferred drug (2 groups)	0.31[b]
Excluded variables	AFM age		Time since AFM discovered substance misuse	

[i]Mothers, wives, ex-wives, husbands = 1; Sisters, daughters, grandmothers, girl-friends, female cousins = 2; Others = 3. [ii]Currently admitted = 1; Others = 2. [iii]North, central-west = 1; Others = 2. [iv]Marijuana, cocaine, crack = 1; Alcohol, other = 2. [v]superscripts refer to the significance of R change at that step ([a] $p < 0.001$ [b] $p < 0.01$ [c] $p < 0.05$).

Table 6. Tests of additive and moderation models of the influence on coping on the relationship between impact and symptoms, using Cop-Eng and Cop-Tol as the coping variables

	R (adj. R^2)	F	t
Cop-Eng Model 1	0.40 (0.16)	$F_{(2, 2967)} = 290.2$[a]	
FMI			14.27[a]
Cop-Eng			5.26[a]
Cop-Eng Model 2	0.44 (0.19)	$F_{(3, 2966)} = 234.4$[a]	
FMI			2.66[b]
Cop-Eng			7.26[a]
FMI X Cop-Eng			10.14[a]
Cop-Tol Model 1	0.46 (0.21)	$F_{(2, 2985)} = 398.7$[a]	
FMI			9.99[a]
Cop-Tol			14.45[a]
Cop-Tol Model 2	0.47 (0.22)	$F_{(3, 2984)} = 288.5$[a]	
FMI			2.42[c]
Cop-Tol			1.91
FMI X Cop-Tol			7.36[a]

([a] $p < 0.001$ [b] $p < 0.01$ [c] $p < 0.05$)

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Figure 1. How AFM symptoms varied (means) with the combined influence of impact and coping