Behavioral and Psychological Symptoms of Dementia in developing countries

The 10/66 Dementia Research Group*

ABSTRACT

Background: Little is known about the prevalence of, or associations with behavioral and psychological symptoms of dementia (BPSD) in developing countries.

Methods: Individuals diagnosed as having dementia according to DSM-IV criteria (mild and moderate cases as defined by the Clinical Dementia Rating scale only), together with their main caregiver, were recruited from 21 centers in 17 developing countries. People with dementia were directly assessed with the Community Screening Interview for Dementia and the Geriatric Mental State Schedule (GMS); GMS data were processed by the AGECAT computer program to yield diagnostic information on 8 psychiatric syndromes. Caregivers answered direct questions about behavioral symptoms of dementia (BSD) and completed the Zarit Burden Inventory.

Results: At least one BSD was reported in 70.9% of the 555 participants. At least one case-level AGECAT psychiatric syndrome (not including the organic syndrome) was exhibited by 49.5% of people with dementia. Depression syndromes (43.8%) were most common followed by anxiety neurosis (14.2%) and schizophreniform/paranoid psychosis (10.9%). Caregivers were more likely to report BSD in people with dementia who were married, younger and better educated. More advanced dementia, poorer functioning and the presence of depression or anxiety were each associated with BSD. BSD, and psychiatric syndromes (anxiety neurosis and schizophreniform/paranoid psychosis) predicted caregiver strain after controlling for cognitive impairment. BPSD are poorly understood, leading to shame and blame.

Correspondence should be addressed to: Dr. Cleusa P. Ferri1 and A/Prof. David Ames.2
1 Section of Epidemiology, Box 060, Institute of Psychiatry, De Crespigny Park, Denmark Hill, London SE5 8AF, U.K. Phone: +44 207 848 0136. Fax: +44 207 277 0283. Email: c.ferri@iop.kcl.ac.uk.
2 Department of Psychiatry, Level 7, Charles Connibere Building, Royal Melbourne Hospital, PARKVILLE VIC 3050, Australia. Phone: +61 3 8344 5598. Fax: +61 3 9342 8954 5. Email: dames@unimelb.edu.au. Received 10 Nov 2003; returned to authors for revision 11 Dec 2003; revised version received 30 Jan 2004; accepted 4 Feb 2004.

* The 10/66 Dementia Research Group is a collective of researchers from the developed and developing regions of the world. (See pp. 23–24).
Conclusions: BPSD are common among people with dementia in developing countries, though we found marked regional variations. Representative population studies are needed to clarify prevalence and impact, but our research suggests considerable unmet need, with much scope for intervention. Raising awareness of the problem should be the first step.

Key words: Dementia, behavioral and psychological symptoms, developing countries, AGECAT

Introduction

The symptoms of dementia can be aggregated into two major groups, namely, decline in cognitive function and behavioral and psychological symptoms. The term “behavioral and psychological symptoms of dementia” (BPSD), defined as “symptoms of disturbed perception, thought content, mood, or behavior that frequently occur in patients with dementia” has won wide acceptance since its proposal at a consensus conference organized by the International Psychogeriatric Association (Finkel et al., 1996; Brodaty and Finkel, 2003). Although BPSD have been the focus of an increasing amount of research in the developed world (Lyketsos et al., 2000; Brodaty and Finkel, 2003), only one detailed population-based study of their prevalence and associations has been undertaken in the USA (Lyketsos et al., 2000) and little is known about their manifestation in individuals with dementia in developing countries, despite the fact that two-thirds of people with dementia live in these countries and this proportion will rise over the next few decades (The 10/66 Dementia Research Group, 2000).

One might anticipate that cultural and environmental factors could have a strong influence upon both the expression of BPSD and their perception by caregivers as problematic. However, in a unique study, Murray et al. (1999) found that there was a certain commonality of experience among 280 spouse-caregivers of people with dementia from 14 European countries. Loss of communication abilities, loss of memory and aggression were reported to be the three hardest symptoms with which to cope.

The premature institutionalization, increased costs of care, caregiver strain and impaired quality of life associated with BPSD all argue for more attention to be directed to this problem. Cross-cultural studies may bring valuable insights. In this paper we report on BPSD expressed by people with dementia from 21 centers in 17 developing countries, using a combination of quantitative and qualitative methods. We hypothesize that BPSD are independent predictors of caregiver strain after adjusting for clinical severity of dementia in this population.
Methods

Centers and participants

The 21 centers contributing data were all members of the 10/66 Dementia Research Group (The 10/66 Research Group, 2000; Prince et al., 2003). Fourteen centers were in Latin America: Argentina (Buenos Aires), Brazil (São Paulo, Botucatu and São José do Rio Preto), Chile (Santiago/Valparaiso), Cuba (Havana), Dominican Republic (Santo Domingo), Guatemala (Guatemala City), Mexico (Mexico City and Guadalajara), Panama (Panama City), Peru (Lima), Uruguay (Montevideo) and Venezuela (Caracas). Four centers were in India: Bangalore, Chennai (SCARF), Goa and Thrissur. There were two Chinese centers in the People’s Republic of China (Beijing and Hong Kong SAR) and one in Taiwan (Taipei). Nigeria (Anambra) was the sole African center. Three additional centers, which contributed data on other aspects of dementia to the 10/66 data set (Prince et al., 2003), did not collect data on BPSD.

In each center, the study focused upon participants with mild to moderate dementia living in the community, who had been recruited for the purposes of a dementia diagnosis validation study (Prince et al., 2003). Each center sought to recruit 30 persons with dementia, though some contributed more, some fewer than this figure. Recruitment methods differed, depending upon local circumstances. Centers were asked to identify community cases of dementia, either from a recent local population-based research study, or by sampling a district using community health care workers and local people as key informants to propose possible cases. The advantage of the latter approach was that cases would not necessarily have been identified on the basis of prior contact with specialist services. Centers were permitted to recruit on the basis of service contact only when there was no practical alternative, but all participants were required to live in their own homes with an informal caregiver who would consent to act as informant. A preliminary unstructured interview was used to establish that the informant was the individual most directly responsible for providing care to the person with dementia. Local clinicians confirmed the clinical diagnosis of dementia according to DSM-IV criteria (American Psychiatric Association, 1994), completing proformas describing their findings, and rating dementia severity with the Clinical Dementia Rating Scale (CDR), (Morris, 1993). Only those classed by the CDR as having mild (1) or moderate (2) dementia were included.

Measures

A full account of the development and use of the measures employed is given in recent papers from our group (Prince et al., 2003; 2004). All study instruments were translated from English and back-translated into English by local investigators who were fluent in both English and the local language(s) to be
used in the study. The local language version of each translated instrument was reviewed by local key informants, including elderly persons without cognitive impairment, community leaders, health workers and researchers to check its acceptability and conceptual validity.

The following instruments were used:

1) The Community Screening Interview for Dementia (CSI ‘D’) (Hall et al., 1993) consists of a test of cognitive function administered to the person with dementia (COGSCORE) and an informant interview, enquiring after the everyday and cognitive functioning of the person with dementia (RELSCORE).

2) Impact upon the caregiver was assessed using the Zarit Burden Interview (ZBI) (Zarit et al., 1980) as a measure of strain. The ZBI has 22 items that assess the caregiver’s appraisal of the impact that involvement with their relative has had on their lives. It includes questions such as: ‘Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?’ and “Do you feel strained when you are around your relative?”. It has been very widely used in the USA and Europe, and also in Taiwan and Japan, but not in developing countries. Although its items had strong face validity across a wide range of cultures, some concerns were expressed that the strong tradition of duty of care and veneration of elders in Asian cultures might make it difficult for caregivers to acknowledge strain where it existed.

3) Psychological symptoms of dementia (PSD) were assessed by means of the A3 version of the Geriatric Mental State schedule (GMS) (Copeland et al., 1976; Copeland et al., 1986), a semi-structured interview administered by a trained interviewer, assessing the presence and severity of symptoms of cognitive impairment, psychosis, affective disorder and anxiety. GMS comprises a clinical interview and an extensive observer rating section. These data were processed by the AGECAT computer programme (Copeland et al., 1986), which produces a level of confidence from 0 (absent) up to 5 (highly confident) for the presence of each of eight psychiatric syndromes (organic, schizophreniform/paranoid and manic psychoses, depressive psychosis and neurosis, hypochondriacal, obsessional, phobic and anxiety neuroses). Syndromes with a confidence level of 3 and above are those which a psychiatrist usually would designate as a “case” worthy of psychiatric intervention, whereas those with a confidence level of 1 or 2 represent symptoms which a psychiatrist would be unlikely to class as needing specific psychiatric help (Copeland et al., 1986). For this report, psychological symptoms were defined as the presence of AGECAT case level syndromes, excluding the organic syndrome which is usually exhibited at level 3 or above by people with dementia. In stage
one of the AGECAT output, multiple case-level diagnoses (up to 9) may be generated. We used this level of output for analysis rather than stage 2 (which utilizes hierarchical rules to refine diagnosis to a single one from a choice of 9) as many people with dementia have significant psychiatric symptoms in more than one domain (e.g. depression AND anxiety) and we wished to capture and describe the whole array of significant psychiatric symptoms exhibited by this population.

4) Five open-ended questions were asked to elicit information on care arrangements, and positive and negative aspects of providing care, i.e.

a) What do you find difficult about caring for the person with dementia?

b) How do you think that people react to the person with dementia?

c) Can you tell me about anyone or anything that helps you in caring for the person with dementia?

d) Can you think of any additional help that would make it easier for you to go on looking after the person with dementia?

e) Is there anything that you gain, personally, from caring for person with dementia?

Caregivers were encouraged to discuss their attitudes, beliefs and experiences. Responses were recorded verbatim. As in the EUROCARE study (Murray et al., 1999), local investigators coded the answers to the first of these questions for spontaneous mention of any of six common behavioral symptoms of dementia (BSD): agitation, aggression, repeated vocalizations, wandering, sleep disturbance and incontinence. If the caregiver mentioned the presence of BSD which could not be classed under one of these headings, the participant was classed as having “other BSD”. These data were summarized in a single variable as the number of BSD (range 0–7), then dichotomized into BSD present (one or more BSD) or absent (none).

Data analysis

The Distribution of Behavioral and Psychological Symptoms of Dementia

For ease of presentation, the frequencies of psychological and behavioral symptoms are presented for each of the four 10/66 regional networks: India and S. Asia, China and S.E. Asia, Latin America and the Caribbean and Africa. The effects of region upon individual BSD and PSD were studied using $\chi^2$ tests, and upon the total number of BSD and PSD, using Kruskal Wallis tests.

Associations with BSD

Associations between the presence of BSD and a) the demographic characteristics of the person with dementia and their caregiver and b) the clinical
characteristics of the person with dementia, were estimated as odds ratios (OR) with 95% confidence intervals. Logistic regression was used to identify those demographic characteristics which were independently associated with BSD having adjusted for clinical severity.

ASSOCIATIONS BETWEEN BSD AND CAREGIVER STRAIN
We compared the effect of BSD upon caregiver strain with those of other indicators of clinical severity. First, in univariate analyses we estimated the proportion of the variance in caregiver strain accounted for by BSD, cognitive impairment (COGSCORE) and psychological symptoms of dementia (GMS case level schizophreniform/paranoid psychosis, depression and anxiety disorder). We then tested for an independent effect of BSD upon caregiver strain, adjusting for all of these clinical severity indicators as factors or covariates (as appropriate) using generalized linear modeling.

CAREGIVERS’ RESPONSES TO OPEN-ENDED QUESTIONS
Six centers (Bangalore, Thrissur, and Goa in India, and the centers in Nigeria, Chile and the Dominican Republic) translated transcripts of responses to the open-ended questions into English. These were subjected to detailed qualitative analysis and themes relevant to the knowledge, attitudes and beliefs of caregivers and others to BPSD are presented.

Results
The distribution of BPSD
Data on BSD and psychological symptoms were available for 555 participants, and their informants from 21 centers. (The total recruitment for 24 centers was 729 subjects). There were 87 Indian, 387 Latin American, 61 Chinese and 20 African participants. Thirty eight percent of the informants were spouses, 42% children and 8% were sons-in-law or daughters-in-law of the people with dementia; 13% of informants had another relationship (e.g. friend, cousin). (Percentages add to 101% owing to rounding). These data, sorted by region, are presented in Table 1. Across the entire sample of 555 individuals with dementia, 70.9% were reported to exhibit at least one BSD and 16.3% had three or more such symptoms.

Figure 1 illustrates the prevalence of six defined BSD (plus “other BSD”) among people with dementia recruited in the three main regions surveyed. Although vocal disturbances were most common in Latin America, agitation, wandering, incontinence and sleep disturbance were commonest in India. The expression of aggressive symptoms was similar in all three regions. Overall,
Table 1. General characteristics of the population by region (n = 555)

<table>
<thead>
<tr>
<th>DEMOGRAPHIC VARIABLES</th>
<th>AFRICA (n = 20)</th>
<th>LATIN AMERICA (n = 387)</th>
<th>CHINA (n = 61)</th>
<th>INDIA (n = 87)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person with dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (%)</td>
<td>60.0</td>
<td>41.3</td>
<td>44.3</td>
<td>42.5</td>
</tr>
<tr>
<td>Married (%)</td>
<td>–</td>
<td>42.9</td>
<td>57.4</td>
<td>55.2</td>
</tr>
<tr>
<td>Mean age (sd)</td>
<td>71.6 (7.7)</td>
<td>77.3 (6.8)</td>
<td>76.1 (6.2)</td>
<td>75.3 (8.2)</td>
</tr>
<tr>
<td>Completed primary education (%)</td>
<td>–</td>
<td>63.0</td>
<td>42.6</td>
<td>50.6</td>
</tr>
<tr>
<td>Mean cognitive test score (sd)</td>
<td>13.4 (4.6)</td>
<td>20.6 (6.9)</td>
<td>21.7 (4.5)</td>
<td>19.5 (7.2)</td>
</tr>
<tr>
<td>CDR moderately severe (vs mild) (%)</td>
<td>35.0</td>
<td>46.0</td>
<td>52.5</td>
<td>57.5</td>
</tr>
<tr>
<td>The caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (%)</td>
<td>5.0</td>
<td>15.8</td>
<td>36.1</td>
<td>24.1</td>
</tr>
<tr>
<td>Married (%)</td>
<td>80.0</td>
<td>58.7</td>
<td>91.8</td>
<td>88.5</td>
</tr>
<tr>
<td>Mean age (sd)</td>
<td>46.0 (10.6)</td>
<td>55.5 (15.3)</td>
<td>59.2 (12.3)</td>
<td>50.1 (14.3)</td>
</tr>
<tr>
<td>Completed primary education (%)</td>
<td>60.0</td>
<td>85.5</td>
<td>86.8</td>
<td>69.8</td>
</tr>
<tr>
<td>Relationship to person with dementia (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>16.7</td>
<td>39.0</td>
<td>60.0</td>
<td>20.8</td>
</tr>
<tr>
<td>Child</td>
<td>33.0</td>
<td>39.0</td>
<td>35.6</td>
<td>60.4</td>
</tr>
<tr>
<td>Son or d-in-law</td>
<td>50.0</td>
<td>5.2</td>
<td>2.2</td>
<td>12.5</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>16.8</td>
<td>2.2</td>
<td>6.3</td>
</tr>
</tbody>
</table>

there was a significant tendency for people with dementia from China to have the fewest reported BSD (mean rank 223), and those from India to have the most (mean rank 293), with Latin Americans intermediate (mean rank 267; Kruskall-Wallis test $\chi^2 8.1$, 2 degrees of freedom, $p = 0.02$). Overall, 49.5% of those with dementia met AGECAT case level criteria for one or more psychiatric syndromes (excluding the organic syndrome). Depression was the commonest (43.8%) followed by anxiety neurosis (14.2%), schizophreniform/paranoid psychosis (10.9%), phobic neurosis (10.4%), manic/hypomanic psychosis (7.6%), obsessional neurosis (3.6%), and hypochondriacal neurosis (0.9%). There was considerable comorbidity, particularly for those with depressive syndromes, 47.9% of whom also met criteria for one or more other syndromes. The regional prevalence of the three commonest AGECAT psychiatric syndromes (schizophreniform/paranoid psychosis, depression and anxiety) is displayed in Figure 2. All three syndromes were least common in Chinese and most common in Latin American participants. This contrast was most marked for syndrome cases of depression which affected 51% of Latin Americans and 38% of Indians but only 12% of Chinese with dementia. Phobic neurosis and manic/hypomanic psychosis were only identified in a subset of Latin American centers. There was a marked effect of region on the distribution of numbers of psychological syndromes identified, with most in those from Latin America (mean rank 292), fewest in those from China (mean rank 170) with
Figure 1. Regional variation in caregiver reports of behavioral symptoms affecting participants with dementia ($n = 535$)

Note 1: LAC = Latin American countries.

Note 2: The single African center is omitted from this figure because of the small number of participants (20).

Indians intermediate (mean rank 228); Kruskall-Wallis test $\chi^2 46.2$, 2 degrees of freedom, $p < 0.001$.

### Associations with BSD

No caregiver characteristics were associated with reports of BSD. For people with dementia, being married (OR = 1.55 (95% confidence intervals 1.08–2.22)) and having completed primary education (OR = 2.28 (1.57–3.31)), were each associated with a significantly higher likelihood of one or more BSD being reported by the caregiver. Age was inversely associated with a 2% risk reduction with each one-year increment in the age of the person with dementia; OR 0.98 (0.95–1.00). Having adjusted, using logistic regression for the effect of clinical dementia rating (CDR) severity, for each of the above variables, the odds ratios were: for being married 1.56 (1.08–2.26), for completed primary education 2.39 (1.64–3.50), and for each one year increase in age 0.97 (0.95–1.00).

Table 2 summarizes associations between CDR severity, COGSCORE, RELSCORE, and the three commonest AGECAT syndromes on the likelihood of the presence of one or more BSD in the person with dementia. Moderate
(as opposed to mild) dementia rated using the CDR, poorer functioning as rated by RELSCORE and the presence of either depression or anxiety all significantly increased the likelihood of one or more BSD being reported.

**Associations between clinical features and caregiver strain**

Caregiver ZBI scores varied from 0 to 78 with a mean (SD) of 36.7 (16.6). In univariate analyses, greater cognitive impairment as measured by lower COGSCORE, the presence of schizophreniform/paranoid psychosis, depression or anxiety neurosis AGECAT syndromes, and one or more BSD exhibited by the person with dementia were each associated with higher caregiver ZBI scores (see Table 3). In a subsequent multivariable analysis (Table 3) the largest
Table 2. Univariate associations between clinical characteristics of the person with dementia, and caregivers’ report of the presence of one or more behavioral symptom of dementia

<table>
<thead>
<tr>
<th>CLINICAL CHARACTERISTICS OF THE PERSON WITH DEMENTIA</th>
<th>OR (95% CI) FOR REPORTED PRESENCE OF 1 OR MORE BSD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CDR</strong></td>
<td></td>
</tr>
<tr>
<td>Mild (1)</td>
<td>1</td>
</tr>
<tr>
<td>Moderate (2)</td>
<td>1.89 (1.34–2.67)</td>
</tr>
<tr>
<td><strong>CSI’D’ COGSCORE</strong></td>
<td></td>
</tr>
<tr>
<td>25.28+</td>
<td>1</td>
</tr>
<tr>
<td>21.15–25.27</td>
<td>1.31 (0.81–2.10)</td>
</tr>
<tr>
<td>15.99–21.13</td>
<td>1.57 (0.98–2.51)</td>
</tr>
<tr>
<td>0–15.95</td>
<td>1.59 (0.98–2.58)</td>
</tr>
<tr>
<td><strong>CSI’D’ RELSCORE</strong></td>
<td></td>
</tr>
<tr>
<td>0–10.86</td>
<td>1</td>
</tr>
<tr>
<td>11–14.50</td>
<td>1.28 (0.79–2.06)</td>
</tr>
<tr>
<td>15–19.14</td>
<td>1.54 (0.96–2.49)</td>
</tr>
<tr>
<td>19.44+</td>
<td>1.95 (1.18–3.22)</td>
</tr>
<tr>
<td>SP</td>
<td>1.51 (0.86–2.66)</td>
</tr>
<tr>
<td>D</td>
<td>1.95 (1.18–3.22)</td>
</tr>
<tr>
<td>AN</td>
<td>2.34 (1.36–4.01)</td>
</tr>
</tbody>
</table>

Notes:
1. CDR = Clinical Dementia Rating scale dementia severity level (higher scores equate to greater impairment).
2. CSI’D’ = Community screening instrument for dementia.
3. COGSCORE = Cognitive test score from CSI’D’ (lower scores equate to greater impairment).
4. RELSCORE = Score for cognitive and functional impairment taken from caregiver responses to CSI’D’ (higher scores equate to greater impairment).
5. SP, D, AN = AGECAT syndrome case (confidence level 3 or greater) of schizophreniform/paranoid psychosis, depressive neurosis or psychosis, or anxiety neurosis.

component of the variance in caregiver ZBI was explained by cognitive test score (CSI ‘D’ COGSCORE) and BSD. The presence of anxiety neurosis and schizophreniform/paranoid psychosis was independently associated with caregiver strain, but depression had no independent effect.

**Qualitative analysis**

Cognitive impairment was occasionally cited as a particular problem for caregivers:

Sometimes he forgets our names – that is what is difficult. That at such an age he should have this problem is painful for us.  

[Bangalore, India]

More usually, where cognitive impairment is referred to, it is the consequent
### Table 3. The association between behavioral symptoms of dementia and caregiver strain (Zarit Burden Inventory), before and after adjusting for other clinical factors

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>CRUDE ASSOCIATIONS (UNIVARIATE ANALYSES)</th>
<th>FULLY ADJUSTED MODEL (MULTIVARIABLE ANALYSIS(^1))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F-VALUE</td>
<td>P-VALUE</td>
</tr>
<tr>
<td>CSI ‘D’ cognitive test score (COGSCORE)</td>
<td>34.4</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>One or more behavioural symptoms of dementia</td>
<td>26.4</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>SP(^2)</td>
<td>47.0</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>D(^2)</td>
<td>14.2</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>AN(^2)</td>
<td>55.8</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>

Notes: R Squared = 0.190 (Adjusted R Squared = 0.182)
1. Linear modeling (LM).
2. GMS/AGECAT syndrome case (level 3 or more) of schizophreniform/paranoid psychosis (SP), depressive psychosis or neurosis (D), or anxiety neurosis (AN).
behavioral symptoms that trouble the caregiver most:

As she is forgetful she needs to be told certain things repeatedly, again and again. Even then, she will ask the same thing again. For example she will keep saying that people are hiding things, if she can’t find something, then this starts. Repeated explanations do not work.

[Thrissur, India]

Infrequently, functional impairment is identified as the major problem:

Controlling her is difficult. She won’t talk to anybody, even when strangers come, she’ll go sit with them. She leaves work unfinished. She does not talk to family members. She cannot wash her clothes properly – proper washing is not done.

[Thrissur, India]

Overwhelmingly though, BPSD are identified as the main focus of concern:

When she leaves home and goes out it is difficult for us, we don’t know when she’ll be back. It is also difficult to see her cry – then we also feel sad.

[Bangalore, India]

He always wanders in the compound. If he goes out at times he comes back, otherwise I will have to go after him. Only two of us are here. Once he is outside the house I need to keep a watch on him. He is suspicious and gets angry very easily. He hits me at times.

[Thrissur, India]

She spits on the floor, makes a mess everywhere, spills water, and in the bathroom she makes an awful mess. She fights, argues, talks, and when you tell her something, she does not know what you are talking about.

[Dominican Republic]

Caregivers reported strain associated with managing BPSD from a variety of expected sources, the physical and emotional strain of providing care often with inadequate support from other family members, the financial strain consequent upon having to cut back on work to care. One striking example from Thrissur, Southern India, of a daughter-in-law caring for her husband’s mother, will serve for many:

Q. What do you find most difficult caring for your mother-in-law?
A. She is very abusive and says all kind of bad words when she is angry. It is almost impossible to control her. She tries to hit others.
She sometimes passes urine in her clothes. Cleaning up and getting her clothes changed is a difficult task.

Q. How do you think that people react to your mother-in-law’s illness?
A. People say that the old lady is mad.

Q. Can you tell me about anyone or anything that helps you in caring for your mother-in-law?
A. My husband helps to bring her back when she tries to go away. He carries her or restrains her using force. Sometimes even when she is irritable she listens to him. My children help me in cleaning the place.

Q. Can you think of any additional help that would make it easier for you to go on looking after your mother-in-law?
A. If we had some money we would have taken her to a good hospital. Because of her illness my husband does not go for work as he needs to be at home to help us in looking after her. We need financial help. We had sent one request to the government for some help but there is no reply.

Q. Is there anything that you gain, personally, from caring for your mother-in-law?
A. No, This is my fate. This is a punishment.

Particularly noteworthy, though is the way in which many caregivers felt shame about the changed behavior of their relative:

She keeps wanting to go home. She feels cheated and deceived. She behaves like a child and greets me instead of me greeting her. She behaves embarrassingly. We continue locking the door every time. We feel ashamed; it is a useless life.

[Anambra, Nigeria]

He always packs bags and wanders away saying to go home. He gets lost and I look for him. Only my children know; we did not want others to know because of the shame. They think the man is reaping his fruits; he used to be harsh and at a point he moved in with a harlot. Now I am telling neighbors because he gets lost so if they see him they should bring him back.

[Anambra, Nigeria]

On occasion, blame did indeed appear to have attached to the caregiver, who was considered in some way responsible for the alteration:

Family members think we are the cause for his illness – they think we deserve all that is happening to us. Other than family, we don’t really care. My mother is not very comfortable to ask for help. People will blame her for my father’s problems. It is better not to ask anybody.

[Bangalore, India]
Discussion

Among 555 people with dementia from 17 developing countries 70.9% were reported by their caregivers to have BSD. There were regional differences for individual behaviors with high rates of agitation, wandering and sleep disturbance among Indian participants, and high rates of vocalization (calling out and repeated questioning) among Latin American people with dementia. Overall, numbers of reported BSD were highest in India, intermediate in Latin America and lowest in China. Half of all people with dementia were identified as experiencing significant psychological symptoms of dementia. Each of the three main AGECAT syndromes, depression, anxiety neurosis and schizophreniform/paranoid psychosis were commonest among people from Latin America and least common among those from Chinese centers, with Indian centers intermediate. The distribution of numbers of AGECAT syndromes followed the same regional trend.

We would urge caution in the interpretation of our finding of regional variation in the distribution of BPSD experienced by people with dementia. The differences for psychological symptoms are in the direction that would be expected from other work with GMS/AGECAT which has tended to find the lowest numbers of functional psychiatric syndrome cases among those living in South East Asia (Kua, 1992). This may reflect the impact of cultural factors as well as possible "real" differences in depression prevalence. Likewise, the propensity for Indian caregivers to report more and Chinese caregivers fewer BSD may reflect more upon the cultural acceptability of disclosure to a stranger than upon real differences in caregiver experience.

BSD were more frequently reported by the principal caregiver when the person with dementia was married, was relatively well educated, and was younger. Again, these differences are more likely to reflect ascertainment bias than true differences in the exhibition of these behaviors between these subgroups. The other main associations with BSD were indicators of clinical severity, particularly global severity (CDR), cognitive impairment and psychological symptoms (depression and anxiety). These seem more likely to be causally implicated.

This study had some methodological weaknesses. People with dementia who were identified and selected to participate were almost certainly not truly representative of all cases in the populations studied. Factors affecting recognition and awareness of dementia such as education, social class and physical location may have played a variable role in different centers. BSD were not ascertained in a structured systematic fashion. The open-ended question used to elicit BSD ‘What do you find most difficult about caring for the person with dementia’ is likely to have underestimated the true prevalence, with selective underascertainment of less troublesome symptoms and it lacked a specific question
about apathy. GMS/AGECAT has not been widely used as a measure of psychological symptoms in the BPSD literature (though it was used in influential early studies of non-cognitive features of dementia (Burns et al., 1990)) and might underestimate prevalence when compared to studies using relatives’ reports on psychological symptoms. It seems that relatives are more likely to report a symptom than for a symptom to be observed by an interviewer (Burns et al., 1990). However, its comprehensive approach, based upon clinical interview and observer ratings, has obvious advantages, particularly for the mild-to-moderate dementia cases included in this study. The study has other strengths, including detailed and rigorous training of personnel, careful development of translated instruments shown to be reliable and valid in a variety of countries and cultures, and diagnosis of dementia according to international operational criteria. It also represents the first systematic attempt to study BPSD in the developing world.

The clearest inference to be drawn from our findings is that both behavioral and psychological symptoms are highly salient to people with dementia and their caregivers in developing countries. The high prevalence of BSD is similar to that reported in studies of people with dementia in developed countries (Lyketsos et al., 2000). The very high prevalence of depressive symptoms may reflect a low threshold for individuals with symptoms of depression to be classed as syndrome cases by AGECAT, but it also indicates that the experience of dementia in the developing world, especially in Latin America, is likely to be distressing and unhappy for a significant number of affected people. The AGECAT schizophreniform/paranoid psychosis syndrome case-diagnosis is determined largely by the presence of delusions and/or hallucinations; the high numbers of schizophreniform/paranoid psychosis syndrome cases indicate that such experiences are at least as common among those with dementia in developing as in developed regions.

The high levels of caregiver strain found in this study cast doubt on the glib assumption that caring for someone with dementia is easier in developing countries because of larger family size, less complex environments and greater social tolerance. As previously reported in developed countries, BSD and psychological symptoms (anxiety and psychosis) were strongly and independently associated with caregiver strain even after adjusting for the effect of cognitive impairment.

Some of the strain experienced by caregivers would seem to arise from or be exacerbated by a lack of awareness on their part and that of others about the nature of the symptoms exhibited by the person with dementia. Three recent studies from India (Cohen, 1995; Patel and Prince, 2001; Shaji et al., 2003) tend to agree regarding the extent of awareness in the different communities studied (with a mixture of focus-group discussion and open-ended interviews). First, the typical features of dementia are widely recognized, and indeed named “Chinnan” (literally childishness) in Malyalam language in Kerala (Shaji et al.,
2003), “nerva frakese” (tired brain) in Konkani language in Goa (Patel and Prince, 2001), and “weak brain” in Hindi in Benares (Cohen, 1995). However, in none of these settings was there any awareness of dementia as an organic brain syndrome, or indeed as any kind of medical condition. Rather it was perceived as a normal, anticipated part of aging. In Goa the likely causes were cited as “neglect by family members, abuse, tension and lack of love” (Patel and Prince, 2001). In Kerala it was reported that most caregivers tended to misinterpret symptoms of the disease and to designate these as deliberate misbehavior by the person with dementia (Shaji et al., 2003). This general lack of awareness has important consequences for family caregivers, who may thereby forgo support and understanding from others. Cohen (1995) on the evidence of his research in Benares speaks of the “outsider narrative” for dementia, that is the explanation of a neighbor, relative or passer-by:-

that the old person receives inadequate respect or support from a particular child. Family members will be far more likely to speak of weak brain, when they speak of it at all as a natural phenomenon, as nothing but old age. Certain kinds of behaviors of old persons, particularly yelling and wandering, are difficult to contain within household space and, when associated with accusations of mistreatment, ultimately require alternative explanations from family insiders against the outside narrative of the Bad Family.

This construction is consistent with the suggestion from Goa that dementia is associated with, indeed caused by family neglect. BSD – wandering, calling out, making accusations – may be taken by outsiders as evidence of neglect or abuse. Caregivers then face a double jeopardy, the strain of care heightened by the stigma and blame that attaches to them because of the disturbed behavior of their relative.

Dementia represents a significant public health challenge for developing countries as their populations undergo rapid demographic change. As has been shown in the developed world, BPSD appear to be common among people with dementia in developing countries. Effective management of these phenomena should be an aspiration for health services. There is no shortage of evidence-based interventions, both pharmacological and non-pharmacological (Brodaty and Finkel, 2003). However, implementation would have enormous resource implications in terms of trained personnel at primary as well as secondary care level with the skills and commitment to carry out assessments and to provide continuing care in the community. Safe drugs (e.g. atypical antipsychotics and SSRI antidepressants) are also expensive or in short supply. A realistic first step may be to focus on raising awareness among policy makers, health care professionals, caregivers and in the general population.
Conflict of interest

Because the editor-in-chief of *International Psychogeriatrics* is a co-author of this paper, the review process was conducted through the office of the deputy editor.

Acknowledgments and description of authors’ roles

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The Dementia Research Group

The 10/66 Dementia Research Group, part of Alzheimer’s Disease International, is a collective of researchers from the developing and developed regions of the world. A full list of members with contact details can be found at [http://www.alz.co.uk/1066](http://www.alz.co.uk/1066)

The following members of the 10/66 Group contributed to the paper:

**Writing committee:** C. P. Ferri carried out the analyses. C. P. Ferri and D. Ames wrote the first draft and coordinated revisions. M. Prince was responsible for the study design in collaboration with regional coordinators and local investigators. He revised the first draft.

**Local Investigators (listed below):** Coordinated the local pilot research studies and are responsible for scientific quality control in each centre. They all participated in the authorship of the paper by reviewing drafts and provided revisions where necessary.

**10/66 India and S Asia** (Regional co-ordinator Add. Prof. Mathew Varghese): Bangalore –, Mathew Varghese and T. Murali, NIMHANS, Bangalore; Chennai (SCARF) – Ms. Latha Srinivasan, Dr. R. Thara, Schizophrenia Research...
Foundation; Goa – Dr. Vikram Patel, Dr. Amit Dias, Sangath, Goa; Thrissur – Asst. Prof. K.S. Shaji, Prof. K. Praveen Lal, Medical College, Thrissur.

**10/66 China and SE Asia** (Regional Co-ordinator, Prof Helen Chiu): China (Beijing) – Prof. Li Shuran, Dr. Jin Liu, Beijing University; Taiwan (Taipei) – Dr. Shen-Ing Liu, Mackay Memorial Hospital, Ms. Li-Yu Tang, Catholic Sanipax Medico-social Educational Foundation.

**10/66 Latin America and Caribbean** (Regional Co-ordinators Dr. Daisy Acosta (Dominican Republic) and Dr. Marcia Scazufca (Brazil): Argentina (Buenos Aires) – Dr. Raúl Luciano Arizaga, Hospital Santojanni (GCBA). Brazil (São Paulo) – Dr. Marcia Scazufca, Dr. Paulo Rossi Menezes, Universidade de São Paulo; Brazil (Botucatu) – Dr. Ana Teresa de A. R. Cerqueira, Botucatu Medical School – UNESP; Brazil (São José do Rio Preto) – M. Cristina O. S. Miyazaki and Neide A. Micelli Domingos, FAMERP Medical School; Chile (Santiago/Concepción/Valparaíso) – Dr. Patricio Fuentes G. Hospital Del Salvador, Dr. Gustav Rohde C, Universidad Valparaíso; Cuba (Havana) – Dr. Juan de J. Llibre Rodríguez, Dra. Tania Laucerique Pardo, Facultad de Medicina “Finlay-Albarran”, Universidad Medica de la Habana; Dominican Republic (Santo Domingo) – Dr. Daisy Acosta, Universidad Nacional Pedro Henriquez Ureña (UNPHU), Lic. Guillermina Rodriguez, Asociación Dominicana de Alzheimer (ADA); Guatemala (Guatemala City) – Dr. Josué Avendaño, Diana García Santana; Mexico (Mexico City) – Dra. Ana Luisa Sosa, Dra. Yaneth Rodriguez Agudelo, National Institute of Neurology and Neurosurgery; Mexico (Guadalajara) –, Irma E. Velazquez-Brizuela, CIBO-IMSS, Dr. Miguel A. Macías-Islas, HECMNO-IMSS; Panama (Panama City) – Dr. Gloriela R. de Alba, Paitilla Medical Center Hospital, Dr. Gloria Grimaldo, Santa Fe Hospital; Peru (Lima) – Dr. Mariella Guerra. Instituto Nacional de Salud Mental “Honorio Delgado-Hideyo Noguchi”, Universidad Peruana Cauetano Heredia, M. Víctor González, Instituto Peruano de Seguridad Social – ESSALUD; Uruguay (Montevideo) – Ana Carina San Martin and Maria Ximena Palabé, University of Uruguay; Venezuela (Caracas) – Dr. Aquiles Salas, Universidad Central de Venezuela, Faculty of Medicine, Dr. Ciro Gaona Yánez, Fundación Alzheimer’s Venezuela.

**10/66 Africa:** Nigeria (Anambra) – Dr. Richard Uwakwe, Nnamdi Azikiwe University Teaching Hospital.

**Others:** J. Copeland trained investigators in India and China. M. Dewey processed the GMS data. Both contributed to the authorship of the paper by reviewing drafts and providing revisions where necessary.
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