

# Ageing and mental health in a developing country: who cares? Qualitative studies from Goa, India

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## ABSTRACT

**Background.** While there is a growing body of epidemiological evidence on the prevalence of mental illnesses in late-life in developing countries, there is limited data on cultural perceptions of mental illnesses and care arrangement for older people.

**Method.** This qualitative study used focus group discussions with older people and key informants to investigate the status of older people and concepts of late-life mental health conditions, particularly dementia and depression, in Goa, India.

**Results.** Vignettes of depression and dementia were widely recognized. However, neither condition was thought to constitute a health condition. Dementia was construed as a normal part of ageing and was not perceived as requiring medical care. Thus, primary health physicians rarely saw this condition in their clinical work, but community health workers frequently recognized individuals with dementia. Depression was a common presentation in primary care, but infrequently diagnosed. Both late-life mental disorders were attributed to abuse, neglect, or lack of love on the part of children towards a parent. There was evidence that the system of family care and support for older persons was less reliable than has been claimed. Care was often conditional upon the child's expectation of inheriting the parent's property. Care for those with dependency needs was almost entirely family-based with little or no formal services. Unsurprisingly, fear for the future, and in particular 'dependency anxiety' was commonplace among older Goans.

**Conclusions.** There is a need to raise awareness about mental disorders in late-life in the community and among health professionals, and to improve access to appropriate health care for the elderly with mental illness. The study suggests directions for the future development of locally appropriate support services, such as involving the comprehensive network of community health workers.

## INTRODUCTION

By 1990, a clear majority (58%) of the world's population aged 60 years and over were already to be found living in developing countries. By 2020 this proportion will have risen to 67%. Over these 30 years this oldest sector of the population will have increased in number by 200% in developing countries as compared to 68% in the developed world (Murray & Lopez, 1996). This demographic transition will be accompanied by economic growth and industrialization, and by profound changes in social organization and in the pattern of family

life. For older, as with younger people, mental health conditions are an important cause of morbidity and premature mortality. Among the neuropsychiatric conditions, dementia and major depression were the two leading contributors accounting respectively for one-quarter and one-sixth of all disability adjusted life years (DALYs) in this group (Murray & Lopez, 1996). If the age-specific prevalence of dementia in developing countries matches that observed in developed countries, then by 2025 nearly three-quarters of all cases would be living in the developing world, a total of 24 million people out of the estimated 32 millions living with dementia worldwide (Prince, 1997).

Studies from India have demonstrated a

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prevalence of dementia in persons aged over 65 years ranging from 1.8 to 4.5% (The 10/66 Dementia Research Group, 2000). Prevalence rates for depression in a community sample of elders has varied from 6% in South India (Venkoba Rao, 1993) to > 50% in rural West Bengal (Nandi *et al.* 1997). It is now widely accepted that socio-cultural and regional factors modulate health perceptions, illness presentations and interactions between the potential consumers and providers of health care services (Patel, 2000). It is essential that these factors be taken into account in prioritizing, designing and delivering new services. This is clearly a crucial issue with respect to services for older people in developing countries, where currently there is little, if any, formal health or social welfare provision, and where there is a heavy reliance on informal care from families. Qualitative research can be used to explore in detail people's attitudes, perceptions and experiences examining 'not only what people think but how they think and why they think that way' (Kitzinger, 1995). Qualitative research can usefully complement epidemiological research, both by setting an appropriate agenda and by generating hypotheses for later quantitative studies.

The aims of the study described in this paper were first, to investigate the understanding and opinions of Goan people, from a variety of age groups and backgrounds, regarding the health experiences of older people. We focused on the two major mental health conditions of late life, dementia and depression. Since the wider consequences of deteriorating mental health in late-life could be better understood with reference to the family structures and broader social and community context, we also wished to assess perceptions of the status, roles and relationships of older persons in Goan society. We anticipated that the findings of this study would inform the development of ecologically sensitive programmes of epidemiological and health service research into dementia and late-life depression in Goa.

## METHOD

### Setting

Goa is the smallest state in India. The primary language is Konkani. Goa has better health and development indices than most other Indian

states (Population Research Centre *et al.* 1995), 41% of the population live in urban areas, compared with 26% for India. Goa has a higher proportion of persons aged  $\geq 60$  (6–7%) than does the rest of India. Its declining infant mortality, fertility and adult mortality are typical of populations in the advanced phase of demographic ageing. Goa has > 1 doctor for every 1000 persons, as compared with < 1 doctor for every 2000 persons in the rest of the country. More than 90% of all births are conducted in hospitals. An extensive network of public and private medical care facilities ensures that health care is relatively easily accessed by the majority of the population (Patel *et al.* 2000).

### Procedure

Data was collected in focus group discussions (FGD). The methodology of conducting FGD is described elsewhere (Khan *et al.* 1991; Patel *et al.* 1995). Two teams of two interviewers conducted the FGD. The interviewer teams were trained in the use of FGD by the first author (V. P.). Two researchers conducted each FGD; one facilitated the group while the other recorded the proceedings, noting key themes and monitoring verbal and non-verbal interactions. All FGDs were audiotaped, allowing the original material to be reviewed in the preparation of the record of the group proceedings. Nine FGD were conducted in Konkani, one in English and three in both languages. The FGD lasted between 45 and 90 min.

### Subjects

Subjects were recruited from two main sources: (a) older persons living in the community or in old age homes; and, (b) key informants from the community including *panchayat* (village government) councillors, multi-purpose health workers, primary care doctors, and family care-givers of elderly persons with disability or dementia. Subjects were recruited by purposive sampling. The aim of the study and implications of participation were explained to the group. Subjects were then invited to participate on the basis of this information. FGD were held in a range of settings; in north and south Goa, in rural and urban areas, and among Konkani and English speakers. In all 13 groups were held as follows.

*Older persons*

Five FGD were conducted with a total of 37 older people. Three FGD involved older persons resident in homes for the aged, as follows: (1) Missionaries of Charity, Panaji ( $N = 6$ , aged 50–70); (2) Asilo Home for the Aged, Panaji ( $N = 6$ , aged 66–83); and, (3) Asilo Home for the Aged, Mapusa ( $N = 6$ , aged 65–89).

Two FGD were conducted with older persons living in the community: (1) Holy Spirit Church, Margao ( $N = 10$ , aged 60–80, older members of the local congregation); and, (2) Clube Tennis de Gaspar Dias, Panaji ( $N = 9$ ; aged 63–72, mainly relatively affluent retired professionals).

*Key informants*

A total of eight FGD were conducted with the following groups: (1) three FGD with health workers: one with primary health centre doctors ( $N = 3$ ), two with multi-purpose health workers (MPHWs) ( $N = 17$ ), i.e. community-based health workers; (2) one FGD with village councillors (who are residents of the village) ( $N = 5$ ); and, (3) four FGD with caregivers of older persons with disabilities or dementia ( $N = 26$ ); comprising members of church groups caring for older persons living at home, and caregivers of older persons admitted to a public psychiatric hospital or to a private hospital specializing in stroke rehabilitation.

*Focus group discussions (FDG)*

Group members were asked first to describe what they felt to be common health problems among older people. Three case vignettes were then presented to the group describing an older person with depression; an older person with early dementia; and then the same older person with advanced dementia. The vignettes did not mention depression or dementia by name, but described an older person with the condition as they might be encountered by a member of the same family or community (see Appendix for the full case vignettes). After each vignette the groups were asked to consider: Is this a health problem?; What do you call it?; What care does this person need?; What care is available in your community?; and, What should be done for this person?

The second section of the FGD explored themes related to general aspects of ageing; the

status of older persons and their roles and activities, both in the family and in the wider community. The key themes were: What is the position of older people within family hierarchies and within local society?; What are the important roles for older people who are not in paid work?; What are the extent, the nature, and the limits of the care arrangements for dependent older persons?; and, What resources are there for older persons in the community?

**Data analysis**

M. P. and V. P. conducted the analysis. In the first instance this involved detailed scrutiny of the notes and records from all FGDs. The constant comparison technique was used to identify all data relevant to the research questions posed. The task of content coding included ordering the data in relation to the objectives of the study; categorizing answers that had similar characteristics; and examining the data for possible associations between variables (Patel *et al.* 1995). As a reliability check, the two samples were analysed separately, one by each of the investigators, who then cross-checked their codings for similarities and discrepancies in content and organization of the data. Themes that recurred across FGD were more likely to represent a broad strand of opinion, and were therefore of special interest.

**RESULTS****The health status of older persons***Health conditions*

We recorded all health conditions mentioned as being prevalent among older persons, together with the number of groups in which they had been discussed (Table 1). The lists consisted almost entirely of chronic, non-communicable diseases; mental health conditions were frequently volunteered.

Key informants cited various causes. Prominent among these, mentioned in six out of eight key informant groups, were the gradual degeneration of health as part of old age and neglect, lack of care or abuse by the family. Other causes recorded were alcohol abuse, poor diet, lack of exercise and poverty. Older persons were less likely to volunteer any attributions; the commonest explanations being a natural part of growing old, heredity and ‘God knows’. Doctors

Table 1. *Common health conditions among older people*

FGD with carers ( $N = 8$ )	FGD with elders ( $N = 5$ )
Blood pressure/hypertension (6)	Blood pressure (4)
Mental health problems/tension (6)	Respiratory problems, e.g. coughs, colds, panting, bronchitis (4)
Diabetes (6)	Visual problems, e.g. failing vision, cataracts, blindness, glaucoma (4)
Heart disease (5)	Rheumatism/aches and pains (4)
Rheumatism/aches and pains (5)	Heart disease (3)
Weakness (3)	Paralysis/strokes (3)
Strokes/paralysis (3)	Mental health problems/worry/insomnia/excitability (2)
Sensory deficits, e.g. hearing and visual problems (2)	Deafness (2)
Alcohol abuse (2)	Weakness (2)
Falls and fractures (1)	Breast cancer (1)
Tuberculosis (1)	Diabetes (1)
Cholesterol (1)	Cholesterol (1)
Anaemia (1)	Incontinence (1)
Asthma (1)	Forgetting things easily (1)

Figures in parentheses are the number of FGD in which the item was recorded.

said that older persons comprised a significant proportion of primary-care clinic attenders, but that they mostly presented with minor ailments and needed only attention, reassurance or time to allow them to vent their feelings. These most often involved worries about health, family conflicts and property. Multi-purpose health workers (MPHWs) were in contact with many older persons in their catchment areas. One MPHW said that since many older persons had no one in whom to confide, it was important that MPHWs were able to spend some time to listen and counsel older people. Another suggested that MPHWs should encourage older people to be active and provide them with roles that might give them respect, such as working with youth organizations or clubs.

#### *Mental health conditions*

##### *Depression*

Most older participants and key informants identified the depression vignette as being a psychological or mental problem. Terms frequently used to describe the vignette were tension, mental problem, depression and worry. The presentation was considered by participants in each FGD to be fairly common; one participant said 'Five out of 10 families have such problems'. However, most felt that this was a social, rather than a health problem. Common attributions were family conflict, financial difficulties, worries about children, neglect and abuse, loneliness and boredom. The commonest remedy suggested by key informants was that older people with such problems needed

moral support, love and affection. Families needed to be educated about such problems and taught to value and succour their seniors. Visits by the parish priest, prayers, medication, counselling and advice on how to adjust to old age, going outdoors and good food were among other interventions suggested by key informants. Older persons highlighted a caring family, a positive attitude, spiritual programmes, 'laughter clubs', talking to others, prayer, keeping up with varied interests, watching television and seeing a psychiatrist as potentially effective interventions. All groups expressed similar views regarding the limited nature of community resources. Neighbours were of less help than in the past since many people in urban areas now lived in flats. There were no clubs or societies other than those run by the Catholic Church. Church groups prayed for such people and gave advice on problem solving.

##### *Dementia*

In none of the FGD was dementia volunteered and named as a cause of ill-health during the open discussion. However, two cases of persons with probable dementia were described, unprompted, in FGD with key informants. For example, one key informant described a man who could not take care of himself, needed to be fed by his wife, and was doubly incontinent. He had to be reminded of everything. If he left his house, very often his neighbours had to get him back. The key informant explained that 'he had some defect in his brain, the memory part of his brain is destroyed because his diabetes has become too high'.

The vignette on early dementia was widely recognized in each FGD, other than by primary care doctors who said they had rarely seen such a presentation. The commonest terms used to describe the vignette described nervous or psychological illness, such as *nerva frak* or *nervachem* (weak-nerve); nervous breakdown; mental problem; brain problem; depression; and absent-mindedness. In two FGD, the terms 'dementia' and amnesia were mentioned. The vignette on late dementia was recognized as being less common. Many key informants saw this as a physical health problem but one for which a doctor could do nothing. The primary care doctors said that they did not encounter such cases in their clinical practice. They also remarked that terms like Alzheimer's disease and dementia were associated with stigma and were best avoided in clinical practice, especially since a person diagnosed with dementia was typically refused admission to old-age homes. Many participants recognized the vignettes as typical of people known to them in their village or in their families. They volunteered additional observations of characteristic behaviours, such as 'behaving like small children', eating food at odd hours, accusing others and being unhygienic.

The commonest attribution among both older persons and key informants was that the presentation was the result of ageing. Many felt that it was a natural process, though they did acknowledge that few became as unwell as did the person in the advanced dementia vignette. Neglect by family members, abuse, tension and lack of love were potential causes. Less commonly mentioned causes were lack of blood circulation; poverty; stress earlier in life; paralysis (stroke); weakness; and blood pressure.

All participants felt that persons such as described in the vignette needed help, and, potentially, constant support. Better care could be provided if the family recognized there was a problem. Older persons suggested continual reminders, talking to others, watching TV and listening to music, brain 'tonics' and medical treatments. The family was the only source of care since there were no resources in the community. One key informant said that families had to be told that they 'will have to wait patiently until they (the older person) die'.

### General issues related to ageing in Goa

#### *The status of older persons in Goan society*

Key informants concurred that, in general, older people do command respect in Goan society. However, many of the older participants felt that this respect was on the wane. The younger generation did not enjoy the company of the older generation in social gatherings and tended to avoid them. Many participants felt that older people were given no respect in public places. One older participant said 'no one has any regard or respect for us, on the contrary we have to respect others'. Some older people remarked that nowadays their married children 'told them what to do'.

#### *Dependency*

Some key informants noted that many older people did not like to be dependent on their children, and preferred to do as much as possible on their own. Older participants corroborated this view; some said that they were not happy in their child's home either because of a son's illness (often alcohol dependency) or abuse and neglect. Children were furthermore 'authoritative' and wanted things done their way. One older participant remarked that 'in your own home you have respect, but it is difficult to get the same respect in your child's home'.

Some key informants also pointed out that some older people preferred to live independently, particularly those who could afford it. However, they risked becoming isolated and lonely. Some older participants expressed concern for the future. While they were fit and able to walk around they did not have trouble with their children; however, they were very unsure what would happen to them if they should become bedridden. Then they would see themselves as a burden to their family and local hospitals were 'horrendous' for older persons. Many participants expressed the view that it was the duty of families and, especially, younger family members to look after older people. One participant suggested that caring for older people was necessary because 'older people are very important to the family since they are a lot of help in the house'.

In each of the key informant FGD, participants described instances of older persons, known to them, who were being neglected.

Participants acknowledged that it was difficult to generalize since the position of older persons varied considerably according to family circumstances. The main reason that was cited was for neglect was the breakdown of family ties. The younger generation was seen as having less time to care for older people; sometimes both husband and wife were in full-time employment, sometimes children had to leave their family homes to seek employment out of the area.

#### *Economic factors in family care and support*

Children's support of their parents was reported to be contingent upon an expectation of inheritance. Older participants reported that children often fight for their share of property, and that parents were caught in the middle of these disputes. Many older participants and key informants highlighted that care for the parent often deteriorated once the property rights had been transferred. One commented 'very often the children throw their parents out of the house once they have become a burden to them' and another that under these circumstances 'most often the parents are not looked after by the children'. One key informant, describing a sick older person, said 'the parent was shifted from a private room to a general ward in the hospital'. Older participants knew of cases where children had ill-treated or harassed parents and even thrown them out of their own homes to gain control of the property. Children were also reported sometimes to resent the expense of medical care and treatments for parents, especially when some of the children felt they were shouldering more than their fair share of the cost. Costs of care were often high; due to lack of adequate public health care for older persons, many families resorted to private medical care, which was expensive in the long-run.

#### *Admission to old-age homes*

It was becoming more common for older people to move into residential care homes, referred to in Goa as 'old-age homes'. However, this option was mainly available to those who were in good health and had the means to pay. The majority of old-age homes did not accept individuals who were 'destitute' or who were suffering from any health condition likely to limit their capacity for self care. The residents of old-age homes described their reasons for moving into resi-

dential care. In a few cases chronic deteriorating health or acute episodes of illness were mentioned as reasons for admission. However, in many cases the older persons were in good health, and 'approaching age' or worries about ability to look after oneself in the future underpinned the move. Many of the residents had no family to look after them. Some had family who were either unwilling or unable to support them. This theme was reflected in the many residents who complained that their family never visited them after their admission to the home. Several reasons were cited for the withdrawal of family support. In some cases children had migrated abroad. In several cases the resident had quarrelled with family members. Others reported that families did not want to care for older persons because of the 'financial burden' of doing so. Residents had experienced being 'shuffled from family to family'; at least in the old-age home they had security. Many residents expressed bewilderment that their families seemed to have forgotten them after their admission.

#### *Roles and activities*

In the community, elders were involved in household work (e.g. cooking), economic production (e.g. farming), caregiving (e.g. looking after grand-children) and recreational pursuits (e.g. fishing and watching TV). Many older persons were clearly very busy and active around the home. Housework was spoken of as 'endless'. This could be a source of family conflict. The commonest theme related to the 'modern' daughters-in-law who resented housework in favour of holding down jobs outside the home, with the result that older parents were often left with the domestic chores. Key informants described older people being reduced to 'servants' in their own homes. In contrast to older persons living in the community, residents of old-age homes, while comfortable, identified boredom and lack of activity as a concern. One older person said 'mostly we are just sitting around'. Another commented that 'it would be nice if we were allowed to go out sometimes'. The lack of visitors and the minimal contact with the outside world was often mentioned as a cause of unhappiness. As with the community residents, those institutional-based activities that were listed were mostly non-recreational.

### *Community resources*

Village *panchayats* can provide a monthly sum of Rs 100 for welfare for 'needy elders'. Put in context, this would be sufficient to buy 5 kilos of rice or sugar. However, the process is long-winded and few older persons avail themselves of the scheme. There is also a scheme for financial support for widows though the amounts are again insufficient to meet basic needs. Some villages have clubs but few older people use them because they tend to focus on youth activities. There are no clubs organized exclusively or mainly for older people. Neighbours and relatives are the main providers of social support. The clergy also plays an important role and, for those older persons who are Catholics, the church is a focal point for socializing and support. The market also provides an important focus for social activity.

## **DISCUSSION**

The study described in this paper is, to the best of our knowledge, the first broadly based qualitative investigation of ageing and mental health in India. Qualitative research has its drawbacks, notably limited generalizability due to the recruitment of small, convenience samples (Khan & Manderson, 1992). However, this study recruited participants from a wide range of geographical, sociodemographic and professional contexts in Goa. The data from the 13 FGD show such a convergence and commonality of themes that we believe that, taken together, they represent a valid perspective on the status and health experiences of older people in contemporary Goan society.

Mental health conditions were recognized both by older participants and by key informants as occurring commonly among older people, and as having an important impact on their quality of life, and on the lives of their family members. However, there were no equivalent terms for depression or dementia in the Konkani language. Even the English-speaking FGD only once recorded the use of the term dementia. The vignettes of depression and dementia evoked widespread recognition but were rarely conceptualized as health conditions.

In Goa, the symptoms of early dementia tended to be explained as brain weakness or

deterioration, but crucially, also as a normal feature of ageing. Advanced dementia, while being seen as a physical health problem, was one for which it was felt that the doctor could do nothing. Other authors have commented on the Hindi phrase *sathiyana*, customarily translated as senility, but more literally 'sixtyish' (Cohen, 1995). Other regional languages have similar constructs, simultaneously conveying the concept of advanced chronological age and intellectual decline. Unsurprisingly, given the fatalistic view of 'brain weakness', primary health care doctors in Goa had little first hand experience of managing dementia. An important finding in our study was the widespread recognition of the dementia vignette by local multi-purpose health workers, who identified many of their active community caseload as sufferers. The implication would be that MPHWs would be a useful focus for the development of a community-based dementia support service. They could be used to identify a target group (not an easy task in the absence of any other health service contact) and also to implement a simple intervention. Thus, they might be trained to educate caregivers, and to support them, perhaps through the medium of caregiver support groups.

Depression was recognized as being particularly common, but was again generally not regarded as a health condition. These findings suggest that lack of awareness about psychosocial causes or misattribution of symptoms are not the main reasons for the finding that depression presents with somatic symptoms. Instead, depression is not viewed as a mental illness in the biomedical sense; the somatic symptoms that co-exist with psychological symptoms are presented since they fit the explanatory model that the former are medically determined. The finding is corroborated by qualitative research focusing on depression and anxiety disorders in Goa (Patel *et al.* 1997). As with dementia, depression was considered to be the result of family conflict, neglect and abuse. While family discord and lack of support may undoubtedly play a part in the genesis of depression, the prominence of these explanatory models may simply reflect the lack of an alternative narrative. Education of primary care doctors with regard to the clinical features and treatability of late-life depression is certainly

indicated. The apparent willingness of MPHWs to take on a supportive counselling role suggests that with appropriate training they might become effective therapists in their own right.

Alzheimer's Disease International and its member national societies have identified raising awareness among the general community and among health workers as a global priority (Graham & Brodaty, 1997). In Goa there is no awareness of dementia as a well-demarcated clinical syndrome. This is as true of the medical profession as of the wider community. In this respect Goa is probably typical of other parts of India. This general lack of awareness has important consequences. First, there is no structured training on the recognition and management of dementia at any level of the health service. Secondly, dementia is stigmatized, for example sufferers are specifically excluded from residential care, and often denied admission to hospital facilities. Thirdly, while families are the main caregivers, they must do so with little or no support or understanding from other individuals or agencies.

Residential care homes for older persons are rare in developing countries; however, in the most rapidly developing regions, their numbers are rising fast. Our study showed that older persons enter such homes when they are relatively well, usually because they lacked a family to care for them in the event of deteriorating health, or because they feared becoming a burden on their relatives, feared inadequate support, and therefore wished to maintain their independence from the family. This constellation has been reported in two previous Indian ethnographic studies (Vatuk, 1990; Cohen, 1995). It has been referred to as 'dependency anxiety' (Vatuk, 1990) and is differentiated from what Vatuk terms 'Western feelings of guilt and low self-worth associated with the shame of dependence upon one's children'. Thus, in contrast to guilt about becoming a burden on younger relatives, elders in India feared being abandoned or neglected. Goan old-age homes, as a rule, did not admit those with permanent disabilities and specifically excluded those with dementia. One reason for this was because they do not have facilities or manpower to care for high-dependency individuals. There was, therefore, no local continuing care provision for those with dementia, or for those who lacked

both family support and financial means. The homes themselves were adequate in some respects but concerns must be expressed about the isolation of residents from their families and from their local community, and at the lack of structured activities. These homes undoubtedly represent a transitional phase in what is likely to become an extended network of public and private sector facilities. Important priorities would include a system of registration and inspection of homes, training of careworkers, and provision of medical services for residents.

Older people are among the most vulnerable groups in the developing world, in part because of the continuing myths that surround their place in society (Tout, 1989). Traditionally, elders have been venerated in Indian society and this remains the dominant theme in how families care for elders today (Venkoba Rao, 1993). However, this study has also demonstrated that care is not guaranteed for all elders; indeed, instances of neglect and abuse were often mentioned. The assumptions that the extended family always provides a safety net for elders risks perpetuating complacency among health policy makers, social welfare and health care providers. Although families are the principal caregivers for the aged, it is also clear that this arrangement is not always to the benefit of either the family or the older relative. The answer to the central question for this study, 'who cares for older people in Goa?', is clearly 'the family'. However, the single dominant theme across all focus groups has been the concern that both respect for older people and the caring traditions of the extended family are changing, rapidly.

In conclusion, this qualitative study has demonstrated two significant findings. First, that although the symptoms of depression and dementia are well recognized, they are much less likely to be conceptualized as illnesses, and certainly not as mental illnesses. Secondly, although the majority of elders continue to live in their own homes and are well-cared for by their families, there are growing instances of abuse of older people and neglect, which signal the need for a long-term policy for the care of elders in India. An unconsidered imposition of Western models of care would be highly inappropriate, and unlikely to succeed. Thus, in the setting of low awareness of and preparedness

for mental health problems in the elderly in the medically orientated primary care system, interventions may need to focus on supporting carers in home-based programmes using community health workers. Future priorities for research are also evident. Prevalence and incidence studies primarily directed towards describing disease distributions and identifying risk factors, should also include studies of care arrangements for older people, and estimates of the impact of providing care on caregivers. Pilot studies describing care arrangements for elders with dementia and depression have recently been completed in Goa. Findings from these research studies will be disseminated to the community and to health professionals via local media experts, lay publications, workshops and awareness campaigns.

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## APPENDIX

### Vignette on depression

Mrs Naik is aged 73. She complains of different troubles at different times, general aches and pains and general weakness of the body and tiredness. She is not doing her housework as she usually does. She finds it difficult to fall asleep. In addition, she feels worried about problems such as money, her children and her flat. She is irritable with close relatives and friends and she cannot relax and enjoy herself properly.

### Vignette on early dementia

Mr D'Souza is 75-years-old. Recently he has begun to be forgetful. He confuses peoples' names, even those he knows well. He often seems not to be able to remember things from one moment to the next. One example was when he went to the market to

buy food and came back with nothing, having forgotten what he went out for. He repeats himself in conversation, and always seems to talk about the past. His family first noticed the problem 1 year ago. Since then it has been getting steadily worse.

### Vignette on established dementia

Mr D'Souza is now 78-years-old. He has difficulty in recognizing his wife and other close family members. He sits in a chair for most of the day. He never starts a conversation but will respond to questions by smiling or saying something, but his answers do not usually make sense. Sometimes he gets restless and agitated, asking over and over again 'When are we going out?'. If he wanders out of the house he gets lost and has to be brought back by neighbours. His wandering can be a particular problem at night. Sometimes he gets short-tempered and abusive for no reason. He needs to be reminded to go to the toilet, but is still incontinent of urine.

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