

Research papers

South Asian and white older people and dementia: a qualitative study of knowledge and attitudes

Sara Turner

Older People's Service, Springfield University Hospital, London, UK

Alison Christie

Department of Psychology, University of Surrey, Guildford, UK

Emma Haworth

Canterbury Christ Church University College, Salomon's Centre for Applied Social and Psychological Development, Southborough, Tunbridge Wells, UK

ABSTRACT

Despite the increasing number of older people from minority ethnic groups, there is little published research on their understanding of dementia. Work which does exist suggests that South Asian older people, compared with older people from the white majority population, may have different views about what constitutes a mental illness, who it is appropriate to consult about mental illness, and willingness to access and accept services. With the change in the age structure of the population and changes in intergenerational relationships, it is important to identify what barriers might exist to South Asian older people choosing to access care. This study aimed to discover whether there were differences in views about the nature, causes and treatments for dementia, and who participants believed should provide care. Ninety-six South Asian and 96 white older people (age range 58–85 years) were interviewed using a semi-structured approach. A thematic analysis, drawing on the procedure of Interpretative Phenomenological Analysis revealed a number of themes, which were then coded into

NVivo software in order to conduct a content analysis. The Z test for difference in proportions was then used to assess the significance of differences found between the two groups from the content analysis. These combined analyses revealed that South Asian older people had much less specific knowledge about dementia and were much more likely to see it as part of the normal ageing process. Possibly as a consequence, they were less likely to think that there were treatments available. More South Asian than white older people thought that care should be provided by family or friends. White older people perceived family and friends as the first choice but thought that the state should also provide care. This study supports the need to acknowledge culture when considering access to care, and also highlights the need to provide more information to South Asian older people and their families about dementia and available treatments and services.

Keywords: dementia, South Asian and white older people

Introduction

This study addresses South Asian and white older people's views about the nature of dementia, about its causes and available treatments, and about who should care for people with dementia. Over the last decade the number of South Asians in the population

has increased considerably, especially in London, and the number of South Asians presenting with dementia is therefore certain to increase, with major implications for health services (Lowdell *et al*, 2000). Rait *et al* (1996) graphically refer to the 'triple whammy' of

age, ethnicity and socio-economic deprivation experienced by older people from minority ethnic groups and other researchers (Chaudhry and Au, 1994; Rait and Burns, 1997) also note that minority ethnic groups tend to be under-represented as users of psychiatric services. The possibility that there are significant hindrances to South Asian elders who might need care for dementia is becoming all the more important. The age structure is changing, and there is likely to be an increase in the need for formal care in ethnic minority communities that have hitherto been assumed to be reliant on the informal care structures of extended families (Department of Health, 1998). Although some studies have shown that the majority of South Asian older people do live with their children or extended families (Bowes and Dar, 2000; Lowdell *et al*, 2000) researchers note this way of life may be diminishing, and also highlight changing intergenerational relationships and the growing need for assistance from outside the family (Chaudhry and Au, 1994; Guglani *et al*, 2000; Rait *et al*, 2000).

Goldberg and Huxley's framework for understanding the recognition and treatment of mental health problems describes a number of 'filters' that operate in the 'pathway to care' (Goldberg and Huxley, 1980). These operate at the level of the individual, the general practitioner (GP) and the mental health service. Bhui and Bhugra (2002) suggested a number of cultural factors that should be considered when looking at how these filters operate, and that have to be understood by service providers. These filters include culture-specific beliefs about when a mental health problem exists; what stigma attaches to it; whom it is appropriate to consult; language barriers; and perceptions of the appropriateness of services. All these factors impact on the individual-level filter, and some also may influence the willingness of GPs to refer on to health or social services (Donaldson, 1986; Beliappa, 1991; Chaudhry and Au, 1994; Ebrahim, 1996; Bhui, 1997; Bhugra, 2002; Bhui and Bugra, 2002). Other research suggests that current services may not be seen as acceptable by the South Asian population, and that there is a considerable amount of work to do in building culturally sensitive services (Department of Health, 1998; Bowes and Dar, 2000; Seabrooke and Milne, 2004).

There is little extant published research on dementia in minority ethnic groups, less still on South Asians (Adamson, 2001). A study in the United States identified a variety of cultural understandings of dementia in minority groups and found that the meanings that different ethnic groups assign to dementia influence their care-giving and help-seeking behaviour, for example whether formal approaches to healthcare providers such as the GP are seen as appropriate (Dilworth-Anderson and Gibson, 2002). In the UK, a small-scale qualitative study found that overall awareness of dementia among South Asians was low, and

explanations tended towards social conditions, other medical conditions, the effect of medication, and spiritual problems (Adamson, 2001). Another small-scale study found that GPs thought that South Asians perceived dementia as a normal part of ageing, and therefore sought help late in the disease process. They also thought that there was significant stigma attached to dementia and a lack of culturally appropriate services (Seabrooke and Milne, 2004). Adamson's study (2001) raises the question that this lack of understanding and beliefs about dementia may also be prominent in the white majority population. However, Rait and Burns (1997) point out that because fewer people have lived to old age in South Asian countries in the past and people may have migrated before their parents grew old, many South Asian older people may not have had the experiences necessary to recognise dementia, and may have a different appreciation of treatment. These factors could compound reluctance on the part of older people from minority ethnic groups and their carers to seek help from mental health services.

Despite the recognition of these issues, the number of studies of dementia involving people from minority ethnic groups remains low. It has frequently been stated that more studies are needed in this area, particularly studies with adequate numbers to allow meaningful comparisons of white and non-white subjects (Dilworth-Anderson and Gibson, 2002; Hinton, 2002; Lampley-Dallas, 2002). Qualitative research methods have been proposed as a useful way of achieving this type of understanding, as such methods can allow differences that matter to be seen both within and between groups, but these methods have been under-utilised in the past (Hinton, 2002). This study adopted a mixed method approach: using qualitative analyses to gain a thorough understanding of participants' views, but also utilising quantitative analyses in the final stages to establish the magnitude of any differences in views between the South Asian and white older people. Hanson *et al* (2005) state that utilising both quantitative and qualitative analyses in a study can enrich results in ways that one method would not allow.

Purpose of the study

The current study was part of South West London and St George's Mental Health NHS Trust's programme to improve services for people from minority ethnic groups. The study aimed to provide more information about the mental health needs of South Asian older people, and to contribute relevant information to the development of pathways to care for depression and dementia as required by the National Service Framework for Older People (Department of Health, 2001). This qualitative study was part of a larger study, and

used open-ended questions on dementia to investigate whether South Asian older people have different views from older people in the white majority population about the causes of and treatment for dementia, and whether this would lead them to consider that different forms of help would be appropriate.

The following specific questions were tested.

- Will South Asian older people have different views, in comparison to those of white older people, about the nature of dementia?
- Will South Asian older people have different views, in comparison to those of white older people, about the causes of and treatments for dementia?
- Will South Asian older people see dementia as a problem that should be managed by the family rather than by the state?

Methods

Local research approval

Following South West London and St George's Mental Health NHS Trust procedure, the study was submitted to both the local research ethical committee and the research and development committee of the trust. The trust accepted it onto its Culyer database.

Study design

The aspect of the research reported here was a qualitative study of a community sample of South Asian and white older people in two South London boroughs, Merton and Wandsworth. Semi-structured interviews using open-ended questions were used to explore participants' views about dementia. Interviews were conducted in one of four Asian languages, Gujarati, Hindi, Punjabi and Urdu, or in English.

Participants and sample populations

There were 192 participants, 96 South Asian and 96 white older people, between the ages of 58 and 85 years living in the community. The South Asian population comprised people who defined themselves as originating from the Indian subcontinent and Sri Lanka, but because of routes of migration may have been born elsewhere such as East Africa. The white population only included people born in Great Britain whose first language was English. They were chosen from GP lists to be approximately similar to the South Asian sample with respect to sex, age and area of residence.

The South Asian sample was recruited through two local South Asian organisations and three local GP practices. The white sample was recruited through the

same GP practices as the South Asian sample. Only one person from any household was interviewed. None of the participants was known to have a diagnosis of dementia.

Procedures

Translation, user consultation and pilot work

In order to translate the questions from English to the four Asian languages, a careful process of translation and back-translation was completed by an assistant psychologist working with a number of people from the South Asian community. For each language the important issue was to find the most appropriate term for 'dementia'. This was clarified through pilot work, which was mainly in the form of consultation with South Asian older people. The interview as a whole was piloted with two older people.

Conduct of interviews

The interview was completed face to face with participants by a trained interviewer fluent in the participant's preferred language, and most were conducted in the participants' homes, unless otherwise requested. Interviews were only completed after a consent form was signed. Seven open-ended questions about dementia formed part of the interview schedule and a verbatim written record of the responses was made.

Analysis

All 192 responses were transcribed as they were recorded on the interview schedule. The analysis incorporated three steps. Firstly, a thematic analysis was carried out, which drew on the procedure of Interpretative Phenomenological Analysis to identify the main themes from the transcripts. These themes were then entered into NVivo software in order to conduct a content analysis. Finally, the *Z* test for difference in proportions was employed to assess the differences between the two groups from the content analysis.

Thematic analysis

A thematic analysis attempts to glean the main themes from interview responses, to give an overall summary and representation of sayings, feelings, beliefs and metaphors expressed by respondents. These themes can incorporate sub-themes, and can be titled to best reflect the views they are encompassing. The themes then form the categories by which the text can be indexed. The steps taken to identify the emerging themes from the interview responses were based on the process of interpretative phenomenological analysis (Smith, 1996a). This methodology is committed to understanding and foregrounding respondents'

perspectives through the interpretation of the investigator. The outcome is therefore considered a co-construction between the participant and the researcher as it emerges from the researcher's engagement with the transcripts (Smith, 1995). The steps of the thematic analysis are delineated in Box 1.

Box 1 Steps of thematic content analysis

- 1 Two researchers read through the interview responses independently and noted first impressions.
- 2 The transcripts were then read more thoroughly, noting emerging connections between responses, to form potential themes. At this point any thoughts, reflections or interpretations were also recorded.
- 3 Major themes and sub-themes were then established and organised, incorporating the potential themes from step 2. Any further themes arising from the responses at this point were also included. Each theme was titled to best reflect the original responses.
- 4 All themes were then arranged as categories in a nodal tree and allocated numerical codes. Sub-themes were included in the number coding.
- 5 The two researchers then independently numerically coded the transcripts of collated interview responses using the nodal tree.
- 6 The two researchers then checked their agreement of themes. Any discrepancies were noted and discussed.
- 7 These discrepancies were also discussed with the research leader as another independent contributor. Final themes were then established. A nodal tree and set of category descriptions were constructed and written.
- 8 The nodal tree, category descriptions and interview transcripts for each question were then given to two external volunteers, to check inter-rater reliability.

Validity and reliability

Validity can be improved in a number of ways in qualitative research, all of which require the exercise of judgement by both the researcher and the reader (Mays and Pope, 2000). Two suggested methods of assessing internal validity and reliability of qualitative research are internal coherence and the presentation of evidence (Smith, 1996b). It is also important to consider personal and intellectual biases of those conducting the study (Mays and Pope, 2000).

INTERNAL COHERENCE

Internal coherence refers to whether the themes interpreted from the transcript are internally consistent and are justified by the original responses. Throughout the process of the analysis, two researchers worked independently on the transcripts and discussed the emerging themes.

RELIABILITY

While analysis based on Interpretive Phenomenological Analysis does not normally include a test of inter-rater reliability, the researchers thought it was important to ascertain the degree to which the transcripts would consistently be assigned to themes/categories by independent readers unconnected with the study or its hypotheses. It was thought important to establish reliable themes, as the analysis was to be continued using a content analysis and statistical tests. Inter-rater reliability was determined: for a quarter of the responses, two external raters were allocated to look at each question and were provided with details of the themes and the transcripts. Inter-rater reliability was set at 75% (Krippendorff, 1981). If this level was not reached, themes were adapted or merged and sent out to a further two raters. This formed part of the evolving process of the analysis. Eventually a final set of themes was reached for each question.

PRESENTATION OF EVIDENCE

The presentation of evidence suggested by Smith (1996b) allows the reader to make some assessment of the interpretation made by the researchers. The themes and nodal trees are presented in boxes, and the text and quotes from respondents are included with notes of the theme they illustrated.

RESEARCHER CHARACTERISTICS, PRIOR ASSUMPTIONS AND EXPERIENCES

It is noted that the researchers and raters were all from a different age group from the participants and from different ethnic backgrounds from the South Asian participants in the study. Therefore, it is likely that differences existed in the assumptions and world views of the researchers and participants. The researchers also approached the transcripts with an existing contemporary framework of older adult psychology, and were interested in any differences between the two groups. While the dataset was analysed for themes as a whole and without necessarily knowing the ethnicity and sex of the participants, it is acknowledged that the researchers' assumptions will have influenced theme development to some degree.

Content analysis

Once the themes from each question achieved inter-rater reliability of 75% or above, the nodal trees were constructed in the QSR NVivo program. Seven nodal trees were constructed in total. The transcripts were also entered into the database and coded by theme/category. NVivo permitted a comparison of patterns and frequencies between the South Asian and white samples. Attributes of the interviewees such as personal experience could also be factored into this analysis. Although considerable variation in the patterns and frequencies *within* the two groups is highly likely, the current focus was on patterns and frequencies *between* groups.

Quantitative analysis and statistical tests

In the final stage of analysis a quantitative method of analysis was applied. Where, through content analysis, the frequencies of themes appeared different between the South Asian and white older people, statistical comparisons were conducted to allow some understanding of the magnitude of the differences. This quantitative analysis was seen as augmenting the qualitative analysis: thematic content analyses enable a thorough understanding of participants' responses; quantitative analyses then enable some understanding of the generalisability of findings from samples to populations (Hanson *et al*, 2005). The large sample sizes were seen as contributing to the appropriateness of this final-stage analysis. When comparing responses between the two groups, the *Z* test for difference in proportions was used to test for a significant difference ($P < 0.05$). When the difference was significant this is stated in the text. A table of the *Z* values is included at the end of the results.

Findings

Demographic information

The participants were selected so that the groups were similar in age (average = 69 years) and gender mix (49 men and 47 women in each). Almost 80% of the South Asian sample was Muslim (47.9%) or Hindu (31.3%); 96.9% of the white sample was Christian. The South Asian participants practised their religion more frequently. The majority of the South Asian sample described themselves as Indian (42), Pakistani (31) or Sri Lankan (7); the largest language groups were Urdu (29), Gujarati (21) and Punjabi (19). Participants had lived in the UK between 4 and 56 years (average = 30 years), and most came into Great Britain from either Pakistan (34), East Africa (32) or India (17).

South Asians were less likely to be single (3% compared with 18%), and more likely to be widowed

than their white counterparts. They were no more likely to live alone than white participants (27.1% in each sample), but were more likely to live as part of an extended family (41.6% compared with 9.4%). Similar proportions in each group were educated beyond secondary level (South Asians 39.6% and white participants 38.5%), but South Asians were more likely to have had either no formal education or to have only attended primary school (11.5% compared with 0%). Almost 80% of all participants were retired. More from the South Asian sample had never been in paid employment (15.6% compared with 2.1%), and more of the white group remained in employment (14.6% compared with 3.1%). From the South Asians who had worked, more were homemakers (16.7% compared with 4.2%) and professional/managerial workers (43.8% compared with 29.2%), and fewer were manual workers than the white participants (11.5% compared with 32.3%). Although this information provides an overall comparison of the two groups, it is also acknowledged that there was diversity within both groups.

Thematic content analysis

Nature of dementia: what do you think are the kinds of things that happen to people who have dementia? What do people with dementia have difficulty with?

As similar themes emerged in the answers to both questions (Box 2), these answers were analysed together.

Both South Asian and white older people commonly mentioned memory problems. Many people just used general terms such as 'forgetfulness' or 'loss of memory' without elaborating (32 South Asian (SA), 33 white respondents), but more people from both groups mentioned specific memory problems such as forgetting names, no longer recognising people, or forgetting to eat meals or take medication (45 SA, 61 white respondents).

[They] forget about things that happened in their lives, lack of recognition of their own relatives, don't remember anything about past and present ... (SA man; theme: memory loss detailed)

[They] forget. [They] don't remember people or places they've been or things they've done ... (white woman; theme: memory loss detailed)

Overall, however, significantly more white (94) compared with South Asian (77) older people mentioned memory problems.

Both South Asian and white older people also frequently mentioned personal care problems, and these were also more likely to be described by the respondents in specific ways such as problems with

Box 2 Themes emerging from answers to the questions: ‘What do you think are the kinds of things that happen to people who have dementia?’ and ‘What do people with dementia have difficulty with?’

- Cognitive and memory changes: memory loss general, memory loss detailed, communication problems, concentration and complex tasks, personal care problems general, personal care problems specific, household management
- Physical: physical weakness, risk to self and from others, sleep problems, visual and auditory decline, disconnection and disorientation, personality change/loss, psychiatric manifestations, anxiety, isolation, depression and loss of self-esteem
- Behavioural: temperament and aggression, inappropriate behaviour
- Social: loss of personal relationships, loss of independence and interest
- Opinions about dementia
- Don’t know
- Everything

cooking, washing and toileting (29 SA, 45 white respondents) rather than in more general terms such as stating ‘they cannot take care of themselves’ (14 SA, 17 white respondents). For both memory and personal care problems, white respondents were significantly more likely than the South Asian group to describe the effects of dementia in a detailed way (45 SA, 61 white (memory); 29 SA, 45 white (personal care problems)).

The other differences in the responses between the two groups were that white older people were significantly more likely than the South Asian group to mention the presence of other difficulties, for example that people with dementia may become disorientated and disconnected from reality (12 SA, 23 white respondents), a risk to themselves and from others (11, 22), or lose their independence and interest (5, 13).

‘My mother would go out in the night. [She would] forget to turn the kettle off and burn it [and] cook dinner at the wrong times of day. People outside don’t understand ...’ (white woman; themes: disconnection and disorientation, risk to self and from others, inappropriate behaviour)

Significantly more South Asian (27) than white older people (1) stated they did not know what happened to people with dementia or did not know what people with dementia would have difficulty with. Twelve of these South Asian respondents answered that they did not know in response to both the questions.

What do you think are the things that cause dementia?

Most people interviewed were able to give some account of what they believed caused dementia (83 SA, 86 white older people). Themes that emerged are shown in Box 3.

Box 3 Themes emerging from answers to the question: ‘What do you think are the things that cause dementia?’

- Ageing
- Physical/organic disease
- Psychological problems: depression, worry/stress
- Inherited social factors: loneliness, sudden life events/shock, adverse early life experiences, social problems/factors
- Environment/lifestyle: lifestyle, environment, aluminium
- Use of brain: overuse, underuse
- God’s will
- Don’t know

South Asians (47) were much more likely than white older people (22) to see dementia as part of the normal ageing process.

‘... when you grow old certain parts of your body go, similarly your brain has this ... it loses stimulation, brain cells die ...’ (SA woman; theme: ageing)

‘[It is the] natural process of decay and people becoming old ...’ (SA man; theme: ageing)

White older people (45) mentioned physical disease/organic causes without mentioning ageing much more frequently than South Asians (17).

‘... cells connected with memory cease to function, not getting messages or dying off, chemical lack or physical loss ...’ (white woman; theme: physical/organic disease)

‘... can’t be old age because it happens to young people too. Something in the brain, something breaks down. Wouldn’t say it was a way of life or anything like that ...’ (white woman; theme: physical/organic disease)

Far fewer South Asian and white older people mentioned other causes such as sudden life events or shock (9, 12), loneliness (8, 8) or worry and stress (12, 6).

Do you think that there are any treatments for dementia?

One-third of all South Asian respondents (32) stated they did not know if there were any treatments for dementia; this compared with just under one-sixth (15) of the white respondents. Almost another third of the South Asian respondents (28) believed there was no treatment for dementia. A similar number of white

older people also believed there was no treatment available (23). Themes that emerged are shown in Box 4.

Box 4 Themes emerging from answers to the question: ‘Do you think that there are any treatments for dementia?’

- No/none
- Treatments: vague response, tablets/medication, Aricept, counselling/therapy, reminiscence, physical treatment/cell transplant, stimulation/social support, diet
- Palliative: home help/practical, TLC (tender loving care), palliative medicine
- Euthanasia
- Don’t know

‘... don’t know, don’t think anything can be done. People just go downhill. I’ve never seen anyone ever come out of it ...’ (SA woman; theme: no/none)

‘... don’t think so. I’ve never heard of anyone getting it and being cured ...’ (white man; theme: no/none)

Twenty-two white older people mentioned medication as a treatment for dementia. This contrasted with only seven South Asian respondents. However, it is noted that the health authority agreement that donepezil could be used locally was reported in the newspaper in January 2001. The NICE guidelines (National Institute for Clinical Excellence, 2001) recommending donepezil as a treatment for dementia were published in mid-January 2001 and reported in the newspapers at the end of January 2001. These publications could have influenced respondents’ attitudes towards whether dementia was treatable and what type of treatment was available for dementia, since more white respondents interviewed after the publications compared with those interviewed before the publication date stated that they believed medication was a treatment for dementia. Also, more white than South Asian respondents interviewed after the publication date mentioned medication as a treatment, and this may reflect differences in reading of the publications between the two groups. Interviews with 81 South Asian and only 18 white older people had been completed by this time.

‘... Yes, finding [the] right medication to replace what’s decreasing in the body, so memory is aided ...’ (white woman; theme: tablets/medication)

‘What I read about, yes, drugs to control the brain cells from dying off too quickly ...’ (white man; theme: tablets/medication)

Twelve South Asian and 14 white older people gave responses indicating that they did believe there was

treatment available, but they did not state what that treatment was or did not know what it might involve.

‘... think they can, why not? I can’t say what they are ...’ (SA woman; theme: treatments, vague response)

‘... they try to treat people. Don’t know of any particular treatment. They are in the stage of trial and error because they don’t know enough about it ...’ (white man; theme: treatments, vague response)

Both groups discussed other types of intervention, such as counselling, social support and palliative medicine, much less frequently.

Caring for people with dementia

The respondents were asked two separate questions: ‘If an old person becomes very forgetful and unable to take care of him/herself, who should take care of him/her?’ and ‘Where should this be?’. There were clear differences between the South Asian and white older people’s responses and this was true for their responses to both questions. Themes that emerged are shown in Box 5.

Box 5 Themes emerging from answers to the questions: ‘If an old person becomes very forgetful and unable to take care of him/herself, who should s/he be taken care of by?’ and ‘Where should this be?’

- Who: family and friends only, state, family first choice (then state), family and/or state
- Where: own/family home only, state, own home/family home first choice (then state), own home/family home and/or state
- Reasons: cultural differences, stage of illness, existence/availability of family, generational differences, advantages of care at home, advantages of state care, individual’s own decision
- Don’t know/other/opinions

Over one-third (37) of the South Asian older people said that only family or friends should care for people with dementia. This compared to under a tenth (9) of the white respondents.

‘... if the family is there, they should look after them and also close friends ...’ (SA woman; theme: family and friends only)

Following a similar pattern, nearly one-half of all South Asian respondents (45) believed care should only be provided in the person’s own or family home, a significantly greater number than the white respondents (18).

‘[They should be cared for in their] home, either by family or by outside carer[s] coming into the home ...’ (SA woman; theme: own/family home only)

Twenty-seven South Asian older people stated that the family was the first choice in terms of caring for the person with dementia, followed by the state as second choice. Thirty-nine white older people gave this response, the most frequent response by the white group. There was no significant difference between the two groups.

‘... family. If family is not there it is the duty of the state ...’ (SA woman; theme: family first choice, then state)

‘[They should be cared for] firstly by the family, afterwards [by] social services. [It is] hard for family to deal with dementia so [they should do] as much as they can, then [the person should be] put into care ...’ (white man; theme: family first choice, then state)

Similarly, over one-third (34) of the white respondents believed the person’s own home or family home should be the first choice for where they are cared for, but that other options were available. One-quarter (24) of South Asian respondents believed this. There was no significant difference between the two groups.

‘[It] depends on [the] circumstance. If they can be treated in [their own] home it is preferable ... even if they don’t know where they are they can sense where they are ...’ (white man; theme: own home/family home first choice, then state)

Twenty-six of the white respondents believed the state should care for people with dementia, the second most frequent response by white older people. Only nine South Asian older people gave this type of response.

‘... they should be taken into care where they can get medical needs and day-to-day needs taken care of ... somewhere where they can have 24-hour care. I don’t think family should necessarily be burdened with them unless they volunteer ...’ (white man; theme: state)

Following a similar pattern, almost one-third (29) of white older people believed care should be provided in state facilities, a significantly greater number than South Asian respondents (10).

Some respondents also gave reasons for their answers. When discussing who should care for the person with dementia, only South Asian older people mentioned cultural reasons (8 and 0 respectively).

‘... family. In our culture family is responsible. In this country the government is responsible ...’ (SA woman; themes: family and friends only, cultural differences)

‘[It] depends on the circumstances. [If you] think of our background, we think it should be the family, but young [people] have jobs and problems [and you’re] not always living together, so it’s difficult ...’ (SA woman; themes: family and friends only, existence/availability of family)

White older people (15) were more likely than South Asian older people (2) to mention the stage of the illness as being a contributing influence to their views both about who should take care of the person with

dementia and about where this care should be provided.

What things would make it difficult to care for an old person who had dementia living in their own home or living with their family?

The perceptions of factors that may make it difficult to care for a person with dementia were very similar between the South Asian and white older people: there were more similarities in the answers of the two groups than there were differences. Themes that emerged are shown in Box 6.

Box 6 Themes emerging from answers to the question: ‘What things would make it difficult to care for an old person who had dementia living in their own home or living with their family?’

- Skills deficits and their effects: personal care problems, disconnected and disorientated, temperament and aggression, communication and stimulation
- Responsibilities and their effects: carer stress and depression, isolation and lack of independence, 24-hour responsibility
- Needs of carer: support and respite, knowledge and training, caring disposition, finances and facilities
- Other: duty not burden, burden not duty, cultural differences
- Don’t know
- Opinions

Approximately two-thirds of both South Asian (64) and white (62) respondents thought that difficulties with personal care would make it difficult for a person with dementia to be cared for in their own home. Almost half of the white respondents (45) and one-third of the South Asian older people (34) also stated that it would be a 24-hour responsibility. There was no significant difference between the two groups.

‘... they need someone there all the time to make sure medicines are taken on time, feed on time, hygiene and safety. You need someone there all the time ...’ (SA man; themes: personal care problems, 24-hour responsibility)

‘... carers have to be young and committed to looking after [the] person 24 hours a day [and] devoted to the task of keeping them fed and clean and getting them up ...’ (white woman; themes: caring disposition, 24-hour responsibility, personal care problems)

Temperament and aggression were also mentioned a number of times by both South Asian (14) and white (18) respondents.

‘... they have to be very tolerant as sometimes the older person can be rude and aggressive ...’ (SA woman; theme: temperament and aggression)

White older people (23) also considered carer stress and depression to be a factor that would make caring for a person with dementia difficult; this compared with only nine South Asian respondents.

Although the numbers are small, significantly more white (7) than South Asian (1) older people also mentioned that lack of appropriate knowledge and training on the part of the carer would make caring difficult. Three South Asian older people mentioned cultural differences. None of the white respondents mentioned this subject.

‘[The] attention of the family [would make it difficult]. In western societies strong family ties don’t exist.’ (SA man; theme: cultural differences)

‘... in Asian countries it is possible to look after an individual, but not here as no one has time ...’ (SA man; theme: cultural differences)

When might someone go into a nursing home?

Themes that emerged in response to this question are shown in Box 7.

Box 7 Themes emerging from answers to the question: ‘When might someone go into a nursing home?’

- Never
- Illness-related factors: general/severe, temperament and aggression, risk to self and from others
- Person to care factors: no one to look after them, carer unable to cope, should not impose on family
- Other: decision of professional/family/individual, last resort, cultural reasons, don’t know, opinions/other

The three most frequent responses were the same for South Asian and white respondents. Firstly, both South Asian (33) and white older people’s (39) most frequent response was that people were most likely to go into a nursing home in the later stages of dementia.

‘... when their condition gets very bad and no one is able to take care of them and they need very specialised care ...’ (SA woman; theme: illness-related factors general/severe)

‘... in the later stages, when the person gets so bad they need someone to watch over them 100% of the time ...’ (white man; theme: illness-related factors general/severe)

Secondly, one-third of South Asian older people (32) believed people were most likely to go into a nursing home if there was no one to look after them. Under one-quarter (21) of white older people stated this. Thirdly, 33 white older people believed that people might go into a nursing home if the carer was unable to cope; significantly fewer South Asians (19) gave this response.

‘... when you know that you can no longer cope. When it’s affecting you, your health. When they become a worry to you ...’ (white woman; theme: carer unable to cope)

The themes referred to in the interviews are summarised in Table 1.

Discussion

This study specifically tested three main questions: will South Asian older people have different views compared with white older people about (1) the nature of dementia; (2) the causes of and treatments for dementia; and (3) who should care for people with dementia? The findings outlined above are discussed here.

Knowledge about the nature of dementia

Overall, these findings corroborated those of Adamson (2001) demonstrating that South Asian older people do have a poorer understanding of the nature of dementia compared to white older people. Interestingly, the South Asian and white older people did not have *different* views about how dementia presents, with the majority of both groups mentioning memory and personal care problems; rather, the South Asians had an overall *poorer understanding*. On the one hand this lack of knowledge could be interpreted in line with Rait and Burns’ (1997) ideas that, because many South Asian older people may have migrated before their parents grew old, they may not have had experiences of dementia. On the other hand it could be argued that it is the effect of a culture more influenced by western science that has enabled the white older people to have a greater understanding of and more familiarity with dementia. In addition, as people from the same majority western culture in which the study was conducted, the white older people may just have been those most able to explain the nature of dementia in a manner congruent with the western, medical understanding of it. However, this still has important

Table 1 Themes referred to in the text

Question	Theme	SA	White	Significance <i>P</i> < 0.05, <i>n</i> = 96, 96
Nature of dementia	Memory loss general – not elaborated (e.g. forgetfulness, loss of memory; not elaborated)	32	33	ns
	Specific memory problems (e.g. forgetting names, forgetting medication)	45	61	
	Memory problems (mentioned specifically)	77	94	<i>Z</i> = 3.98
	Detailed description of memory problems	45	61	<i>Z</i> = 2.31
	Detailed description of personal care problems	29	45	<i>Z</i> = 2.38
	General description of difficulty taking care of self	14	17	ns
	Specific difficulties in dementia: disoriented and disconnected from reality	12	23	<i>Z</i> = 2.06
	Specific difficulties in dementia: risk to self or others	11	22	<i>Z</i> = 2.10
	Specific difficulties in dementia: loss of independence and interest	5	13	<i>Z</i> = 1.98
	No knowledge of what happened in dementia/ what difficulties a person would have	27	1	<i>Z</i> = 5.31
Causes of dementia	Normal ageing	47	22	<i>Z</i> = 3.76
	Disease process (without mentioning ageing)	17	45	<i>Z</i> = 4.33
	Sudden life events, shock,	8	12	ns
	Loneliness	8	8	ns
	Worry, stress	12	6	ns
	Don't know	17	14	ns
Treatments for dementia	Medication	7	28	<i>Z</i> = 3.09
	Treatment exists but not elaborated	12	14	ns
	No treatment for dementia exists	28	23	ns
	Don't know	32	15	<i>Z</i> = 2.85
Caring for people with dementia: who should provide care	Only the family should care for the person	37	9	<i>Z</i> = 4.80
	Family first, then the state	27	39	ns
	State should provide care	9	26	<i>Z</i> = 3.26
Caring for people with dementia: where	Only in the person's own home	45	18	<i>Z</i> = 4.15
	Own home as first choice but with other options	24	34	ns
	State should provide facilities	10	29	<i>Z</i> = 3.41
Reasons for care decision	Cultural reasons	8	0	
	Stage of illness	2	15	<i>Z</i> = 3.29
What would make care difficult?	Difficulties with personal care	62	64	ns
	24-hour responsibility	45	34	ns
	Temperament and aggression	18	14	ns
	Carer stress	9	23	<i>Z</i> = 2.80
	Lack of carer knowledge/training	1	7	<i>Z</i> = 2.12
Reasons for going into a nursing home	Need for specialised care	33	39	ns
	If carer could not cope	19	33	<i>Z</i> = 2.26
	No one to look after the person	32	21	<i>Z</i> = 2.26

implications for how to detect dementia in South Asian older people living in western societies.

The causes of dementia

The South Asian respondents were significantly more likely than the white older people to perceive dementia as being caused by the ageing process, whereas the most frequent response by the white group was that dementia was caused by a physical, organic disease, again reflecting a much clearer understanding about dementia. These findings provide support for the GP's beliefs in Seabrooke and Milne's (2004) study and previous research that found people from non-western cultures are likely to attribute dementia to the ageing process (Dein and Huline-Dickens, 1997). Low numbers of South Asians mentioned social factors as a cause of dementia, in contrast with Adamson's (2001) and Beliappa's (1991) findings that South Asians are likely to attribute the causes of dementia to social factors, intra-familial problems or loss events. It was noticeable in this study that only eight South Asians mentioned social problems; however, all of these referred to family issues, for example 'being let down by your family'. The one white person who felt social problems contributed to the onset of dementia mentioned employment rather than family stressors.

The treatment of dementia

Both South Asian and white older people demonstrated little understanding of available treatments. From the minority of people who did believe there were treatments, more whites mentioned medication, indicating some differences in views about treatment between South Asian and white older people. The South Asian older people did not appear to think medication was not appropriate, as Beliappa (1991) found when questioning South Asians about mental distress in general; their responses appeared more indicative of a lack of knowledge about the available treatments and perhaps about dementia in general. It is plausible to consider that if an illness is considered part of the ageing process, rather than caused by an organic disease, then treatment with the use of medication may be considered less relevant or just not considered.

Caring for people with dementia

Most South Asian respondents felt that only family or friends should care for people with dementia. Most white older respondents felt that while family should be the first choice, the state should also be available to provide care. The South Asian responses could reflect the tradition in South Asian families to 'look after

their own' (Department of Health, 1998), but may also reflect the fact that the South Asian older people did not perceive dementia to be caused by an organic problem amenable to medical treatment. On the other hand, the white older people who did believe dementia was caused by a physical problem that could be treated medically were significantly more likely to think people with dementia should be looked after by the state, that is to say the medical and nursing professions. It is also possible that the South Asian older people were expressing unwillingness to access services; as Bowes and Dar (2000) found. However, although a number of South Asian older people qualified their responses about who should care for a person with dementia, with discussions about the duty of the family and the differences between cultures in care-giving practices, no respondents directly mentioned an unwillingness to access services. In all, only eight South Asians mentioned cultural factors.

In this study the beliefs of both the South Asian and the white older people appear to be logically linked to beliefs and knowledge about causes and available treatment. We therefore conclude, in line with Dilworth-Anderson and Gibson (2002), that the meanings assigned to dementia are derived from cultural beliefs and also relate to values and beliefs about care-giving practices and who is seen as appropriate to provide care and why, and that the latter may follow from the former.

Implications for practice

In the context of Goldberg and Huxley's (1980) framework, this study demonstrates that in considering a pathway to care for people with dementia, there are clear filters operating at the individual level, and that these are culturally related, demonstrated by the difference in responses between the South Asian and white older people. This supports Bhui and Bhugra's (2002) assertion that service providers need to acknowledge culture when considering access to services. South Asian older people are unlikely to present to mental health services with concerns about dementia if they believe that it is caused by the normal ageing process; that is to say, that they do not perceive it as a health problem and in addition they have cultural beliefs that people should be looked after within the family, and so do not perceive it as appropriate to consult professional help and support. It is important to emphasise that the South Asian older people in this study did not perceive health services as inherently inappropriate or culturally unacceptable; rather, they were not seen as appropriate to the problem of dementia. This has clear implications for increasing education about dementia within minority ethnic populations, particularly about its causes and

available treatments. If knowledge about its organic nature is increased, so too *early* presentation to health services may increase. In addition, health providers, particularly those in primary care, may need to be more active in screening for dementia in minority ethnic groups, and not expect difficulties associated with dementia to be raised unprompted. Increased education is also necessary within the majority population: in this study there was also a lack of knowledge about dementia among the white older people, particularly about available treatments.

Conclusion

This study has added to the small body of research on dementia in minority ethnic groups. The use of a qualitative research approach has allowed meaningful comparisons between samples from the minority and majority populations, and facilitated exploration of the reasons for people's responses. Importantly, this study has furthered understanding as to why South Asians are under-represented in mental health services, and revealed the areas of hindrance that will need to be targeted to change this representation in services for older people with dementia. These implications are even greater with likely future changes in family structure. Notable in this study was that 27.1% of the South Asian sample, the *same* proportion as the white sample, were living alone; a far greater percentage than that found by previous researchers (7–8% in Lowdell *et al*'s (2000) study).

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ADDRESS FOR CORRESPONDENCE

Dr Sara Turner, Consultant Clinical Psychologist, Older People's Teambase, Springfield University Hospital, London SW17 7DJ, UK. Tel: +44 (0)20 8682 6301; fax: +44 (0)20 8682 6868; email: sara.turner@swlstg-tr.nhs.uk

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