# The development of APEND (Attitudes of People from Ethnic miNorities to help-seeking for Dementia): a questionnaire to measure attitudes to help-seeking for dementia in people from South Asian backgrounds in the UK

**JC Hailstone[1], N Mukadam[2], T Owen[1], C Cooper[2], G Livingston[2]**

[1] Department of Clinical Psychology, Royal Holloway, University of London, Egham, UK

[2] Division of Psychiatry, University College London, London, UK

Running head: A questionnaire measure of South Asian attitudes towards help-seeking for dementia

Key words: dementia; help-seeking; questionnaire; attitudes; minority ethnic (ME); South Asian

Key points:

-People from South Asian backgrounds are a minority ethnic group that present relatively late to dementia services.

-We present a valid and reliable questionnaire measure of attitudes that influence willingness to seek help for dementia in UK-based South Asian people.

-This questionnaire could assess the impact of interventions to encourage earlier help-seeking.

Word count: 3499

Financial contributions: This work was supported by the National Institute for Health Research (author N.M., grant number DRF-2012-05-141).

**Abstract**

*Background.* People from South Asian backgrounds present to dementia services relatively late, often responding to crises. We aimed to devise and validate a Theory of Planned Behaviour questionnaire to measure attitudes that predict medical help-seeking for UK-based South Asian people, to assess the effectiveness of future interventions promoting earlier help-seeking.

*Methods.* We used focus groups to establish the content validity of culturally-relevant questionnaire items, then asked participants to complete the questionnaire. We analysed reliability and validity and established the concurrent validity of questionnaire attitudes through correlation with willingness to seek help from a doctor for memory problems. We also correlated the scale with knowledge of dementia.

*Results.* The strongest predictor of willingness to seek help was perceived social pressure from significant others around help-seeking; these attitudes were associated with beliefs about the views of family members, and embarrassment around help-seeking. Willingness to seek help was also strongly associated with attitudes about the benefits of seeing a doctor for memory problems, attitudes which were related to specific beliefs about what doctors can do to help. Attitudes in the questionnaire predicted 77% of variance in willingness to seek help, but no relationship was found with dementia knowledge.

*Conclusions.* We present the APEND questionnaire (Attitudes of People from Ethnic miNorities to help-seeking for Dementia), a valid and reliable measure of attitudes that influence help-seeking for dementia in people from South Asian backgrounds, which could assess the impact of intervention studies. We suggest interventions target attitudes specified here, rather than dementia knowledge.

## Introduction

United Kingdom (UK) dementia policy for earlier detection and diagnosis of dementia was established because of multiple benefits for the individual and their families, including improved care planning and avoiding unnecessary institutionalisation (Department of Health, 2009). Dementia appears to be more common in BME (Black and Minority Ethnic) groups (All-party parliamentary group on dementia, 2013; Moriarty *et al.* 2011) yet they use services later in the illness than their White British counterparts, often when there are severe impairments or in response to a crisis (Cooper *et al.* 2010; Mukadam *et al.* 2011b). People of South Asian origin comprise around a third of the UK BME populations (Office for National Statistics, 2009).

Family members are an important influence on help-seeking in people from South Asian backgrounds, as they may notice early dementia symptoms such as memory problems (La Fontaine *et al.* 2007; Mukadam *et al.* 2011a). Cultural expectations regarding caring for family members and respect for the family hierarchy may prevent discussion of dementia symptoms and delay seeking external help and support (La Fontaine *et al.* 2007; Lawrence *et al.* 2008; Mukadam *et al.* 2011a). Stigma and shame surrounding dementia in South Asian communities may also influence help-seeking (Adamson, 2001; Bowes and Wilkinson, 2003; Mukadam *et al.* 2011a). Some people from South Asian backgrounds believe that General Practitioners (GPs) fail to notice or to provide help for symptoms due to prioritising physical health (La Fontaine *et al.* 2007; Mukadam *et al.* 2011a).

In addition to these cultural attitudes, two other types of barrier to help-seeking for dementia have been identified in South Asian and other BME groups (summarised in Mukadam *et al.* 2011b). Firstly, beliefs about healthcare, such as that there is no value in getting a diagnosis of dementia (La Fontaine *et al.* 2007; Mukadam *et al.* 2011a). Secondly, quantitative as well as qualitative evidence suggests less dementia knowledge and misattributions of the causes of symptoms, delay medical help-seeking (Seabrooke and Milne, 2009; Watari and Gatz, 2004; Werner, 2003).

We used an established model of health-related behaviour: the Theory of Planned Behaviour (Ajzen, 1991) to quantify the influence of culturally relevant attitudes on help-seeking. Social normative influences measured using the Theory of Planned Behaviour are of central importance in addressing cultural attitudes about professional help-seeking for mental health issues (Mak and Davis, 2013; Mo and Mak, 2009). We hypothesised that the Theory of Planned Behaviour could similarly capture the influence and involvement of family members in decisions about help-seeking for dementia in people from South Asian backgrounds (La Fontaine *et al.* 2007; Lawrence *et al.* 2008; Mukadam *et al.* 2011a).

The Theory of Planned Behaviour predicts that three types of attitude directly influence "behavioural intention" or willingness to seek help for early dementia symptoms (see Figure 1). Behavioural attitudes (BA) represent views about whether or not to seek help, which are influenced by behavioural beliefs (BB) about advantages or disadvantages of help-seeking. Normative beliefs (NB) identify individuals or groups that would approve or disapprove of help-seeking, and influence attitudes about whether significant people in a person's life approve or disapprove of the behaviour (subjective norms; SN). Finally, control beliefs (CB) are about factors which influence the likelihood of seeking help for dementia, and also the ease or difficulty of seeking help (perceived behavioural control (PBC)). The influence of specific socio-cultural attitudes can be investigated via indirect Theory of Planned Behaviour beliefs (Mak and Davis, 2013; Mo and Mak, 2009).

*[Insert Figure 1 here]*

We aimed to use the Theory of Planned Behaviour to develop and validate a questionnaire by assessing whether attitudes found in UK-based people from South Asian backgrounds are associated with willingness to seek help from a GP for memory problems. A secondary aim was to investigate the relationship between knowledge about dementia and willingness to seek help in this population.

## Methods

This was part of a larger research project led by N.M. approved by the National Research Ethics Service.

We proceeded in two stages: 1) Qualitative interviews to develop and pilot Theory of Planned Behaviour belief-based measures for a questionnaire. 2) A questionnaire study to validate the instrument.

### *Participants*

We recruited first and second generation South Asian adults originating from the Indian subcontinent, by purposively sampling community organisations and then snowballing to reach participants outside these organisations. We continued to recruit until we had participants of either gender, differing ages and religions, a range of educational levels and countries of origin. We used paid interpreters from community centres where requested for focus groups. We asked only English-speaking participants to complete the questionnaire. All participants gave informed consent.

***Qualitative interviews***

We used a vignette (see Figure 2) of Mrs Chaudry, a South Asian older adult with memory difficulties strongly suggestive of early dementia in focus groups or in individual interviews, if less than four participants came to a group. The vignette was developed as part of a larger qualitative study to prompt discussion around barriers and facilitators to help-seeking (Mukadam *et al.* 2015).

*[Insert Figure 2 here]*

***Questionnaire Study***

Participants completed the questionnaire either in a community setting or online (SurveyMonkey, 2014). The questionnaire comprised:

*Background participant information*

We collected: age, sex, marital status, education, employment status and occupation, ethnicity, country of birth, first language and religion. We also asked about personal experience of dementia: knowing someone well with dementia or caring for someone as a family or paid carer.

*Theory of Planned Behaviour attitudes questionnaire (see Table 3)*

Participants were asked to imagine they were experiencing memory problems as in the vignette (see Figure 2). Questionnaire items were developed using beliefs informed by our interviews and previous literature; described further below. Items were scored on a seven-point rating scale from 1 (strongly disagree) to 7 (strongly agree).

*Dementia knowledge questionnaire*

We measured knowledge of dementia using the Dementia Knowledge Questionnaire (Graham *et al.* 1997): a short measure covering basic epidemiology, aetiology and symptoms of dementia. It has been validated in family carers of people with dementia (Graham *et al.* 1997), and in South Asian older adults (Purandare *et al.* 2007).

*Power calculation*

We calculated that a sample size of 37 was needed for the questionnaire study, using a 95% confidence level, 80% power and assuming a minimum clinically significant association of 0.4 between direct Theory of Planned Behaviour attitudes and willingness to seek help (Dunn and Everitt, 1995; Mak and Davis, 2013; Schomerus *et al.* 2009).

### *Analyses*

We used qualitative analysis of the audio-taped and transcribed focus group discussions and interviews to identify indirect behavioural, normative and control beliefs (see Theory of Planned Behaviour model in Figure 1) about help-seeking for dementia. We first analysed transcriptions for themes about beliefs that facilitate or hinder help-seeking for memory problems, these analyses were designed to additionally inform a larger study (Mukadam *et al.* 2015) (see this paper for a detailed description). Next, we used elicitation questions from Theory of Planned Behaviour guidance (Ajzen, 2006; Francis *et al.* 2004) to identify and structure indirect belief items from focus group themes (see Table 2). We compared indirect beliefs with previous research, and discussed them with the group of researchers to establish content validity.

We used Stata for statistical analyses (StataCorp, 2007). We assessed associations between willingness to seek help and Theory of Planned Behaviour attitudes and with dementia knowledge respectively using Pearson's correlation. Where normality assumptions were not met, we used Spearman's rank correlation. We also examined association of the combined contributions of Theory of Planned Behaviour attitudes on willingness to seek help, using bootstrapped linear regression with 95% confidence intervals (CI) using 2000 replicates (Francis *et al.* 2004).

## Results

### *Participants*

58 people (34 female), with an average age of 60.0 years (standard deviation (SD): 15.1, range 18-83) and 11.4 average years of education (SD: 6.4, range 0-23) took part in the qualitative interviews. 15 focus group participants completed and gave feedback on a pilot questionnaire. These results were not included in the quantitative analyses.

We analysed 51 participants responses (26 written, 25 online) who completed the questionnaire, excluding three online participants' responses (one did not complete background items; two were not from a South Asian ethnic group). None of the participants had previously completed the pilot questionnaire study. We read the questionnaire to four participants who found reading English difficult. 34 participants (66.7%) were female. The average age of participants was 50.6 years (SD: 21.8, range 18-85) and years of education was 14.4 years (SD: 3.6, range 0-22). Table 1 shows further socio-demographic characteristics. There was a heterogeneous representation of ethnicities (mainly Indian, Pakistani and Sri Lankan), countries of birth, first languages and religious backgrounds. Approximately a fifth of participants reported personal experience of caring for someone with dementia, and over half of participants had known someone with the condition well.

*[Insert Table 1 here]*

***Questionnaire development***

We developed three items each for intention to seek help (IN) and direct attitudes: behavioural attitudes, subjective norms and perceived behavioural control using standardised Theory of Planned Behaviour formats (Ajzen, 2006; Francis *et al.* 2004). We developed indirect beliefs using qualitative analyses as described above. A summary of themes identified and questionnaire items subsequently developed are displayed in Table 2. For each indirect belief (BB, NB, CB), corresponding outcome evaluations (OE), motivation to comply (MC) and power of control (PoC) ratings were developed respectively (Ajzen, 1991). These quantify the perceived likelihood, importance or desirability of outcomes specified in the beliefs (Ajzen, 1991). We made modifications to questionnaire items based on feedback from piloting; Table 3 shows all questionnaire items.

*[Insert Table 2 here]*

***Item analysis and internal consistency***

Inter-item correlation coefficients indicated sufficient internal consistency between the three help-seeking intention items (rho 0.61 - 0.76; all coefficients $p<0.001$, df=49), and between the three perceived behavioural control items (rho 0.39 - 0.72; all coefficients $p<0.001$, df=49). Inter-item correlation coefficients for the three behavioural attitudes (BA) items ranged between rho 0.82 and 0.90 (all coefficients $p<0.001$, df=49), however one item (BA1) was removed due to high inter-item correlation (rho >0.85) indicating redundancy (Campbell and Fiske, 1959). For subjective norm (SN) items, inter-item correlation was sufficient between SN1 and SN2 (rho=0.60, $p<0.001$, df=49), but not for SN3 (rho<0.30) and this item was removed from further analyses (Francis *et al.* 2004).

The final set of seven direct attitude items: two behavioural attitudes (BA2, BA3), two subjective norms (SN1, SN2) and all three perceived behavioural control (PBC) items attained an acceptable level of internal consistency ($\alpha=0.86$). For further analyses, composite scores were derived using an average rating across final items for each attitude (BA, SN, PBC), and across all three intention items (Francis *et al.* 2004).

***Relationship between attitudes and willingness to seek help***

Table 3 shows questionnaire ratings (N=51). All direct attitude and intention ratings were negatively skewed, with average ratings indicating favourable help-seeking intentions and attitudes.

*[Insert Table 3 here]*

Participants who were more likely to consider that seeking help from their doctor for memory problems would be good and useful: rho=0.70, p<0.001, df=49, approved of and expected by those important to them: rho=0.74, p<0.001, df=49, and as easy to achieve and under their control: rho=0.64, p<0.001, df=49, were more willing to seek help.

The combined model explained 77% of the variance in willingness to seek help for memory problems ($R^{2=}$ 78.0, adjusted $R^2$=76.5; Wald $\chi^2$ (3, 47) = 102.6; p<0.0001). In the model, anticipated social pressure from important others was most strongly associated with willingness to seek help (B=0.80, β=0.63, CI (0.42: 1.17), p<0.0001). Appraisals of seeking help as good and useful, were also strongly associated with intention (B=0.59, β=0.45, CI (0.25: 0.92), p=0.001). Judging that seeking help is easy and under the person's control was not associated with willingness to seek help (B=-0.12, β=-0.10, CI (-0.49: 0.25), p=0.54).

***Relationship between specific beliefs and willingness to seek help***

Participants indicating greater agreement that doctors are able to provide help for memory problems in terms of: treatments (BB1*OE1), understanding about the cause of problems (BB2*OE2), and information about services (BB3*OE3), were more likely to consider that seeking help from their doctor for memory problems would be good and useful (correlations with behavioural attitudes: rho=0.79, rho=0.63, rho=0.68 respectively; all coefficients p<0.001, df=49). Participants indicating greater agreement with these three beliefs (analysed using a composite of three weighted beliefs $\Sigma BB_i*OE_i$ (Francis *et al.* 2004)) were also more likely to indicate that they would seek help from a doctor for memory problems (rho=0.68, p<0.001, df=49).

Participants who considered that family members think that they should seek help from a doctor for memory problems (NB1*MC1) were more likely to believe that people important to them approve of and expect help-seeking (correlation with subjective norms: rho=0.33, p=0.02, df=49). In contrast, participants with a greater belief that seeking help from a doctor for memory problems is embarrassing (NB4) were less likely to believe that significant others approve of or expect help-seeking (rho= -0.41, p=0.003, df=49). The combined influence of these two beliefs, in which the influence of NB4 was reversed in analysis (Ajzen, 1991), was associated with willingness to seek help (rho=0.53, p<0.001, df=49).

Neither the normative beliefs about the influence of the views of community members (NB2*MC2), nor that seeking help means being disloyal to family members (NB3), were associated with social pressure to seek help (correlation with subjective norms: rho=0.07, p=0.62, and rho= -0.09,

p=0.55 respectively; both df=49). Also, no relationship was found between believing that memory problems would not be prioritised over physical health problems in GP appointments (CB1*PoC1) and perceiving that seeking help is easy and under the person's control (correlation with perceived behavioural control: rho= -0.05, p=0.71, df=49).

***Relationship between dementia knowledge and willingness to seek help***

The average Dementia Knowledge Questionnaire score was 8.9 out of 19 (SD: 3.9, range 2-18; N=51); higher than scores reported previously in people from South Asian backgrounds: median=3 out of 19 ( $25^{th}$ -$75^{th}$ percentile: 2-5; N=191) (Purandare *et al.* 2007). Knowledge score was not related to willingness to seek help from a doctor for memory problems (rho=-0.18, p=0.21, df=49), or with attitudes found to predict help-seeking (behavioural attitudes: rho=-0.20, p=0.16, subjective norms: rho=-0.11, p=0.46, perceived behavioural control: rho= -0.22, p=0.11; all df=49).

## Discussion

The final questionnaire developed: APEND (Attitudes of People from Ethnic miNorities to help-seeking for Dementia) is a valid and reliable questionnaire which measures UK-based people from South Asian backgrounds' attitudes towards help-seeking from a doctor for dementia (see Appendix). We established face, content and then concurrent validity through its association with a measure of willingness to seek help from a doctor for memory problems. The questionnaire can be used to investigate the impact of interventions aiming to increase help-seeking for memory problems in this ethnic group.

Willingness to seek help from a doctor for memory symptoms was largely explained by attitudes, accounting for 77% of the variance. This is more than in studies of intention to seek professional help for mental health problems (41 to 61%; Mak and Davis, 2013; Mo and Mak, 2009; Schomerus *et al.* 2009), and an average of 39% of variance in behavioural intention reported in a meta-analysis of 185 Theory of Planned Behaviour studies (Armitage and Conner, 2001).

Attitudes related to social pressure: that significant others would approve of or expect help-seeking from a doctor for memory problems, were most strongly associated with willingness to seek help, similar to findings for mental health problems (Mak and Davis, 2013; Mo and Mak, 2009). Our findings that beliefs about family members' views of help-seeking were perceived as social pressure and, influenced willingness to seek help from a doctor, are consistent with other studies (Lawrence *et al.* 2008; Mukadam *et al.* 2011a). As in other studies, those that found it more embarrassing or stigmatising to seek help for memory problems, were less likely both to perceive social pressure to seek help, and to indicate that they would see a doctor (Bowes and Wilkinson, 2003; La Fontaine *et al.*

2007). An intervention could target attitudes that help-seeking might benefit the family as well as the person with dementia, for example that seeking help is not giving up responsibility for caring, but can help the family to support a relative with dementia to live as well as possible (Mukadam *et al.* 2015).

Attitudes about perceiving help-seeking for memory problems as useful and good was strongly associated with willingness to seek help. "Behavioural attitudes" are commonly strong predictors in Theory of Planned Behaviour studies of other health behaviours including help-seeking for mental health problems (Armitage and Conner, 2001; Mo and Mak, 2009; Schomerus *et al.* 2009). Specific beliefs that doctors can provide help for memory problems in terms of: treatments, understanding about the cause of problems, and information about services, were associated with more positive attitudes about the benefits of help-seeking and greater willingness to seek help. These addressed healthcare-related beliefs previously identified as barriers (La Fontaine *et al.* 2007; Mukadam *et al.* 2011b). They highlight potential targets for interventions around what help is available, for example, promoting the view that sometimes understanding the cause of memory problems can provide reassurance that you do not have dementia (Mukadam *et al.* 2015).

Participants who considered seeking help from their doctor for memory problems as easy to achieve and under their control, were more willing to seek help. However, this was not an important factor compared to other attitudes. This is consistent with Theory of Planned Behaviour findings for mental health issues (Mo and Mak, 2009; Schomerus *et al.* 2009). A belief that memory problems would not be prioritised over physical health problems in GP appointments was not associated with reduced sense of ease or control over help-seeking for memory problems. The minor influence of these attitudes may reflect the perceived ease of seeing a doctor (Schomerus *et al.* 2009), as high rates of general attendance at GP appointments are reported in people from South Asian backgrounds (Scaife *et al.* 2000).

General knowledge of dementia was not associated with willingness to seek help for memory problems or with attitudes found to predict help-seeking. This may be because the average knowledge was much higher than previously (Purandare *et al.* 2007) and this barrier is now less relevant, possibly because of higher levels of dementia knowledge due to a general increase in the UK population with awareness campaigns (Department of Health, 2011). In addition, our sample was younger, entirely English speaking, and possibly more educated, so may have had greater exposure to information about dementia available via the UK media (Werner, 2001). Nonetheless, our findings predict that tailored interventions targeting relevant attitudes could more successfully influence help-seeking behaviour than information, which is similar to other health conditions including mental health issues (Gulliver *et al.* 2012a; Naylor *et al.* 2012; Robertson, 2008; Zeh *et al.* 2012).

***Limitations***

Positive attitudes do not always translate into seeking help from a professional (Gulliver *et al.* 2012a; Gulliver *et al.* 2012b). This is important as we found frequent favourable attitudes and willingness towards help-seeking for memory problems, which may also be because we interviewed a self-selected sample consisting of a relatively high proportion of individuals that had cared for someone with dementia (Alzheimer's Society, 2012). This may limit the generalisability of our findings but should not affect the usability of the questionnaire in measuring attitudes. To further investigate the relationship between knowledge of dementia and attitudes to help-seeking there is a need for replication in larger samples, with examination of the influence of educational experiences and exposure to information about dementia. Also, we asked participants about their views of seeking-help for memory problems for themselves after depicting memory problems in an older relative in the vignette. It may be more valid to assess help-seeking for a family member rather than for one-self, particularly with younger participants.

The questionnaire was in English, and the sample had above average education (United Nations Development Programme, 2013) which may be representative of English-speaking South Asian people living in London (Ahmed and Lemkau, 2000; Lymperopoulou and Parameshwaran, 2014) but not the wider South Asian community. Some of the focus group participants were non-English speaking and had an overall lower educational level. It will be important to develop translated versions for future research and clinical use and to explore whether it detects change in attitude.

## Conclusions

We present a valid and reliable measure of attitudes that influence help-seeking for dementia in people in the UK from South Asian backgrounds: an ethnic minority group that present relatively late to dementia services. The questionnaire will help assess the mechanism of any change and because of the relationship between attitudes and willingness to seek help, assess the likely impact of any intervention. We plan to use it to assess the impact of an intervention to encourage help-seeking for dementia in people from South Asian backgrounds.

## Acknowledgements

This work was supported by the National Institute for Health Research (NIHR); author N.M. grant number: DRF-2012-05-141. This paper presents independent research funded by the NIHR. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

We would like to thank Hansa and Shilpa Bavishi, the Hindu Cultural Society and Haringey Asian Carers Support Group for their help with recruitment.

**Conflict of interest**

None.

## References


Adamson J. (2001). Awareness and understanding of dementia in African/Caribbean and South Asian families. *Health Soc Care Community* 9, 391-396.

Ahmed SM, Lemkau JP. (2000). Cultural issues in the primary care of South Asians. *J Immigr Minor Health* 2, 89-96.

Ajzen I. (1991). The Theory of Planned Behavior. *Organ Behav Hum Decis Process* 50, 179-211.

Ajzen I. (2006). Constructing a Theory of Planned Behavior questionnaire. (http://people.umass.edu/aizen/pdf/tpb.measurement.pdf). Accessed 9 February 2015.

All-party parliamentary group on dementia (2013). *Dementia does not discriminate.* Alzheimer's Society: London.

Alzheimer's Society (2012). Dementia 2012: A national challenge. (www.alzheimers.org.uk/dementia2012). Accessed 7 February 2015.

Armitage CJ, Conner M. (2001). Efficacy of the Theory of Planned Behaviour: A meta-analytic review. *Br J Soc Psychol* 40, 471-499.

Bowes A, Wilkinson H. (2003). 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Health Soc Care Community* 11, 387-396.

Campbell DT, Fiske DW. (1959). Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychol Bull* 56, 81-205.

Cooper C, Tandy AR, Balamurali TB, Livingston G. (2010). A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. *Am J Geriatr Psychiatry* 18, 193-203.

Department of Health (2009). Living well with dementia: A national dementia strategy. (https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy). Accessed 10 February 2015.

Department of Health (2011). Raising dementia awareness. (https://www.gov.uk/government/news/raising-dementia-awareness). Accessed 9 February 2015.

Dunn G, Everitt BS. (1995). *Clinical biostatistics: An introduction to evidence-based medicine*. Edward Arnold: London.

Francis JJ, Eccles MP, Johnston M *et al.* (2004). *Constructing questionnaires based on the Theory of Planned Behaviour.* Centre for Health Services Research, Newcastle University: Newcastle upon Tyne.

Graham C, Ballard C, Sham P. (1997). Carers' knowledge of dementia and their expressed concerns. *Int J Geriatr Psychiatry* 12, 470-473.

Gulliver A, Griffiths KM, Christensen H, Brewer JL. (2012a). A systematic review of help-seeking interventions for depression, anxiety and general psychological distress. *BMC Psychiatry* 12, 1-12.

Gulliver A, Griffiths KM, Christensen H *et al.* (2012b). Internet-based interventions to promote mental health help-seeking in elite athletes: An exploratory randomized controlled trial. *BMC Psychiatry* 14, 1-12.

La Fontaine J, Ahuja J, Bradbury NM, Phillips S, Oyebode JR. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. *J Adv Nurs* 60, 605-614.

Lawrence V, Murray J, Samsi K, Banerjee S. (2008). Attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK. *Br J Psychiatry* 193, 240-246.

Lymperopoulou K, Parameshwaran M. (2014). *How are ethnic inequalities in education changing?* Centre on Dynamics of Ethnicity, University of Manchester: Manchester.

Manikandan S. (2011). Measures of central tendency: Median and mode. *J Pharmacol Pharmacother* 2, 214-215.

Mak WW, Davis JM. (2014). The application of the Theory of Planned Behavior to help-seeking intention in a Chinese society. *Soc Psychiatry Psychiatr Epidemiol* 49, 1501-15.

Mo PK, Mak WW. (2009). Help-seeking for mental health problems among Chinese: The application and extension of the Theory of Planned Behavior. *Soc Psychiatry Psychiatr Epidemiol* 44, 675-684.

Moriarty J, Sharif N, Robinson J. (2011). *Black and minority ethnic people with dementia and their access to support and services.* Social Care Institute for Excellence: London.

Mukadam N, Cooper C, Basit B, Livingston G. (2011a). Why do ethnic elders present later to UK dementia services? A qualitative study. *Int Psychogeriatr* 23, 1070-1077.

Mukadam N, Cooper C, Livingston G. (2011b). A systematic review of ethnicity and pathways to care in dementia. *Int J Geriatr Psychiatry* 26, 12-20.

Mukadam N, Waugh A, Cooper C, Livingston G. (2015). What would encourage help-seeking for memory problems amongst UK-based South Asians? A qualitative study. *BMJ Open* 5, e007990.

Naylor K, Ward J, Polite BN. (2012). Interventions to improve care related to colorectal cancer among racial and ethnic minorities: A systematic review. *J Gen Intern Med* 27, 1033-1046.

Office for National Statistics (2009). Resident population estimates by ethnic group. (http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Population+Estimates+by+Ethnic+ Group). Accessed 1 February 2015.

Purandare N, Luthra V, Swarbrick C, Burns A. (2007). Knowledge of dementia among South Asian (Indian) older people in Manchester, UK. *Int J Geriatr Psychiatry* 22, 777-781.

Robertson R. (2008). *Kicking bad habits: Using information to promote healthy behaviours.* Kings Fund: London.

Scaife B, Heywood P, Neal R. (2000). Socio-economic characteristics of adult frequent attenders in general practice: Secondary analysis of data. *Family Practice* 17, 298-304.

Schomerus G, Matschinger H, Angermeyer MC. (2009). Attitudes that determine willingness to seek psychiatric help for depression: A representative population survey applying the Theory of Planned Behaviour. *Psychol Med* 39, 1855-1865.

Seabrooke V, Milne A. (2009). Early intervention and dementia care: Innovation and impact. *Qual Ageing Older Adults* 15, 34-45.

StataCorp (2007). *Statistical Software: Release 10.* StataCorp Ltd: College Station, Texas.

SurveyMonkey (2014). *SurveyMonkey: Free online survey software & questionnaire tool.* SurveyMonkey Inc: Palo Alto, California.

United Nations Development Programme (2013). Human Development Report 2013: Index Data. ( http://hdr.undp.org/en/statistics/hdi). Accessed 10 February 2015.

United Nations Statistics Division (2008). *ISCO-08: The International Standard Classification of Occupations*. International Labor Office: Geneva.

Watari KF, Gatz M. (2004). Pathways to care for Alzheimer's disease among Korean Americans. *Cultur Divers Ethnic Minor Psychol* 10, 23-38.

Werner P. (2001). Correlates of family caregivers' knowledge about Alzheimer's disease. *Int J Geriatr Psychiatry* 16, 32-38.

Werner P. (2003). Knowledge about symptoms of Alzheimer's disease: Correlates and relationship to help-seeking behavior. *Int J Geriatr Psychiatry* 18, 1029-1036.

Wong N, Rindfleisch A, Burrough, J. (2003). Do reverse-worded items confound measures in cross-cultural consumer research? The case of the material values scale. *J Consum Res*, 30, 72-91.

Zeh P, Sandhu HK, Cannaby AM, Sturt JA. (2012). The impact of culturally competent diabetes care interventions for improving diabetes-related outcomes in ethnic minority groups: A systematic review. *Diabet Med* 29, 1237-1252.

**Figure 1. The Theory of Planned Behaviour model (Ajzen, 1991): used to investigate attitudes associated with intention or willingness to seek help from a doctor for memory problems***

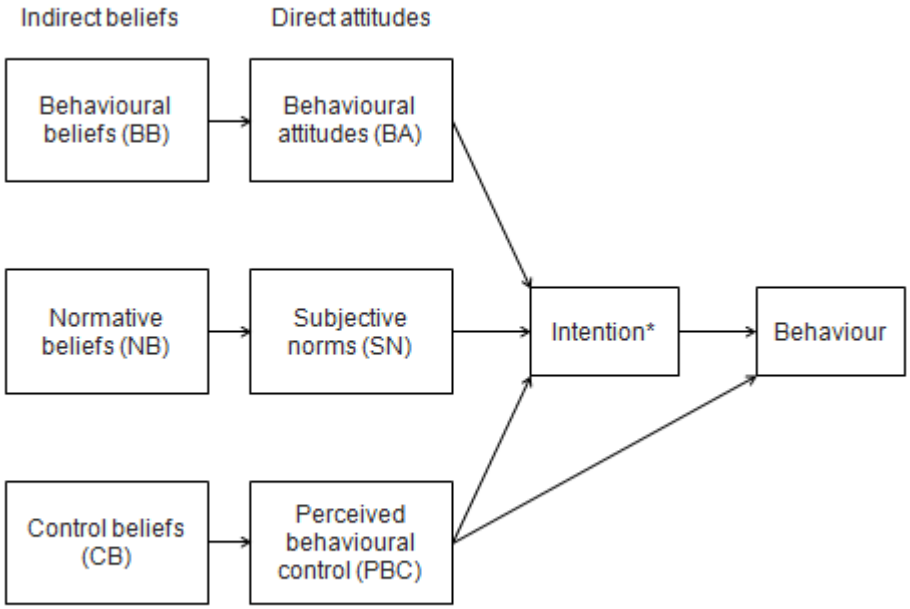

**Figure 2. Vignette used for qualitative interviews and in the questionnaire**

Imagine that Mrs Chaudry is a 70 year old close relative of yours. Family members have noted that she is more forgetful lately. She cannot remember conversations with people and forgets appointments with her doctor. She often misplaces important things like her keys and glasses. She is physically healthy but is concerned about her memory.

**Table 1.** *Socio-demographic characteristics of questionnaire participants (N=51)*

| | | Frequency | % |
|---|---|---|---|
| **Ethnicity** | Indian/British Indian | 40 | 78.4 |
| | Pakistani | 5 | 9.8 |
| | Sri Lankan | 4 | 7.8 |
| | Bangladeshi | 1 | 2.0 |
| | Nepalese | 1 | 2.0 |
| **Country of origin** | India | 12 | 23.5 |
| | UK | 11 | 21.6 |
| | Kenya | 9 | 17.6 |
| | Pakistan | 4 | 7.8 |
| | Sri Lanka | 4 | 7.8 |
| | Tanzania | 3 | 5.9 |
| | Mauritius | 3 | 5.9 |
| | Nepal | 1 | 2.0 |
| | USA | 1 | 2.0 |
| | Fiji | 1 | 2.0 |
| | Ethiopia | 1 | 2.0 |
| | East Africa (unspecified) | 1 | 2.0 |
| **First language** | English | 16 | 31.4 |
| | Gujarati | 13 | 25.5 |
| | Hindi | 7 | 13.7 |
| | Punjabi | 5 | 9.8 |
| | Urdu | 3 | 5.9 |
| | Tamil | 2 | 3.9 |
| | Sinhala | 2 | 3.9 |
| | Telugu | 1 | 2.0 |
| | Creole | 1 | 2.0 |
| | French | 1 | 2.0 |
| **Religion** | Hindu | 23 | 45.1 |
| | Muslim | 8 | 15.7 |
| | Jainism | 7 | 13.7 |
| | Sikh | 6 | 11.8 |
| | Christian | 4 | 7.8 |
| | No religion | 3 | 5.9 |
| **Personal experience of dementia**[a] | Known someone well | 30 | 58.8 |
| | Cared for a family/friend | 9 | 17.6 |
| | Paid carer | 2 | 3.9 |
| **Employment status** | Retired | 20 | 39.2 |
| | Employed | 19 | 37.3 |
| | Student | 9 | 17.6 |
| | Unemployed | 2 | 3.9 |
| | Long-term disabled | 1 | 2.0 |
| **Marital status** | Married/living with partner | 29 | 56.9 |
| | Single | 16 | 31.4 |
| | Widowed | 4 | 7.8 |
| | Divorced | 2 | 3.9 |
| **Occupation classification**[b,c] **(associated skill level)** | Professionals (4) | 16 | 31.4 |
| | Associated professionals (3) | 1 | 2.0 |
| | Clerical support/ service & sales/ machine operators & assemblers (2) | 13 | 25.5 |
| | Elementary occupations (1) | 1 | 2.0 |
| | Managerial roles (n/a) | 4 | 7.8 |
| | Member of armed forces (n/a) | 1 | 2.0 |

[a]Relationship to a person with dementia or Alzheimer's disease; [b]N=36 participants (19 currently employed, 16 retired); [c]We used the International Standard Classification of Occupations and associated skill levels (levels 1 to 4) to categorise open responses (United Nations Statistics Division, 2008); n/a No associated skill level.

**Table 2.** *Development of indirect belief questionnaire items from analysis of focus group themes using Theory of Planned Behaviour elicitation questions (EQ)*[1]

| Beliefs identified from focus group themes | Questionnaire items developed[2] |
|---|---|
| Behavioural beliefs (BB) | |
| *EQ: What are the advantages of seeking help from a doctor for memory problems?* | |
| Doctors can provide treatment for dementia/memory problems | BB1: My doctor would be able to provide treatments to help with memory problems |
| Doctors can provide knowledge about the cause of the problem | BB2: My doctor would be able to tell me what the cause of memory problems is |
| Doctors can provide information about services that are available to provide support | BB3: My doctor would be able to tell me what services are available to help with memory problems |
| *EQ: What are the disadvantages or lack of perceived advantages to seeking help from a doctor for memory problems?* | |
| Doctors cannot provide any treatments for dementia/memory problems | BB1: My doctor would be able to provide treatments to help with memory problems[3] |
| Normative beliefs (NB) | |
| *EQ: Who would encourage or approve of seeking help from a doctor for memory problems?* | |
| Family members should notice memory problems and encourage the person to seek medical help | NB1: My family would think that I should seek help from my doctor for memory problems |
| *EQ: Who would discourage or disapprove of seeking help from a doctor for memory problems?* | |
| Stigma in the community means people hide their symptoms and don't seek external support | NB2: People in my community would approve of seeking help from my doctor for memory problems[3] |
| | NB4: Getting help from my doctor for memory problems would be embarrassing |
| There is an expectation and pride in family members looking after their own, over seeking external/medical help | NB3: Seeking help from my doctor for memory problems would mean being disloyal to family members |
| Control beliefs/factors (CB) | |
| *EQ: What factors would encourage or promote seeking help from a doctor for memory problems?* | |
| None identified. | |
| *EQ: What factors would hinder or inhibit seeking help from a doctor for memory problems?* | |
| Memory problems would not be prioritised over physical health problems in GP appointments | CB1: My doctor would prioritise physical health problems over memory problems in appointments |

[1] We used elicitation questions (EQ) from Theory of Planned Behaviour guidance (Ajzen, 2006; Francis *et al.* 2004) to identify indirect beliefs from focus group themes.

[2]We asked participants to rate indirect beliefs on a scale from 1 (strongly disagree) to 7 (strongly agree).

[3]Negatively worded items were not used on the basis of feedback from piloting; scales using mixed positive and negative wording can be problematic with BME groups (Wong *et al.* 2003).

**Table 3.** *Theory of Planned Behaviour questionnaire items and average ratings obtained (N=51) on scales from 1 (strongly disagree) to 7 (strongly agree)*[a]

| Questionnaire item | | Median[b] | IQR[c] |
|---|---|---|---|
| **Intention or willingness to seek help (IN)** | | | |
| IN1 | If I had memory problems like Mrs Chaudry, I would seek help from my doctor | 6.0 | 5.0-7.0 |
| IN2 | I would expect to go to see my doctor for help, if I had memory problems | 6.0 | 5.0-7.0 |
| IN3 | I would want to go to see my doctor if I had memory problems | 6.0 | 5.5-7.0 |
| **Behavioural attitudes (BA)**[a] | | | |
| BA1* | Overall, I think seeking help from my doctor for memory problems would be: Harmful 1 2 3 4 5 6 7 Beneficial | 7.0 | 6.0-7.0 |
| BA2 | Overall, I think seeking help from my doctor for memory problems would be: Useless 1 2 3 4 5 6 7 Valuable | 7.0 | 5.0-7.0 |
| BA3 | Overall, I think seeking help from my doctor for memory problems would be: Bad 1 2 3 4 5 6 7 Good | 7.0 | 6.0-7.0 |
| **Behavioural beliefs (BB) & outcome evaluations (OE)** | | | |
| BB1 | My doctor would be able to provide treatments to help with memory problems | 6.0 | 4.0-7.0 |
| OE1 | For memory problems, a treatment to help would be desirable | 6.0 | 6.0-7.0 |
| BB2 | My doctor would be able to tell me what the cause of memory problems is | 5.0[n] | 3.5-6.0 |
| OE2 | For memory problems, finding out about the cause would be desirable | 7.0 | 6.0-7.0 |
| BB3 | My doctor would be able to tell me what services are available to help with memory problems | 6.0 | 5.5-7.0 |
| OE3 | For memory problems, finding out about what services are available to help would be desirable | 7.0 | 6.0-7.0 |
| **Subjective norms (SN)** | | | |
| SN1 | Most people who are important to me would approve of seeking help from my doctor for memory problems | 6.0 | 6.0-7.0 |
| SN2 | It would be expected of me that I would see my doctor for memory problems | 6.0 | 5.0-7.0 |
| SN3* | I would feel pressure from people that are important to me, to seek help from my doctor for memory problems | 6.0 | 4.0-7.0 |
| **Normative beliefs (NB) & motivation to comply (MC)** | | | |
| NB1 | My family would think that I should seek help from my doctor for memory problems | 6.0 | 6.0-7.0 |
| MC1 | What my family thinks I should do is important to me | 5.0 | 4.0-6.0 |
| NB2* | People in my community would approve of seeking help from my doctor for memory problems | 6.0 | 4.0-7.0 |
| MC2* | What people in the community think of me matters to me | 2.0[+] | 1.0-4.0 |
| NB3[d]* | Seeking help from my doctor for memory problems would mean being disloyal to family members | 1.0[+] | 1.0-1.0 |
| NB4[d] | Getting help from my doctor for memory problems would be embarrassing | 1.0[+] | 1.0-4.0 |
| **Perceived behavioural control (PBC)** | | | |
| PBC1 | It would be easy to seek help from my doctor for memory problems | 6.0 | 5.0-7.0 |
| PBC2 | It would be my decision whether or not to see my doctor for memory problems | 6.0 | 5.0-7.0 |
| PBC3 | I am confident that I would be able to see my doctor for memory problems if I wanted to | 6.0 | 5.0-7.0 |
| **Control beliefs (CB) & power of control (PoC)** | | | |
| CB1* | My doctor would prioritise physical health problems over memory problems in appointments | 5.0 | 4.0-6.0 |
| PoC1* | Prioritising physical health problems in appointments makes it less likely I would see my doctor for memory problems | 5.0[n] | 4.0-6.0 |

*Items removed from the questionnaire following item analysis. [a] Other rating scales were used for behavioural attitude (BA) items as displayed; [b] We chose the median to measure central tendency, as all ratings were negatively skewed except where indicated: n=normally distributed; + = positively skewed (Manikandan, 2011); [c] Interquartile range (IQR); [d] Corresponding motivation to comply (MC) items were considered inappropriate (Ajzen, 2006; Francis *et al.* 2004).

**APEND Questionnaire:**
**Attitudes of People from Ethnic miNorities to help-seeking for Dementia**

Please read the text in the box below:

Imagine that Mrs Chaudry is a 70 year old close relative of yours. Family members have noted that she is more forgetful lately. She cannot remember conversations with people and forgets appointments with her doctor. She often misplaces important things like her keys and glasses. She is physically healthy but is concerned about her memory.

In order to answer the following questions please imagine that you are experiencing memory problems like Mrs Chaudry. Please respond to each question by circling a number between 1 and 7. Unless otherwise indicated use this scale:

| Strongly disagree | Disagree | Disagree somewhat | Neutral | Agree somewhat | Agree | Strongly agree |
|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |

1. If I had memory problems like Mrs Chaudry, I would seek help from my doctor:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

2. I would expect to go to see my doctor for help, if I had memory problems:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

3. I would want to go to see my doctor if I had memory problems:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

4. It would be easy to seek help from my doctor for memory problems:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

5. It would be my decision whether or not to see my doctor for memory problems:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

6. I am confident that I would be able to see my doctor for memory problems if I wanted to:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

7. Most people who are important to me would approve of seeking help from my doctor for memory problems:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

8. It would be expected of me that I would see my doctor for memory problems:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

9. Overall, I think seeking help from my doctor for memory problems would be:

**Useless 1 2 3 4 5 6 7 Valuable**

10. Overall, I think seeking help from my doctor for memory problems would be:

**Bad 1 2 3 4 5 6 7 Good**

Please turn over

11. My doctor would be able to provide treatments to help with memory problems:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

12. My doctor would be able to tell me what the cause of memory problems is:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

13. My doctor would be able to tell me what services are available to help with memory problems:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

14. For memory problems, a treatment to help would be desirable:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

15. For memory problems, finding out about the cause would be desirable:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

16. For memory problems, finding out about what services are available to help would be desirable:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

17. Getting help from my doctor for memory problems would be embarrassing:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

18. My family would think that I should seek help from my doctor for memory problems:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

19. What my family thinks I should do is important to me:

**Strongly disagree 1 2 3 4 5 6 7 Strongly agree**

**Thank you for completing this questionnaire**

*For researchers: Theory of Planned Behaviour analysis*

| TPB attitude | Scores for items: | | | Analysis |
|---|---|---|---|---|
| Intention to seek help (IN) | 1= ☐ | 2= ☐ | 3= ☐ | IN Sum of scores: 1+2+3 =____ |
| Direct attitudes | | | | |
| Behavioural attitudes (BA) | 9= ☐ | 10=☐ | | BA Sum of scores: 9+10 = ____ |
| Subjective norms (SN) | 7= ☐ | 8= ☐ | | SN Sum of scores: 7+8 = ____ |
| Perceived behavioural control (PBC) | 4= ☐ | 5= ☐ | 6= ☐ | PBC Sum of scores: 4+5+6 = ____ |
| Indirect attitudes | | | | |
| Behavioural beliefs (BB) | 11=☐ | 12=☐ | 13=☐ | BB*OE expectancy value calculation: |
| Outcome evaluations (OE) | 14=☐ | 15=☐ | 16=☐ | (11*14)+(12*15)+(13*16) = ____ |
| Normative beliefs (NB) | 17=☐ | 18=☐ | | NB*MoC expectancy value calculation: |
| Motivation to comply (MoC) | | 19=☐ | | (17*-1)+(18*19) = ____ |