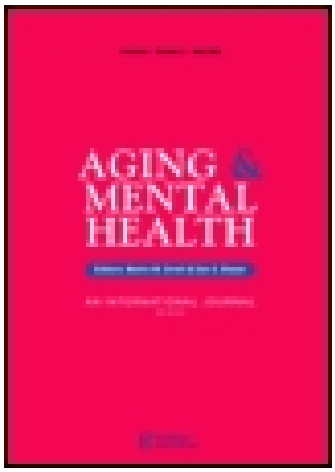
This article was downloaded by: [Kate Davies]
On: 29 June 2015, At: 20:44
Publisher: Routledge
Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



CrossMark
Click for updates

Aging & Mental Health
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/camh20

Adaptation of the Barts Explanatory Model Inventory to dementia understanding in South Asian ethnic minorities

Clarissa M. Giebel[a], David Jolley[a], Maria Zubair[b], Kamaldeep Singh Bhui[c], David Challis[ad], Nitin Purandare[de] & Angela Worden[a]

[a] Personal Social Services Research Unit, The University of Manchester, Manchester, UK

[b] Formerly Personal Social Services Research Unit, The University of Manchester, Manchester, UK, now School of Sociology and Social Policy, The University of Nottingham, Nottingham, UK

[c] Centre for Psychiatry, Wolfson Institute of Preventive Medicine, Barts and the London School of Medicine and Dentistry, Queen Mary University of London, London, UK

[d] Manchester Mental Health and Social Care Trust, Manchester, UK

[e] Formerly Institute of Brain, Behaviour and Mental Health, The University of Manchester, Manchester, UK

Published online: 15 Apr 2015.

To cite this article: Clarissa M. Giebel, David Jolley, Maria Zubair, Kamaldeep Singh Bhui, David Challis, Nitin Purandare & Angela Worden (2015): Adaptation of the Barts Explanatory Model Inventory to dementia understanding in South Asian ethnic minorities, Aging & Mental Health, DOI: 10.1080/13607863.2015.1031637

To link to this article: http://dx.doi.org/10.1080/13607863.2015.1031637

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the "Content") contained in the publications on our platform. However, Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Any opinions and views expressed in this publication are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor and Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages, and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Terms & Conditions of access and use can be found at http://www.tandfonline.com/page/terms-and-conditions

Aging & Mental Health, 2015
http://dx.doi.org/10.1080/13607863.2015.1031637

Routledge
Taylor & Francis Group

Adaptation of the Barts Explanatory Model Inventory to dementia understanding in South Asian ethnic minorities

Clarissa M. Giebel[a]*, David Jolley[a], Maria Zubair[b], Kamaldeep Singh Bhui[c], David Challis[a,d], Nitin Purandare[d,e] and Angela Worden[a]

[a]*Personal Social Services Research Unit, The University of Manchester, Manchester, UK;* [b]*Formerly Personal Social Services Research Unit, The University of Manchester, Manchester, UK, now School of Sociology and Social Policy, The University of Nottingham, Nottingham, UK;* [c]*Centre for Psychiatry, Wolfson Institute of Preventive Medicine, Barts and the London School of Medicine and Dentistry, Queen Mary University of London, London, UK;* [d]*Manchester Mental Health and Social Care Trust, Manchester, UK;* [e]*Formerly Institute of Brain, Behaviour and Mental Health, The University of Manchester, Manchester, UK*

(*Received 17 November 2014; accepted 13 March 2015*)

Objective: Studies indicate a limited understanding of dementia and its associated symptoms, causes and consequences among South Asian older adults. As a consequence, fewer people from this ethnic group receive a diagnosis of dementia. The aim of this study was to adapt the previously designed Barts Explanatory Model Inventory Checklist (BEMI-C), a tool designed to elicit perceptions of mental illness from people with different cultural backgrounds, for use with people with dementia in the South Asian population.
Method: Both a literature review and 25 qualitative interviews were conducted to find themes and perceptions that are relevant to the South Asian culture in recognising and dealing with symptoms of dementia. The emergent themes and perceptions were then added to the BEMI-C through synthesis of findings.
Results: The initial four checklists of symptoms, causes, consequences and treatments from the BEMI-C were retained in the new BEMI-Dementia (BEMI-D) and expanded with six additional themes, including 123 new perceptions relevant to the understanding of dementia. All new themes emerged from the qualitative interviews, some of which were also found in the literature.
Conclusion: Given the national priority of improving dementia awareness and timely diagnosis, the BEMI-D can serve as a useful tool, in research and perhaps practice, to assess the barriers to dementia service uptake in this population and their understandings of dementia. Based on the detailed methodological description of the adaptation of the BEMI-C, this paper further suggests how this tool can be adapted to suit other ethnic minority groups.

Keywords: dementia; South Asian; old age; ethnic minorities; explanatory model; mental health

Downloaded by [Kate Davies] at 20:44 29 June 2015

Introduction

With a growing ageing population and rising numbers of people with dementia (PwD), improving the awareness and recognition of dementia symptoms and causes is prioritised internationally (Department of Health [DH], 2009; Ministry of Health, Welfare and Sports, 2008; Ministry of Social Affairs and Health, 2013). However, implementing these policies in the general population may prove less successful for some groups, given the diversity of nationalities of people living in westernised countries. Studies have suggested that some ethnic minority groups have different dementia understandings (Lawrence, Samsi, Banerjee, Morgan, & Murray, 2011) and reduced rates of presenting to appropriate services compared to the rest of the population (Hinton, Franz, Yeo, & Levkoff, 2005), including use of mental health services (Cooper et al., 2013). In the UK, South Asians represent the largest ethnic minority group (Office for National Statistics [ONS], 2011) which is also growing in other countries worldwide (Australian Bureau of Statistics, 2006; Tran, Kaddatz, & Allard, 2005; United States Census Bureau, 2012). Therefore, a detailed appreciation of this group's understanding of dementia could make an important difference to timely dementia diagnosis and accessing appropriate dementia services.

The symptoms of dementia are multiple, and include in particular deficits with memory and cognition causing problems in performing activities of daily living (Giebel & Challis, 2015). These include preparing a hot meal, doing the laundry or, depending on the severity of dementia, more basic tasks such as toileting, eating and dressing (Giebel, Sutcliffe, & Challis, 2015a). Some PwD also display behavioural changes and can become aggressive (Isaksson, Graneheim, Astrom, & Karlsson, 2011). As PwD become increasingly reliant on their family members or professionals to care for them, their quality of life may be reduced (Andersen, Wittrup-Jensen, Lolk, Andersen, & Kragh-Sorensen, 2004; Giebel et al., 2015a). Consequently, addressing these symptoms is important in responding more effectively to cognitive, behavioural and functional changes and reducing the burden for carers and family (Burns, 2000), and also to improve and maintain a high quality of life for as long as possible. In order to achieve this

*Corresponding author. Email: clarissa.giebel@manchester.ac.uk

© 2015 Taylor & Francis

Downloaded by [Kate Davies] at 20:44 29 June 2015

across the general population, some groups may need to be approached in particular ways.

In line with the literature on other ethnic minority groups, several studies have shown that some South Asians show limited knowledge of the causes, symptoms and consequences of dementia (Bowes & Wilkinson, 2003; Morhardt, Pereyra, & Iris, 2010; Purandare, Luthra, Swarbrick, & Burns, 2007). In a questionnaire study conducted in Manchester, UK, Indian older people showed marked limitations in basic knowledge, epidemiology, aetiology and symptomatology of dementia compared to Caucasian older adults (Purandare et al., 2007). This is the only quantitative study in this field, whilst the majority of literature has addressed understandings and explanations of dementia with a qualitative interview approach (i.e., Adamson, 2001; McCleary et al., 2013). The quantitative findings have been replicated in qualitative studies in various countries, including the UK, USA and Canada (Adamson, 2001; McCleary et al., 2013; Morhardt et al., 2010). Indeed the paucity of literature exploring explanatory models (EMs) of dementia in South Asian older adults is surprising, given the need to improve recognition of dementia symptoms within this ethnic minority group. With international policies in place to improve timely dementia diagnosis and care, the importance of understanding perceptions of different ethnic minorities is highlighted.

People develop theories from a variety of sources so as to understand phenomena such as health and illness (Stacey, 1988). The different ways in which people construe illness may shape their experience, their response, the decision to seek help and from where (Zola, 1973). Such personal explanations for mental distress, also called explanatory models (Kleinman, 1978), have been shown to explain variations in the presentation, assessment and management of mental disorders (Jacob, Bhugra, Lloyd, & Mann, 1998; Mirza, Hassan, Chaudhary, & Jenkins, 2006). Particularly for minority ethnic groups, understandings of mental distress, and specifically of dementia, are found to differ from those of the general population and may influence access to care (Bhui, Bhugra, & Goldberg, 2002; Bowes & Wilkinson, 2003; Eisenbruch, 1990; Hinton et al., 2005; McCabe & Priebe, 2004; Sheikh & Furnham, 2000). To identify these differences, the pre-existing Barts Explanatory Model Inventory Checklist (BEMI-C) (Bhui, Ruedell, & Priebe, 2006; Ruedell, Bhui, & Priebe, 2009) was adapted to focus on dementia in South Asian ethnic minority groups. The BEMI-C was developed to provide a brief, yet detailed assessment of perceptions of mental illness for a variety of ethnic groups by merging quantitative and qualitative approaches (Ruedell et al., 2009). It asks participants very broadly about their understanding of four key areas: symptoms, causes, the consequences of illnesses and preferred treatment methods. The BEMI-C therefore allows participants to talk freely about their illness perceptions, which can provide a rich spectrum of understandings and beliefs. Previous applications of the BEMI-C showed cultural variations in EMs of mental distress between Bangladeshi ethnic minorities and white British (Ruedell et al., 2009), and on a larger scale between Bangladeshi, black Caribbeans and white British (Bhui et al., 2006).

The objective of this paper is to describe the adaptation of the BEMI-C to develop a dementia-specific tool (BEMI-Dementia) to capture understandings of dementia in South Asian ethnic minority groups and highlight the tool's potential uses. To the authors' knowledge, no EM has specifically addressed dementia and this target population, despite the growing number of South Asian older adults potentially affected by dementia in western countries. Hence, this paper addresses an important policy, social and public health issue which has so far received limited attention.

Method

Literature review

As part of a systematic review on barriers and facilitators to recognising mental health and accessing care in South Asian ethnic minorities (Giebel, Zubair, et al., 2015b), the literature on understandings of dementia was assessed for relevant themes and perceptions that were appropriate to develop the BEMI-Dementia (BEMI-D). Eighteen studies were found exploring symptoms, causes, consequences or preferred treatment methods and coping strategies (Acharya & Northcott, 2007; Adamson, 2001; Bhugra et al., 2003; Bowes & Wilkinson, 2003; Dementia Plus, 2001, 2003, 2007; Joshi, Parmar, & Smith, 2008; Lawrence et al., 2006a, 2006b, 2011; MacKenzie et al., 2006; McCleary et al., 2013; Morhardt et al., 2010; Mukadam, Cooper, Basit, & Livingston, 2011; Purandare et al., 2007; Redelinghuys & Shah, 1997; Seabrooke & Milne, 2004). For the purpose of the tool adaptation, all studies were reviewed again specifically for the four elements of the checklist (symptoms, causes, consequences and treatment), a level of detail which was not relevant for the initial review.

BEMI-C and BEMI-I (Bhui et al., 2006; Ruedell et al., 2009)

The BEMI-C consists of four checklists (symptoms, causes, consequences and treatments), each of which include a variety of different conceptual themes (Table 1). Each theme contains a different number of perceptions, and all perceptions mentioned by the participant are rated as present or not in a binary approach. The additional 12-item BEMI-Interview version (BEMI-I) was developed alongside the BEMI-C to enquire about identity, causes, timeline, consequences and cure and control of memory problems in a qualitative interview. The original findings from the BEMI-I (Ruedell et al., 2009) were employed to refine the BEMI-C. In the present study the BEMI-I was used to guide the modification of the BEMI-C into the BEMI-D through collection of qualitative information about perceptions of dementia by South Asians. For this study, some additional subject-specific questions were added to the BEMI-I that were considered relevant to this modification. In particular, the BEMI-I included

Table 1. BEMI-C modification to BEMI-D: checklists and themes.

Checklists	BEMI-C themes	BEMI-D themes
(1) Symptoms	• Somatic	• Somatic/bodily
	• Mental	• Mental
	• Behavioural	• Behavioural
		• Social life and relationships
(2) Causes	• Psycho-social	• Mental state or emotions
	• Supernatural	• Social factors
	• Behavioural	• Culture or lifestyle
	Situational	• Supernatural influences
		• Physical health factors
(3) Consequences	• Psychological	• Skills, abilities and functioning
	• Social	• Mental/psychological well-being
	• Physical	• Social life, roles and relationships
	• Financial	• Financial security and well-being
	• Behavioural	• Physical health and well-being
		• Impact on behaviour/adjustments made for coping
(4) Treatment	• Self	• Self/psychological
	• Social	• Self/behavioural
	• Medical	• Family/friends/community
	• Spiritual	• Formal social support
	• Psychological	• Spiritual/alternative care
		• Medical/bodily

Note: The BEMI-C themes are adapted from Ruedell et al. (2009).

Downloaded by [Kate Davies] at 20:44 29 June 2015

questions on the relationship to the person with memory problems (if the participant did not experience memory problems themselves); how they term memory problems; description, causes, effects and duration of memory problems; how long memory problems are expected to last; whether the person with memory problems (or they themselves with memory problems) go through cycles when the problems fluctuate; the perceived best treatments; and the best person to talk to about the problems.

Piloting interviews

As a second method of developing themes and perceptions for the BEMI-D, besides the literature review, 25 qualitative interviews with the BEMI-I and the BEMI-C were conducted with predominantly younger South Asian Indian and Pakistani people in English or Urdu. For this purpose, the BEMI-I and BEMI-C were translated into Urdu by the researcher and South Asian community leaders. Participants were recruited through community organisations in the locality. Of these participants, 12 were female (48%); 12 were of Indian origin, 2 of whom stated mixed Indian and Pakistani heritage; and 13 were of Pakistani origin. Interviews were conducted in the participants' homes by a member of the research team and were audio recorded. The qualitative data were analysed to identify illness perceptions which were either corroborated by those from the BEMI-C or emerged from the literature review, or were completely new. Newly emerging themes and perceptions for the BEMI-D were reviewed by three members of the research team, including two psychiatrists.

Process of adaptation

Based on findings from both the literature review and the qualitative interviews, four types of items drawn from perceptions of dementia were incorporated into the new BEMI-D. The first were the original items, with some removed as they were considered not relevant for this target population and illness; second were items identified in the interviews but not mentioned in the literature; third were items from both the interviews and the literature; and fourth were items from the literature but not expressed in the interviews. The process of adaptation involved a series of iterations where themes and items were listed in relation to their sources and subsequently reviewed by four of the authors. Information was synthesised thus until the final version, the BEMI-D, was achieved. Figure 1 depicts the process of adaptation.

Results

The four checklists of the BEMI-C (symptoms, causes, consequences and treatment) were modified to include additional dementia-specific overarching conceptual themes and individual perceptions for South Asian minority populations. Table 1 shows the themes of each of the four checklists of both the original BEMI-C and the modified BEMI-D. When adapting the BEMI-C, most new perceptions, and as a result of that themes, emerged from the interview only or both from the interview and the literature, whilst very few perceptions were identified only from the literature. In total, six new themes and 123 new items or perceptions were added to the BEMI-D. Table 2 shows the sources for each perception in the new BEMI-D.

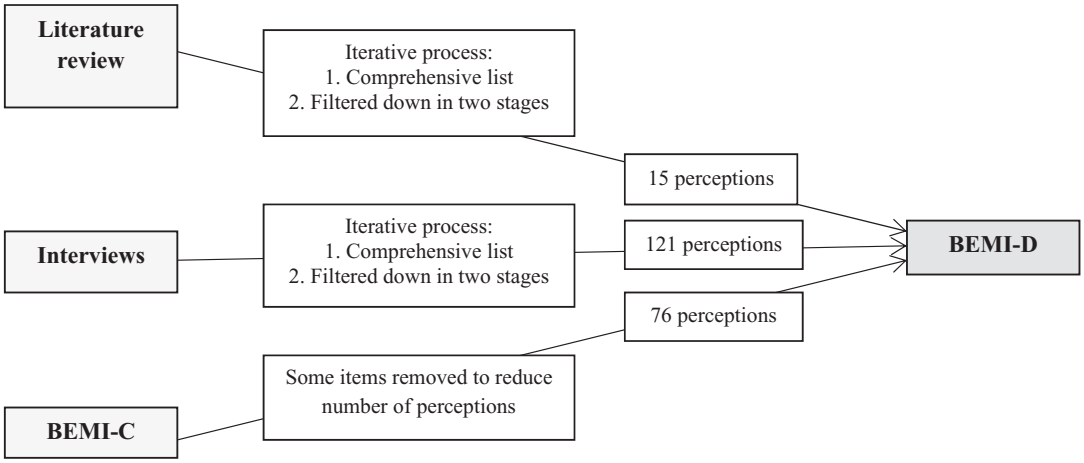


Figure 1. Flow chart of BEMI-D development.

Downloaded by [Kate Davies] at 20:44 29 June 2015

BEMI-D checklist 1: symptoms

Expanding on the BEMI-C and its themes of: (1) somatic/bodily; (2) mental; and (3) behavioural; the BEMI-D incorporates one further theme, (4) social life and relationships. A specific feature for dementia is the loss of the ability to perform daily activities, such as dressing or cooking (Giebel et al., 2015a). This has been identified by some South Asian carers to be a key symptom of their relative's behaviour (Mukadam et al., 2011), and is incorporated into the behavioural theme. Aggression was also reported in the same study, which also forms part of the behavioural theme. Although relatives identified poor memory (Lawrence et al., 2011; Purandare et al., 2007), only a minority appeared aware that dementia can affect other behavioural areas such as mobility or speech (Purandare et al., 2007) or aspects of social life, including isolation. From the interviews in particular, it emerged that when participants felt able to refer to memory problems as possible dementia, they showed greater awareness of the symptoms and could provide more detailed descriptions of the daily memory problems:

> I haven't studied anything about Alzheimer's, but from my experience of him, he has lapses of memory and what he tends to do is remember things from his earlier days than what is happening currently, and a lot of times what happens is he knows who you are but forgets the name [. . .] for example he has just had his breakfast [. . .] it's a complete lapse, he doesn't know what he had, although it's literally five minutes back.
>
> Indian female, family carer

The category mental symptoms also comprises symptoms associated with depression, such as *loneliness*, *suicidal thoughts* and *deterioration in self-confidence*. These perceptions were common in the piloting interviews, suggesting that most participants considered possible symptoms of depression when talking about memory problems and dementia. It is therefore important to note that the BEMI-D is a tool to explore EMs of dementia, but will also capture EMs of depression. This is not unexpected considering that depression is a common comorbid disorder of dementia (Giebel et al., 2015a).

BEMI-D checklist 2: causes

The BEMI-D Checklist 2 on causes comprises five themes: (1) mental state or emotions; (2) social factors; (3) culture or lifestyle; (4) supernatural influences; and (5) physical health factors. In most studies, as well as in the interviews, people ascribed reduced memory functioning to normal ageing (McCleary et al., 2013) although isolation and inactivity were also noted. In one of the only quantitative approaches to understandings of dementia, Purandare et al. (2007) found that only 21% of Indian older adults saw dementia as caused by reduced brain functioning. Other causes highlighted in both interviews and literature were change of environment, such as moving from the country into the city (Adamson, 2001), and a visit to Pakistan (Bowes & Wilkinson, 2003), which both fall under the new theme of culture and lifestyle. Emotional perceptions, such as the death of loved ones or taking antidepressants (Adamson, 2001), and physical health factors, such as diabetes or heart surgery (Mukadam et al., 2011), were also cited. In an interview with a younger Indian participant whose mother had memory problems, the causes of the memory problems were unknown, although physical health factors were provided as one possible cause:

> I'm not actually sure. Some of it might just be age-related, but then my mum has sort of other medical kind of complications and things [. . .] I mean, she did sort of have a bit of heart arrhythmia, so I don't know whether that affected the blood supply to her brain and made her feel a bit light-headed.
>
> Indian male, family carer

Table 2. Specific perceptions of dementia and overarching conceptual themes.

Themes	Per ceptions
Symptoms	
• Somatic/bodily	• Disturbed sleep, *visual deficiency*, *changes in the body*, fatigue, nerves, nausea, *sleepiness*, *incontinence*, *clumsiness*, *falls*, *mobility changes*
• Mental	• *Loneliness*, crying, irritable, nervous/anxious, frightened, loss of interest, *disillusionment*, worrying, suicidal thoughts, feeling guilty, hallucinations, *disorientation*, *confusion*, *deterioration in self-confidence*, *lack of insight*, *forgetting*, *memory stuck in time*, lack of concentration, *change in oneself*, *change in personality*
• Behavioural	• Changes in diet, substance (ab)use, *restlessness*, *avoiding doing things*, obsessive behaviour, neglecting hygiene, aggression, mute, rambling, *excitability*, *repetition*, *loss of skills*
• Social life and relationships	• Social isolation, *difficulties in social interaction*, *loss of social meaning*
Causes	
• Mental state or emotions	• Self-doubt, stress/anxiety/worry, guilt, ***negative thinking***, excessive emotions, *personality*
• Social factors	• Loneliness, *constrained in the house*, *loss of usual environment*, *idleness*, work problems, family problems, bereavement, *life events*, racism, being abused, *inability to talk about problems*, ***traditions***, age, ethnicity, financial problems
• Culture or lifestyle	• Culture, diet, substance (ab)use, *lack of exercise*, *lack of mental stimulation*, *climate*
• Supernatural influences	• Bad luck, fate, weakened spirit, given by God, supernatural influences
• Physical health factors	• Illness, body problem, *lack of sleep*, *some accident*, poison, *side effects of medication*, virus, heredity, *medical reasons*, *something happening to the brain*, *some heart condition/stroke/Parkinson's disease*
Consequences	
• Skills, abilities and functioning	• *Loss of skills*, *slow task completion*, *difficulties in keeping appointments*, *changes to daily life*, *changes in decision-making*
• Mental/psychological well-being	• Focus on body, little concentration, loss of confidence, *changes in identity*, no motivation, *impatience*, negative emotions, *hallucinations*, *forgetting undesirable experiences*, not being bothered, ***dealing with fate***, *changes in personality*, *impact on quality of life*
• Social life, roles and relationships	• *Concerns about social status*, *changes of role*, *difficulties in social interaction*, *changes in social life*, being excluded, being rejected, *ill-treatment*, *increasing caring needs*, *restrictions*, *withdrawal*, unusual existence, ***performance of duties***, *using networks for support*, ***engagement in family/community***, ***engagement in roles according to status***, *changes in living arrangements*, *burden for carers*, *misery caused to person or people around*
• Financial security and well-being	• Losing job, losing financial security
• Physical health and well-being	• Weight changes, ***incontinence***, pain, *death*
• Impact on behaviour/adjustments made for coping	• *Changes in behaviour*, *less prudent actions*, *cautious*, *adjusting own behaviour to age*, *stop enjoying things*, *idleness*, *impact on religious practices*, *using own motivation for coping*, *self-sufficient*, *keeping busy*, *pre-planned routines*, *various safety aids*, listening attentively, *waiting for things to return to memory*, *mental exercises*, ***avoiding being blamed***, religion to cope, ***culture to cope***, substance (ab)use, *professional support*, *medical support*, *exposure to harm*, *changes in use of public/private space*
Treatments	
Self/psychological	• *Raising self-confidence*, *positive thinking*, ***self-talk***, ***maximising control over inner self***, ***dealing with fate***, *keeping happy*, *gaining independence*, *keeping in conversation*
• Self/behavioural	• *Waiting for things to return to memory*, dieting, exercising, keeping busy, *mental exercises*, *writing things down*, *structured life*, *hot bath*, *listening attentively*, *maintaining good vision/hearing*, *consulting books*, *changing environment*
• Family/friends/community	• Talking to family/friends, socialising, *becoming aware of the problem*, *others noticing problems*, *keeping company*, *living with family*, *treating person well*, *inclusion in family activities*, *investing in relationships*, ***performance of duties***, ***engagement in family/community activities***, ***engagement in roles according to status***
• Formal social support	• *Formal support services*, *seeing social services*
• Spiritual/alternative care	• Praying, relaxation/meditation, *traditional healer*, herbal remedies, *dietician*, alternative practitioner
• Medical/bodily	• Talking to GP/nurse, taking medication, hospital treatment

Note: No bold or italics: adapted from the original BEMI-C (Rudell et al., 2009) (76); italics: from qualitative interviews (106); bold and italics: from qualitative interviews and the literature (15).

Downloaded by [Kate Davies] at 20:44 29 June 2015

Downloaded by [Kate Davies] at 20:44 29 June 2015

BEMI-D checklist 3: consequences

Throughout the literature and the interviews, a number of themes of consequences emerged, including (1) skills, abilities and functioning; (2) mental/psychological well-being; (3) social life, roles and relationships; (4) financial security and well-being; (5) physical health and well-being; and (6) impact on behaviour/adjustments made for coping. The interviews identified in particular mood state, social withdrawal and loss of concentration as consequences. As in the symptoms checklist, poorer daily activity performance was also mentioned as a consequence of memory problems. This was regarded as a failure to remember doing something prospectively, such as taking medication, or reduced attention when performing a current task, such as cooking.

> Well, the disadvantages are that she can't remember appointments and things like that or difficulty in getting to places . . . remembering medication . . . sometimes she lets the sink overflow and stuff like that or, you know, leaves pans on the cooker.
>
> Indian male, family carer

Many participants in the interviews described memory problems as having a marked negative impact on the older person and family life:

> If he is with the family then all will be frustrated, children, husband, wife, whoever [he is] living with would get more agitated to do things and plus his mind would not communicate to what his concerns are.
>
> Indian female without memory problems

In some instances, people with memory problems identified restrictions and a loss of independence as a consequence:

> I'm not working or doing any job, so it doesn't affect [my life] a lot . . . cause I'm staying here, and if I was working, teaching, then it would have been very difficult . . . I feel very sad that I am locked in a room.
>
> Pakistani female with memory problems

When carers discussed their experiences with relatives who have memory problems or dementia, some noted that restrictions were self-imposed, with PwD withdrawing from the wider family and social life. In some cases, carers may not attribute social withdrawal as a consequence of memory problems, but rather as a symptom that accompanies forgetfulness, and it could therefore be named either in the first or in the third checklist:

> I think he withdrew himself as well because he felt, in his own mind, useless in one sense [. . .], he wasn't able to hold his own conversation. So slowly over time, he's kind of stepped back and became isolated more so.
>
> Indian male, family carer

BEMI-D checklist 4: treatments

The domain of treatments contains six themes: (1) self/psychological; (2) self/behavioural; (3) family/friends/community; (4) formal social support; (5) spiritual/alternative care; (6) mental; and (7) medical/bodily care. The interviews identified in particular health care, engaging with family, exercise and prayer as treatments. The literature described social support as an important and frequent method of treatment (Lawrence et al., 2011; MacKenzie et al., 2006), which was also highlighted in the interviews. For most interviewees without memory problems, treatment was seen in terms of caring and understanding of the person's memory problems, without reference to specific treatments, such as medication, or the use of health services:

> Mostly lovingly, caring, being very gentle to them, and being kind to them.
>
> Indian female without memory problems

Interestingly, younger generations of family carers were more inclined to identify practical solutions to deal with memory problems, such as the use of diaries to remember appointments or using adaptations to the house and alarms to remind the PwD that food is still cooking on the hob or that the bath is overflowing with water:

> It depends on how serious it is, but if you know it's not that serious you can sort of alleviate some of the problems by keeping a diary or keeping a calendar . . . I don't know, there is probably various aids and things that you can have around the house like smoke alarms or something like that for pots and pans and things and probably you can have the same sort of thing for tabs.
>
> Indian male, family carer

Younger generations may be more exposed to these gadgets than the older generations of family carers, the latter being more likely to hold strong family values and place a greater importance on caring for family and community members. Consistent with the value ascribed to the community, religion was another important approach when dealing with memory or mental health problems (Acharya & Northcott, 2007; Joshi et al., 2008). Through faith in God, self-esteem was considered to be improved in older immigrant women (Acharya & Northcott, 2007), consistent with different treatment approaches emerging from older generations. Maintenance of self-control and self-esteem is regarded as an important form of tackling problems with mental health or memory, whilst many older South Asians view consulting the general practitioner (GP) as inappropriate for problems other than those of a physical nature (Lawrence et al., 2006).

Use of the tool

For the application of the BEMI-D Checklists 1, 2 and 3, the interviewer asks questions in the style of a semi-structured interview about any symptoms, causes and

*Mr ---- **('Patel' for Indian participant; 'Malik' for Pakistani participant)** is 75 years old. Recently he has begun to be forgetful. He confuses peoples' names, even those he knows well. He often seems not to be able to remember things from one moment to the next. One example was when he went to the market to buy food and came back with nothing, having forgotten what he went out for. He repeats himself in conversation, and always seems to talk about the past. His family has noticed that the problem is steadily getting worse.*

Figure 2. Vignette used as part of the BEMI-D.

consequences. In this way, no perceptions are suggested to the participant, and only those responses actually made are marked on the checklists as present. In the event that a participant were to offer very few responses and struggle to provide more answers, the interviewer can prompt for further responses by asking about specific themes, such as bodily or mental symptoms or cultural or physical health factors. For Checklist 4, participants are asked about treatments and whether these were considered, tried or helpful. As before, the themes and individual perceptions are not presented to the participant, and where there are difficulties in responding, the use of prompts is again possible.

Prior to the administration of the BEMI-D, if participants have no memory problems and no experience or knowledge of dementia, they are presented with a vignette to use as a point of reference when completing the BEMI-D. The vignette is shown in Figure 2 and describes the symptoms of a PwD. On the other hand if participants know someone with memory problems or have memory problems themselves, then they answer the BEMI-D in relation to themselves or that person.

Discussion

This paper describes in detail the process of modification of the BEMI-C to the BEMI-D for use with South Asian ethnic minority groups regarding dementia. On the basis of a literature review and qualitative interviews, themes and perceptions specific for the target group were identified and integrated into the BEMI-D. In encompassing a large variety of different beliefs about dementia, the BEMI-D appears as an appropriate tool to assess understandings (or EMs) of the symptoms, causes, consequences and treatments of dementia and their implications for care. With growing ethnic diversity, particularly the numbers of South Asians living in western countries, and increasing numbers of PwD worldwide (ADI, 2009), the BEMI-D is a useful tool for a particular group of the general population that may be difficult to approach without specifically designed assessment tools. For the BEMI-D to be employed in as many settings as possible to reach South Asians of any generation, and especially those with memory complaints, this tool first needs to be further tested within research parameters. Particular questions of interest include: (1) the implications of different understandings for the subsequent care pathway; (2) whether understandings of dementia change over time and what factors influence this; (3) how the patterns of dementia understandings within South Asian groups compare with those of others.

There are several potential uses beyond research for the BEMI-D. One potential use is in clinical settings. In contrast to their low help-seeking for mental health and memory problems, South Asian older adults show similar levels of help-seeking for behavioural and physical problems to indigenous groups (Livingston et al., 2002). Hence, understanding EMs might help in the assessment process, particularly in screening and early identification of divergent perspectives on interventions and treatment (Ascoli, Palinski, Owiti, De Jongh, & Bhui, 2012; Bhui, Ascoli, & Nuamh, 2012; Bhui et al., 2002; Bhui et al., 2006; Eisenbruch, 1990; Ruedell, et al, 2009). Use of the BEMI-D by staff could thus enhance understandings of EMs and permit appropriate adaptation of information and care, improve the chances of timely diagnosis, and increase the chance of adherence to treatment and interventions (Bhui et al., 2006). These activities might benefit from a shortened version of the BEMI-D and work is planned to see if this is possible. Nevertheless, the method of use proposed here is economical in that it is a checklist but not an exhaustive one.

Another possible use of the BEMI-D is in teaching. Members of South Asian ethnic groups have complained about the lack of culturally and linguistically sensitive clinical staff and general services, such as care homes, GP surgeries or other health care services (Dementia Plus, 2001, 2003, 2007; Joshi et al., 2008; Redelinghuys & Shah, 1997; Seabrooke & Milne, 2004). The BEMI-D is a comprehensive tool that encapsulates a diverse range of different understandings about dementia. By teaching staff with a limited acquaintance with South Asian culture about the range of perspectives through the BEMI-D, staff may be enabled to work better with members of that community. Furthermore, employing the tool in teaching could indicate how staff might raise awareness about neurodegenerative disease.

All these potential applications of the BEMI-D could not only improve the understanding of dementia and raise awareness, but also thereby increase rates of diagnosis and access to care; objectives of the English National Dementia Strategy (DH, 2009) are crucial when addressing dementia care in any country. Hence, use of the BEMI-D could not only help with implementation of recent policy guidelines, but could also directly impact on PwD and their families. That is, the earlier people are diagnosed, the earlier the family can adjust to the diagnosis and be better informed about the potential changes that may occur as part of the disorder. Furthermore, in obtaining a diagnosis, family members of South Asian communities know that their relative's symptoms, such as

Downloaded by [Kate Davies] at 20:44 29 June 2015

memory or behavioural changes, are part of the disorder and not part of normal ageing or other factors. Consequently, family members who act as carers will have better access to information on where to seek support or respite care, if required, and may feel more comfortable in accessing home care support, to reduce carer burden, stigma and isolation (Schoenmakers, Buntinx, & DeLepeleire, 2010).

Limitations

Rigorous work has gone into adapting the previously established BEMI-C specifically for South Asians with a focus on dementia. Some limitations were nonetheless present. First, the tool was developed on the basis of a pre-existing tool, with a new literature review and new qualitative interviews. There were only 25 such interviews and it is possible that despite our efforts they were less representative of the overall South Asian population than desired. Second, the tool is at present based upon the understandings of the South Asian population. Naturally, this means that the BEMI-D is only applicable to one specific ethnic group. However, South Asians represent one of the largest groups across different countries worldwide (ONS, 2011; Tran et al., 2005), which makes this group particularly important. Third, given its length, the tool requires a time commitment and early work has employed trained interviewers. Fourth, there remains the issue of content. The tool still needs to be tested to determine whether some of the perceptions are redundant and rarely or never mentioned in interviews. Similarly, administering the BEMI-D to a larger sample may identify beliefs that have neither been highlighted in the literature nor in the qualitative interviews, which would refine the tool. Both aspects would help in creating a more precise, and potentially shorter, version of the BEMI-D. Fifth, the BEMI-D contains certain depressive symptoms reflecting the commonality of these in both depression and dementia and therefore their non-discrete status as perceptions of dementia. Finally, the BEMI-D, although a structured checklist, shares the problem of other instruments designed to capture unique EMs in that the role of interpretation exists from responses to the checklist (Bhui and Bhugra, 2002). Nonetheless, it provides a degree of structure and shape to a complex area of enquiry.

Implications

In addition to the assessment of dementia understandings in research, and potential use in clinical processes, the BEMI-D can contribute to current policy implementation. The English National Dementia Strategy (DH, 2009) aims to (1) raise awareness of dementia and related help-seeking; (2) improve timely diagnosis; and (3) improve easy access to care following a diagnosis. By understanding the range of beliefs about memory problems and their causes and consequences, information, assessments and access to treatment and care can be provided in more culturally sensitive and meaningful ways to the South Asian population.

Acknowledgements

This study was funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-1208-18116). The views expressed are those of the author(s) and not necessarily those of the National Health Service (NHS), the NIHR or the Department of Health. The original principal investigator (PI) for the study was Professor Nitin Purandare, University of Manchester, who tragically died in May 2012.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme [grant number PB-PG-1208-18116].

References

Acharya, M.P., & Northcott, H.C. (2007). Mental distress and the coping strategies of elderly Indian immigrant women. *Transcultural Psychiatry, 44*, 614–636.

Adamson, J. (2001). Awareness and understanding of dementia in African/Caribbean and South Asian families. *Health and Social Care in the Community, 9*(6), 391–396.

Alzheimer's Disease International. (2009). *World Alzheimer report 2009*. London: Author.

Andersen, C., Wittrup-Jensen, K., Lolk, A., Andersen, K., & Kragh-Sorensen, P. (2004). Ability to perform activities of daily living is the main factor affecting quality of life in patients with dementia. *Health and Quality of Life Outcomes, 2*(1), 52–58.

Ascoli, M., Palinski, A., Owiti, J., De Jongh, B., & Bhui, K. (2012). The culture of care within psychiatric services: Tackling inequalities and improving clinical and organisational capabilities. *Philosophy, Ethics and Humanities in Medicine, 7*, 12–19.

Australian Bureau of Statistics. 2006. *Cultural diversity overview*. Canberra: Author.

Bhugra, D., Thompson, N., Piracha, S., Kapoor, J., Oomen, G., & Conolly Wing, J. (2003). Mental health of ethnic minority elders in west London: Pathways into secondary care. *Indian Journal of Psychiatry, 45*(11), 27–30.

Bhui, K., Ascoli, M. and Nuamh, O. (2012). The place of race and racism in cultural competence: what can we learn from the English experience about the narratives of evidence and argument? *Transcultural Psychiatry, 49*, 185–205.

Bhui, K., & Bhugra, D. (2002). Explanatory models for mental distress: Implications for clinical practice and research. *British Journal of Psychiatry, 181*, 6–7.

Bhui, K., Bhugra, D., & Goldberg, D. (2002). Cultural explanations of distress and general practitioners' assessments of common mental disorder among Punjabi and English attendees. *Social Psychiatry and Psychiatric Epidemiology, 37*, 38–45.

Bhui, K., Ruedell, K., & Priebe, S. (2006). Assessing explanatory models for common mental health disorders. *Journal of Clinical Psychiatry, 67*, 964–971.

Bowes, A., & Wilkinson, H. (2003). 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Health and Social Care in the Community, 11*(5), 387–396.

Burns, A. (2000). The burden of Alzheimer's disease. *International Journal of Neuropsychopharmacology, 3*(Supplement 2), 31–38.

Cooper, C., Spiers, N., Livingston, G., Jenkins, R., Meltzer, M., Brugha, T., & Bebbington, P. (2013). Ethnic inequalities in

Downloaded by [Kate Davies] at 20:44 29 June 2015

Downloaded by [Kate Davies] at 20:44 29 June 2015

the use of health services for common mental disorders in England. *Social Psychiatry and Psychiatric Epidemiology, 48*, 685–692.

Dementia Plus. (2001). *Twice a child: Dementia care for African-Caribbean and Asian older people in Wolverhampton*. Wolverhampton, UK: Author.

Dementia Plus. (2003). *Twice a child II: Service development for dementia care for African-Caribbean and Asian older people in Wolverhampton*. Wolverhampton, UK: Author.

Dementia Plus. (2007). *Twice a child III: Asian carers of older people with dementia*. Wolverhampton, UK: Author.

Department of Health. (2009). *Living well with dementia: A national dementia strategy*. London: Author.

Eisenbruch, M. (1990). Classification of natural and supernatural causes of mental distress. Development of a mental distress explanatory model questionnaire. *Journal of Nervous and Mental Disorders, 178*, 712–719.

Giebel, C., & Challis, D. (2015). Translating cognitive and everyday activity deficits into cognitive interventions in mild dementia and mild cognitive impairment. *International Journal of Geriatric Psychiatry, 30*(1), 21–31.

Giebel, C.M., Sutcliffe, C., & Challis, D. (2015a). Activities of daily living and quality of life across different stages of dementia. *Aging & Mental Health, 19*(1), 63–71.

Giebel, C.M., Zubair, M., Jolley, D., Bhui, K.S., Purandare, N., Worden, A., & Challis, D. (2015b). South Asian older adults with memory impairment: Improving assessment and access to dementia care. *International Journal of Geriatric Psychiatry, 30*(4), 345–356.

Hinton, L., Franz, C.E., Yeo, G., & Levkoff, S.E. (2005). Conceptions of dementia in a multiethnic sample of family caregivers. *Journal of the American Geriatrics Society, 53*, 1405–1410.

Isaksson, U., Graneheim, U.H., Astrom, S., & Karlsson, S. (2011). Physically violent behaviour in dementia care: Characteristics of residents and management of violent situations. *Aging & Mental Health, 15*(5), 573–579.

Jacob, K.S., Bhugra, D., Lloyd, K.R., & Mann, A.H. (1998). Common mental disorders, explanatory models and consultation behaviour among Indian women living in the UK. *Journal of the Royal Society of Medicine, 91*(2), 66–71.

Joshi, A., Parmar, D., & Smith, J. (2008). *Report of the community led research project focusing on Gujarati-speaking Asian elders' experiences/views and attitudes of mental health & mental health services in Harrow*. Harrow: Mind in Harrow.

Kleinman, A. (1978). Concepts and a model for the comparison of medical systems as cultural systems. *Social Science and Medicine, 12*, 85–93.

Lawrence, V., Banerjee, S., Bhugra, D., Sangha, K., Turner, S., & Murray, J. (2006a). Coping with depression in later life: A qualitative study of help-seeking in three ethnic groups. *Psychological Medicine, 36*, 1375–1383.

Lawrence, V., Murray, J., Banerjee, S., Turner, S., Sangha, K., Byng, R., Bhugra, D., Huxley, P., Tylee, A., & Macdonald, A. (2006b). Concepts and causation of depression: A cross-cultural study of the beliefs of older adults. *Gerontologist, 46*, 23–32.

Lawrence, V., Samsi, K., Banerjee, S., Morgan, C., & Murray, J. (2011). Threat to valued elements of life: The experience of dementia across three ethnic groups. *Gerontologist, 51*(1), 39–50.

Livingston, G., Leavey, G., Kitchen, G., Manela, M., Sembhi, S., & Katona, C. (2002). Accessibility of health and social services to immigrant elders: The Islington study. *British Journal of Psychiatry, 180*, 369–373.

MacKenzie, J. (2006). Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK. *Dementia, 5*, 233–247.

McCabe, R., & Priebe, S. (2004). Explanatory models of illness in schizophrenia: Comparison of four ethnic groups. *British Journal of Psychiatry, 185*, 25–30.

McCleary, L., Persaud, M., Hum, S., Pimlott, N., Cohen, C., Koehn, S., ... Drummond, N. (2013). Pathways to dementia diagnosis among South Asian Canadians. *Dementia, 12*(6), 769–789.

Ministry of Health, Welfare and Sports. (2008). *Caring for people with dementia, DLZ/Z-U-2853804*. The Hague: Author.

Ministry of Social Affairs and Health. (2013). *National memory programme 2012-2020. Creating a 'memory friendly' Finland*. (Reports and memorandum of the Ministry of Social Affairs 2013:9). Helsinki: Ministry of Social Affairs and Health. Retrieved from www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/Finland#-1

Mirza, I. Hassan, R, Chaudhary, H., & Jenkins, R. (2006). Eliciting explanatory models of common mental disorders using the Short Explanatory Model Inventory (SEMI) Urdu adaptation – a pilot study. *Journal of the Pakistan Medical Association, 56*, 461–463.

Morhardt, D., Pereyra, M., & Iris, M. (2010). Seeking a diagnosis for memory problems: The experiences of caregivers and families in five limited English proficiency communities. *Alzheimer Disease and Associated Disorders, 24*(3, Suppl 1), S42–S48.

Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics, 23*(7), 1070–1077.

Office for National Statistics. (2011). *Ethnicity and national identity in England and Wales 2011*. London: Office for National Statistics. Retrieved from http://www.ons.gov.uk/ons/dcp171776_290558.pdf

Purandare, N., Luthra, V., Swarbrick, C., & Burns, A. (2007). Knowledge of dementia among South Asian (Indian) older people in Manchester, UK. *International Journal of Geriatric Psychiatry, 22*, 777–781.

Redelinghuys, J., & Shah, A. (1997). The characteristics of ethnic elders from the Indian subcontinent using a geriatric psychiatry service in West London. *Aging Mental Health, 1*(3), 243–247.

Ruedell, K., Bhui, K., & Priebe, S. (2009). Concept, development and application of a new mixed method assessment of cultural variations in illness perceptions: Barts Explanatory Model Inventory. *Journal of Health Psychology, 14*, 336–347.

Schoenmakers, B., Buntinx, F., & DeLepeleire, J. (2010). Supporting the dementia family caregiver: The effect of home care intervention on general well-being. *Aging & Mental Health, 14*(1), 44–56.

Seabrooke, V., & Milne, A. (2004). *Culture and care in dementia: A study of the Asian community in North West Kent*. Northfleet: Alzheimer's and Dementia Support Services/MentalHealth Foundation.

Sheikh, S., & Furnham, A. (2000). A cross cultural study of mental health beliefs and attitudes towards seeking professional help. *Social Psychiatry and Psychiatric Epidemiology, 35*(7), 326–334.

Stacey, M. (1988). *The sociology of health and healing*. London: Routledge.

Tran, K., Kaddatz, J., & Allard, P. (2005). South Asians in Canada: Unity through diversity. *Canadian Social Trends. Statistics Canada Catalogue No. 11-008*. Canada: Canadian Bureau of Statistics. Retrieved from http://www.statcan.gc.ca/pub/11-008-x/2005002/article/8455-eng.pdf (accessed April 1, 2015).

United States Census Bureau. (2012). *The Asian population: 2010*. Washington, DC: United States Census Bureau.

Zola, I.K. (1973). Pathways to the doctor – from person to patient. *Social Science and Medicine, 7*, 677–689.