

APPENDIX D: BARTS EXPLANATORY MODEL INVENTORY DEMENTIA Shortened (BEMI-Ds)

(For participants with memory difficulties)

Factors influencing recognition of symptoms of dementia in South Asian elders: Equipping families and professionals to provide sensitive responses and early intervention

Instructions for interviewer:

This version refers to participant's own memory difficulties. Only read out the main question to participant and tick as many of the check-list items to which their response does fit accurately. If the participant uses/introduces new items that do not already exist in the check-list, then tick on the 'other' box and make a note of these additional/new items that they have used. In cases where you are unsure about whether an item (or sets of items) does/do reflect what the participant is referring to, do not tick the item/s but record their response in writing as 'other'. At the end of the participant's response to the main question and before you move on to the next section of the check-list, always ask if there is "anything else" or "anything more" that they would like to add here to their response. Do not show the actual check-list or its items to the participant. If the participant appears to experience difficulties in understanding or responding to the main question, use the specified prompts and probes as an aid to elicit a response from them.

SYMPTOMS / SIGNS OF THE PROBLEM

Question:

- Could you please tell me about all the symptoms or the signs that you feel are part of your memory problem?

Prompts & Probes:

- How can you tell that you have a memory problem? What are the signs of your problem? What symptoms do you experience?
- Are there any: Bodily signs or symptoms? Mental signs or symptoms? Behavioural signs or symptoms? **(Use all three probes, but only if difficulties in getting a response.)**
- Are there any more signs or symptoms of your memory problems that you'd like to add here? **(Ask this in all cases, but especially if only one symptom has been identified.)**

If the response is unclear, ambiguous, incomplete or even unusual, ask:

- What do you mean when you say (this)? Could you please tell me a little more about this?

General

- Loss of skills, abilities or functioning (e.g. loss of daily life skills, communication skills, ability to count, ability to get to places etc.)
- Changes in personality

Somatic / Bodily symptoms

- Having disturbed sleep
- Fatigue / tiredness / sleepiness
- Incontinence
- Falls
- Changes in levels of mobility

Mental symptoms (including those related to mood or emotion)

- Feeling lonely
- Crying or dysphoria (feel down)
- Feeling nervous
- Loss of interest or not being able to enjoy things
- Worrying thoughts or obsessive thoughts
- Hallucinations
- Disorientation (loss of promptness, misjudgment of speed, misidentification of places, time and people, loss of sense of direction and knowledge of one's surroundings) / Confusion
- Not having insight into one's own condition
- Unusual forgetting of things, information or people already known
- Memory stuck many years back in time
- Lack of concentration or not being able to complete tasks

Behavioural symptoms

- Changes in diet or eating habits
- Being restless or continuously moving about
- Not doing a lot of things or avoiding doing things
- Neglecting your hygiene (stop washing yourself, wearing fresh clothes)
- Being aggressive / violent or having fights/quarrels
- Becoming mute or stop talking
- Repeatedly asking the same question or telling the same thing over and over again

Social life and relationships

- Prefer to be alone or no social life
- Difficulties in social interaction or maintaining healthy social relationships
- Loss of social meaning or engagement in socially inappropriate or undesirable behaviours

- Other symptoms / signs (not listed above)

If any of the related symptoms/signs are not listed above, please record them here:

CAUSES / EXPLANATIONS

Question:

- What do you think has caused or contributed towards developing your memory problems?

Prompts & Probes:

- Please tell me about all the things which you feel could have led to you having your memory problems? What are the different things that you think have caused your problems?
- Are your memory problems caused by any: Physical health factors? Lifestyle factors? Cultural or upbringing factors? **(Use all three probes, but only if experience difficulties.)**
- Are there any more causes or things contributing to your memory problem that you'd like to add here? **(Ask this in all cases, but especially if only one cause has been identified.)**

If the response is unclear, ambiguous, incomplete or even unusual, ask:

- What do you mean when you say (this)? Could you please tell me a little more about this? **(Use this to probe more, especially if the participant says the cause is 'old age'.)**

General characteristics

- Your age
- Your ethnicity or race
- Financial problems or poverty
- Climate or weather (including depression because of UK weather or not sweating enough)

Mental state or emotions

- Stress, anxiety, worry or unhappiness
- Emotions (excessive)

Social factors

- Loneliness / isolation from other people
- Being constrained in the house or staying in the same environment
- Idleness or lack of social stimulus / activity
- Work problems (including retirement or lack of work)
- Family or marital/partner problem
- Life events, bereavement or any trauma

Culture or lifestyle

- Your culture / way of life
- Diet, food intake or way of cooking
- Substance (ab-)use (alcohol, tobacco, drugs, medication)
- Lack of exercise
- Lack of mental/brain exercises and stimulation

Supernatural influences

- Bad luck / can affect anyone at any time (random)
- Fate / destiny (deliberate) Given by God (e.g.as test of faith or punishment)

Physical health factors

- Some problem with the body
- Lack of sleep
- Some accident, or bodily injury or damage (e.g. damage or injury to the head)
- Side-effects of medication
- Heredity (genes)
- Medical reasons / Some heart condition, stroke or Parkinson Disease / Illness Bad Health
- Something happening to the brain (e.g. damage to nerve cells, blood circulation problem, or multiple infarctions in the brain)

- Other causes / explanations (not listed above)

If any of the causes/explanations are not listed above, please record them here:

CONSEQUENCES / COPING

Question:

- Could you please also tell me about the consequences you have experienced as a **result** of having your memory problems?

Prompts & Probes:

- Please tell me about how you feel your memory problems have affected you or your life? What are the different consequences or changes you have experienced because of your memory problems?
- Have you experienced any effects on your: Social engagement? Health and wellbeing? Confidence or psychological wellbeing? **(Use all three probes, but only if participant experiences difficulties in responding.)**
- Are there any more consequences or effects of your memory problems that you'd like to add here? **(Ask this in all cases, but especially if only one consequence has been identified.)**

If the response is unclear, ambiguous, incomplete or even unusual, ask:

- What do you mean when you say (this)? Could you please tell me a little more about this?

General

- Impact on quality of life
- Exposure to harm, damage or danger
- Misery caused to the person, their family, the people around
- Changes in use and experience of public and private space

Skills, abilities and functioning

- Loss of skills, abilities and/or functioning
- Taking a long time to complete work or sort out things
- Difficulties in getting to places or keeping appointments
- Changes in decision-making or thinking abilities

Mental / Psychological wellbeing

- Losing confidence and / or self-esteem / No motivation and less outgoing
- Getting impatient or sudden changes in mood
- Negative or unpleasant feelings or emotions
- Hallucinations
- Not being bothered about the problem or taking it philosophically to cope
- Changes in personality

Social life, roles and relationships

- Concerns about or impact on social image and status
- Change of your role (in your family, community etc)
- Difficulties in social interaction or explaining oneself to others
- Being excluded from social activities

- Being rejected or isolated
- Increasing caring needs or becoming dependent on others
- Restrictions faced or loss of choice / control / freedom / independence
- Becoming withdrawn or focused on oneself
- Engagement in family, household and community affairs and activities to cope
- Changes in living arrangements (including moving into a care home or a separate house)
- Burden or difficulties created for care givers or family members

Financial security and wellbeing

- Losing your financial security

Physical health and wellbeing

- Losing or gaining weight or other problems to health
- Incontinence or using nappies to cope
- Pain
- Death

Impact on behavior / Adjustments made for coping

- Stop enjoying things or partaking in activities you enjoy
- Idleness
- Impact on religious practice / prayers
- Following pre-planned routines and standard procedures to cope
- Having various safety aids around the house (such as a smoke alarm)
- Waiting for things to come back to memory
- Using religion to cope
- Using support from professional or voluntary agencies
- Using medical support

- Other consequences (not listed above)

If any of the consequences are not listed above, please record them here:

METHODS / TREATMENTS

Questions:

Would you please now tell me about the methods you have tried to resolve your problem?

- Which ones of these methods have you found helpful? (**Get an answer, relating to whether helpful or not, for each of the methods identified by the participant.**)
- Are there any methods that you did consider but did not actually try? Would you please tell me which ones you did consider but did not try? Would you please also tell me the reasons for not trying these methods you did think about?

Prompts & Probes:

- Have you tried or considered using: Health or care services? Activity? Self-care or traditional remedies? (**Use all three probes, but only if participant experiences difficulties in responding.**)
- Are there any more methods or treatments you have tried, or just considered, that you would like to add here? (**Ask this in all cases, but especially if only one method has been identified.**)

If the response is unclear, ambiguous, incomplete or even unusual, ask:

- What do you mean when you say (this)? Could you please tell me a little more about this?

	Considered	Tried	Helpful
General			
Allowing / gaining independence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consulting books	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self / Psychological			
Raising own self-confidence and not questioning your memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Engagement in positive thinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accepting and dealing with fate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keeping happy (self / via others)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self / Behavioural			
Waiting for things to come back to the memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dieting / fasting / eating good food or different foods (such as almonds)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Exercising (including dancing or walking)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keeping busy / spending time on a hobby or entertainment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinking or use of mental exercises (e.g. crosswords, jigsaws, puzzles etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- Writing things down (e.g. using calendar and diaries and reminders) / Keeping in conversation or re-training of the mind by being reminded about things
- Having a structured life
- Maintaining good vision and hearing (e.g. getting eye tests done, wearing glasses, getting a hearing aid if needed)
- Being taken out or changing environment

Family / Friends / Community

- Talking to your family or friends / Socialising / Keeping company or giving attention or encouragement to the person
- Becoming aware and making others aware of the Problem
- Living with the family
- Treating the person well (i.e. with love and care or respect)
- Inclusion in family, household and social activities / Investing in relationships (e.g. helping others or behaving well with others for a positive response) / Engagement in family, household and community affairs and activities

Formal social support

- Using formal support services / groups (e.g. day care centres, care homes) or talking to other people with similar problems
- Seeing the social services and professional care at home

Spiritual / Alternative care

- Praying yourself or others praying for you
- Relaxation / meditation
- Using herbal remedies
- Seeing a dietician
- Seeing alternative practitioners (e.g. acupuncture, reflexology)

Medical Bodily

Talking to your GP / nurse / Taking medication

Hospital treatment (including asking for referral and/or talking to a specialist / consultant)

Other methods / treatments (not listed above)

If any of the methods or treatments that the participant identified for the third person are not listed above, please record them here. Also remember to ask and record which ones of these were (or should be) considered and/or tried and which ones were (or would be) helpful:
