
THE IDEA STUDY DEMENTIA TRAINING FOR HEALTHCARE WORKERS 2014

Overall aim

Competence in use of the World Health Organisation flowchart to identify dementia and to advise patients and families

This will include

Knowledge of what dementia is, the importance of the condition in sub-Saharan Africa and in Tanzania and the importance of screening for dementia

Awareness that dementia is not normal ageing

Competence in screening for dementia using the IDEA study six item screen (SIDDSA)

Knowledge of common conditions that can appear to be dementia but are not dementia, and how to screen for those.

Awareness of which patients should be referred for further testing.

Awareness of carer burden and the need for advice and support for families

Knowledge and skills to correctly advise family members about dementia and management of dementia.

That there is help available for dementia through the IDEA study

Part 1

What is dementia?

Dementia is not part of normal ageing. Dementia is a syndrome due to illness of the brain. It is usually chronic and progressive in nature. The conditions that cause dementia produce changes in a person's mental ability, personality and behaviour. People with dementia commonly experience problems with memory and the skills needed to carry out everyday activities. Although it can occur at any age, it is more common in older people.

Symptoms of dementia

People with dementia often present with complaints of forgetfulness or feeling depressed. Other common symptoms include deterioration in emotional control, social behaviour or motivation. People with dementia may be totally unaware of these changes and may not seek help. Sometimes it is the family who seeks care. Family members may notice memory problems, change in personality or behaviour, confusion, wandering or incontinence. However some people with dementia and their carers may deny or minimize the severity of memory loss and associated problems. Sometimes the family may think that this is normal ageing and not realise that it is an illness.

Dementia results in decline in mental functioning and usually interferes with activities of daily living, such as shopping, cooking, washing, dressing, eating, personal hygiene and toilet activities.

How common is dementia?

In Hai – 6.4% of older people (70 and above) had dementia in 2010.

There are currently 2.1 million people with dementia in sub-Saharan Africa (2013 estimate)

By 2030, over 70% or three out of four older people in the world will live in developing countries. In sub-Saharan Africa, older people will increase by 75-90% by 2030.

More and more people will get dementia

Risk factors for dementia

High blood pressure, especially in middle age (age 40-60), especially not treated.
Previous strokes, diabetes.

Family history of dementia.

Excessive alcohol.

Low level of school education or illiteracy.

Vitamin deficiency

Relevance to Tanzania – a recent study in Hai found the prevalence of uncontrolled hypertension in older people to be more than 70%. Strokes are also very common in Tanzania. Therefore many people are at increased risk of dementia.

HIV/AIDS causes dementia, and the prevalence of HIV/AIDS is rising in older people as well. This should always be considered as a cause.

Public health programmes should advise healthy diet, encourage children to go to school as long as possible, control HIV/AIDS and encourage treatment for blood pressure in order to reduce risk of dementia

Causes or subtypes of dementia

Alzheimer's disease – most common worldwide

Vascular dementia – caused by stroke or damage to the blood vessels of the brain – usually from high blood pressure

Less common causes

Dementia with Lewy bodies and Parkinson's disease – these are very similar diseases

Frontotemporal dementia

HIV dementia should always be considered.

There are other rarer causes also

Part 2 – How to identify dementia

Identifying Dementia – General principles

To diagnose dementia – the following conditions need to be met.

Memory and another area of the brain function are affected.

AND

The problem has been there for 6 months or more, and is getting worse

AND

It is causing a problem for the person and the family – they are unable to carry out their usual activities or social relationships are affected.

IMPORTANT

There are also a few conditions which are not dementia but can appear to be dementia. It is most important to identify these as these can often be treated.

AND

Dementia cannot be diagnosed without speaking to a family member.

ASSESSMENT

Assessment of memory and cognitive functioning using simple tests

Dementia can be assessed using any locally validated tool – we recommend the IDEA study six item screen – SIDSA. This has been validated in Tanzania

General principles – assess memory, orientation to time and place and language. This means that you are testing different areas of the brain

IDEA study screening instrument for dementia

SIDSA

Preparation for ten-word list (Question 5)

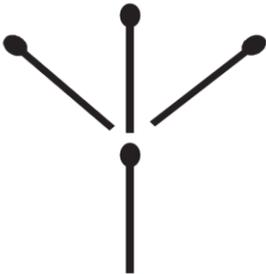
I am going to read out a list of words. Please listen carefully and I will ask you to repeat them back to me once I have finished (read out the words slowly).

First attempt: Now tell me all the words you can remember (tick on the grid the words remembered)

Second attempt: Now I will read out the words again, listen carefully and I will ask you to repeat as many as you can. Now tell me all the words you can remember (tick on the grid the words remembered)

Third attempt: Now I will read out the words one last time, listen carefully and I will ask you to repeat as many as you can. Now tell me all the words you can remember (tick on the grid the words remembered)

	First attempt	Second attempt	Third attempt
Butter (siagi)			
Arm (mkono)			
Letter (barua)			
Queen (mfalme)			
Ticket (tikiti)			
Grass (nyasi)			
Corner (kona)			
Stone (jiwe)			
Book (kitabu)			
Stick (fimbo)			

1	I will tell you the name of something and I want you to describe what it is. What is a bridge? (<i>correct answer: something that goes across a river, canyon or road</i>)	0 if incorrect 2 if correct	Score: ____/2
2	I want you to name as many different animals as you can in one minute.	Number of animals named: ____ 0 for 0-3 animals named 1 for 4-7 animals named 2 for 8 or more animals named	Score: ____/2
3	Who is the chief/head/leader of this village?	0 if incorrect 1 if correct	Score: ____/1
4	What day of the week is it?	0 if incorrect 2 if correct	Score: ____/2
5	Can you tell me the ten words we learned earlier? Try to remember as many as you can.	0 for no words remembered 1 for 1 word 2 for 2 words 3 for 3 words 4 for 4 words 5 for 5 or more words	Score: ____/5
6	Can you make the design shown below using these four matchsticks. I will show you once and then you have to copy exactly) (<i>The examiner should make the design first using the matchsticks and specifically point out to the person that the heads of the matchsticks all need to point the same way. Once the examiner has made the shape, collect up the matchsticks in a bunch and place them in front of the person being interviewed.</i>) 	Score 1 for each part of the design that is performed correctly 1 Middle two matchstick heads pointing same way 1 Outside two matchsticks pointing at an angle 1 Matchstick heads are orientated correctly	Total number of points: ____/3
A.3.10 Repeat matchstick task allowing the patient to see the design above		Score as above	Include only best of 6 and 7
		INCLUDE ONLY BEST OF 6 and 7	Total Score: ____

2.2 Interview key informant (a relative or person who knows the patient well)

Confirmation by interviewing a family member or other person who knows the person well that these problems:

1. Developed fairly recently (they have not had it for their whole life)
2. Have been getting worse AND
3. Are causing regular difficulties in carrying out daily work, domestic or social activities

What to ask –

Have there been recent changes in thinking and, memory and orientation.

Please note: Occasional memory lapses are common in older p Does the person often forget where they put things.

Do they sometimes forget what happened the day before?

Does the person sometimes forget where they are? Or names of family members?

When did these problems start?

Have they have been getting worse over time?

Are there any time periods, lasting days, weeks or longer, when thinking and memory are completely back to normal?

Problems with daily activities – this can be difficult to assess

Identifying problems with daily activities can be difficult if the family minimizes these problems, if the problems are relatively minor, or if families routinely provide extensive support and care for older people. More complex tasks such as managing a household budget, shopping or cooking tend to be affected first. Core self-care activities such as dressing, washing, feeding and toileting are only affected later.

You need to know what are the “usual activities” for older people in your area and for this particular family. Does the person make errors or take longer to carry out tasks, perform them less well, or give up activities without finishing them?

A tool that you can use to assess this area is the instrumental activities of daily living scale for Tanzania
See overleaf

IADL questionnaire Please ask these questions to the RELATIVE of the patient

For each question, please ask 'can the person do this independently, with no difficulty?'

KEY – PLEASE TICK CORRECT BOX

1. Yes, they can do it with no problems, don't need help

2. Yes with a small amount of help or assistance

3. With much assistance

4. They can't do this

1. Wanatoa Historia/**They give histories i.e. of the family, their life, past events.**

1	2	3	4

2. Wana suluhisha/**They settle conflicts.**

1	2	3	4

3. Wanasaidia shughuli ndogo ndogo/**They assist in small works in the home.**

1	2	3	4

4. Wanatoa ushauri/**They give advice.**

1	2	3	4

5. Wanadamisha na kufundisha mila/unyago/**They teach the traditions of society.**

1	2	3	4

6. Ni walinzi wa nyumbani/**They watch over the house when others are out.**

1	2	3	4

7. Wanatunza wajukuu/**they look after the grandchildren.**

1	2	3	4

8. Wanatoa ushawishi/**Persuasion, or changing people's ideas for the better.**

1	2	3	4

9. Wanasaidia katika maswala mazito kama sherehe/**They preside over feasts and ceremonies**

1	2	3	4

10. Wanapangia watu majukumu/**Delegation of responsibilities to others.**

1	2	3	4

11. Wanasimamia haki/**They fight for justice within the family and the community. They ensure fairness.**

1	2	3	4

Conditions which can mimic dementia

There are four conditions which can cause a change in behaviour for an older person

- Dementia
- Delirium
- Depression
- Psychosis

Delirium (VERY COMMON)

How to assess for delirium –

Ask a family member – ‘is this a sudden change?’

How was the person last week – is this normal for them? ‘

If they are not normally like this, suspect delirium.

Is the person physically ill – do they have fever? Could they have malaria? Do they have difficulty breathing or a cough? Do they have pain or frequency passing urine or does their urine smell strongly? Are they able to open their bowels? Do they have HIV/AIDS? An illness, especially an infection can cause delirium very easily in an old person – delirium can lead to death, and is a major risk factor for getting dementia.

It is important to treat the illness straight away – either in your clinic or by referring the person straight away.

DO NOT diagnose dementia until the illness is treated. This is NOT a psychiatric problem and should be treated by medical doctors. If the problem remains after treatment you can re-consider dementia as they may have both.

You can use this tool to assess for delirium – it has been used all over the world and it is very well validated. If the tool is positive – act quickly and find and treat the cause.

Confusion assessment method (CAM)

You need feature 1 and 2 to be present and either 3 or 4. This has very high sensitivity and specificity for delirium

		Present?
Feature 1: Acute Onset and Fluctuating Course	This feature is usually obtained from a family member or nurse and is shown by positive responses to the following questions: Is there evidence of an acute change in mental status from the patient's baseline? Does the (abnormal) behaviour fluctuate during the day; that is, does it tend to come and go, or increase and decrease in severity?	
Feature 2: Inattention	This feature is shown by a positive response to the following question: Does the patient have difficulty focusing attention; for example, is the patient easily distractible, or having difficulty keeping track of what's being said?	
Feature 3: Disorganized Thinking	This feature is shown by a positive response to the following question: Is the patient's thinking disorganized or incoherent, as evidenced by rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?	
Feature 4: Altered Level of Consciousness	This feature is shown by any answer other than "alert" to the following question: Overall, how would you rate this patient's level of consciousness? (alert [normal], vigilant [hyperalert], lethargic [drowsy, easily aroused], stuporous [difficult to arouse], or comatose [unarousable])?	

Depression (COMMON)

Depression is NOT normal sadness from time to time – this is common for everyone. The common symptoms of depression in an old person include lack of interest in activities, loss of appetite (not enjoying food), poor sleep, different body pains and tiredness. Sometimes people worry about the future and think that it will be really bad or that life is not worth living. Sometimes they worry a lot and cannot stop worrying.

Some people with depression need medication and some get better on their own. You should always check if they have thought about ending their life – although this is difficult because it is illegal. It is important as you will be able to help keep them safe – maybe with help from the family if the patient agrees.

If the person appears to have depression you should treat this first – either yourself if you are able or by referring to a mental health worker or doctor. Depression in older adults is a major risk factor for getting dementia.

Psychosis (serious mental illness – less common)

Sometimes people develop serious mental illness in old age. The person may hear things which are not there or become suspicious of their neighbours or family and begin to act strangely.

To assess for psychosis – check with the family (and by testing the patient) that memory and thinking are not affected, and that they are still able to do their daily activities. Also make sure that delirium is not present – delirium can also cause people to think strange things.

If you are not sure whether it is delirium or psychosis – refer for medical treatment. If you are not sure if it is dementia or psychosis – refer to a mental health worker.

NB visual hallucinations (seeing things which are not there) are more commonly delirium rather than psychosis.

Principles of diagnosis

Always exclude delirium first

If delirium is not present – treat as if depressed FIRST

If the person is depressed, they will recover- if not you will not harm them

If they do not have delirium and are not depressed – they could have dementia

If you are not sure, refer to a specialist

Treatable causes of dementia – these may improve with treatment

Thyroid disease – can be diagnosed by blood test and treated by a doctor

Head injury causing slow bleeding into the head

HIV/AIDS

B12 vitamin deficiency

Chronic kidney or liver disease

THE DOSE OF MEDICATION FOR AN OLDER PERSON FOR MOST MEDICATIONS IS A QUARTER OR A THIRD OF THE ADULT DOSE

How to advise the family

It is important to advise the family about dementia. This is because understanding what is happening to a family member and why their relative is acting differently is likely to reduce stress on the family. The family can be taught about the illness and that it is likely to get worse and also what to expect in the future so that they can make plans.

You may explain the following-

This is an illness – what they are doing is not their fault and is not the fault of the family. It is not caused by witchcraft or a curse. It is a disease of the brain.

Explain the symptoms – memory and thinking problems, change in behaviour, difficulty with activities.

The illness cannot be cured, but there are things that can help.

Many people have dementia and there are likely to be other neighbours with similar problems – you are not alone in this.

It can be difficult to look after a person with dementia and therefore other family members should help and you should look after your own health.

How to deal with difficult behaviour

Do not get angry with the person – they may not understand or remember why you are angry and it will make things worse.

If they repeat questions or forget what has been said – repeat it without telling them that they have forgotten – this will make them worry.

If they are not sure who someone is, or what is happening then simply remind them.

Continue to treat them as a wise person and involve them in family activities even if they cannot give advice properly. Encourage them to take part in small works in the home. This will help them to remember what is happening.

If the person accuses you of stealing or other bad things remember this is because of their memory problem – they have simply forgotten where they have put their things, or cannot understand what is happening in the home or who family members are. Do not argue with them, remind them what is happening and try to talk to them about something else so that they forget.

Remember that they may not understand instructions – keep instructions simple. Speak slowly and clearly. If they do not understand, use simpler words and shorter sentences.

Encourage the person to remain independent – if they are able to feed and wash themselves – ensure that they do so.

If they are uncooperative this is often because they do not understand that they need help – remind them and stay calm. You can distract them by talking about something else if necessary.

Show them love and affection – this will reassure them. To lose memory is frightening.

Involve them in the family routine

Feeding and eating

People with dementia often lose weight – encourage them to eat and remind or help them if necessary. Be careful with hot food as they may burn themselves. If they do not swallow well or cough when they swallow refer to a doctor – this may give them pneumonia if the food goes to their lungs. In this case always eat small amounts sitting up, and stiffer foods are best such as maize porridge.

Toileting problems

This can be a sign of severe dementia. It is part of the illness – the person has forgotten how to use the toilet or to know that they need the toilet. It is important to remind them and assist them to do this. It can help to take them to the toilet at regular times to make a routine, especially before bed. They should not have wet clothes because this can damage the skin. Special pads can be bought which can help with this problem.

Getting lost

If the person cannot find their way back to the home it is best to have someone nearby who can watch for them leaving the house and either walk with them or encourage them to come back. It can also help to tell the neighbours that this might happen so they can help the person with dementia go back home.

This training pack is based on the World Health Organisation dementia intervention guide, Alzheimers disease international dementia training resources and 'where there is no psychiatrist – a mental health care manual' by Vikram Patel. All of these sources have been adapted for the project by the IDEA study team

