KICA-caregiver Form-Phase 3

PID_____ Who is being discussed _____

Sex: ☐ Male ☐ Female

Community_____ Date of the Interview_____

Interviewer's Name_____

Language used for interview: ☐Tsimane ☐Castellano ☐ Other _____

Name of family informant_____ Code _____

Does the informant live in the same house as the person being evaluated? ☐Yes ☐ No

How long has the informant known the patient ? _____

Other participants in the interview (apart from the interviewer and informant)

a) _____ Code _____ c)_____ Code _____
b) _____ Code _____

Is [the patient] deceased? ☐Yes ☐ No

If deceased, when did [the patient] die? _____

Place of interview: ☐House of patient being evaluated ☐Mobile clinic ☐Office ☐School ☐Church

☐other _____

Introduction: *The interviewer should inform the family member about the diseases of aging and especially about changes in memory [Note to interviewer: You do not need to get an example of every change. Get some examples, and try to learn how frequently there are problems and how many different problems there are. Focus on persistent problems, not something that happened only once a long time ago. When the changes began, how gradually or suddenly changes were noticed, and whether changes interfere with daily living when asking for examples are especially important.] IF THE PATIENT HAS DIED, ASK QUESTIONS 1- 8, 9, 19-22, 24-31 CONCERNING HOW THE PATIENT WAS DURING LAST APPROXIMATELY 6 MONTHS OF LIFE .*

Does [the patient] have problems hearing?
a) without problems, b) mild problems, c) severe problems, d) deafness
If problems, describe when began and when became severe.
_____

Does [the patient] have problems seeing?
a) without problems, b) mild problems, c) severe problems, d) blindness
If problems, describe when began and when became severe.
_____

Memory

1. Have you noticed that [patient's name] forgets many things a lot of the time?

Kika

a. Never or rarely (0)

If the answer is Yes, then ask if this happens:

b. Sometimes (1)

c. Very often or always (2)

If the answer is b or c, then describe the problem.

_____

_____

Since our last visit, has [the patient's] memory gotten worse?

a) Yes; b) No c) This is the first interview about this patient

If yes, describe what has changed

_____

2. Is [patient name] forgetting the names of family members?

Kika

a. Never or rarely (0)

If the answer is Yes, then ask if this happens:

b. Sometimes (1)

c. Consistently (2)

If the answer is b or c, then describe the problem .

_____

_____

Since our last visit, is [the patient] forgetting names of family members more often?

a) Yes; b) No c) This is the first interview about this patient

If yes, describe what has changed

_____

3. Does [patient name] forget what happened the day before? Like events that recently happened? Will s/he remember tomorrow we've been here?

Kika Bless

a. Never or rarely (0)

If the answer is Yes, then ask if this happens:

b. Sometimes (1)

c. Consistently (2)

If the answer is b or c, then describe the problem.

_____

_____

Since our last visit, is [the patient] forgetting things that have happened more often?

a) Yes; b) No c) This is the first interview about this patient

If yes, describe what has changed

_____

4. Does [patient name] ever get confused where s/he is?
   a. Never or rarely (0)

Kika Bless

If the answer is Yes, then ask if this happens:
   b. Sometimes (1)
   c.Consistently (2)

If the answer is b or c, then describe the problem.

_____

_____

Since our last visit, does [the patient] get confused where he is more often?
   a) Yes; b) No c) This is the first interview about this patient

If yes, describe what has changed

_____

5. Does [patient name] repeat what s/he said, forgetting that s/he said it before?
   a. Never or rarely (0)

Kika

If the answer is Yes, then ask if this happens:
   b. Sometimes (1)
   c. Consistently (2)

If the answer is b or c, then describe the problem.

_____

_____

Since our last visit, is [the patient] repeating himself more often?
   a) Yes; b) No c) This is the first interview about this patient

If yes, describe what has changed

_____

6. Does [patient name] remember when to collect BONOSOL (monthly social security allotment)?
   a. Yes (0)

Kika

If the answer is No, then ask if this happens:
   b. Forgets sometimes (1)
   c. Never or rarely remembers (2)
   d. patient does not receive BONOSOL (999)

_____

_____

7. Does [patient name] get lost when walking to familiar places or visiting homes of family members?

Kika Bless

a. Never or rarely (0)

If the answer is Yes, then ask if this happens:

b. Sometimes (1)

c. Consistently (2)

If the answer is b or c, then describe the problem.

_____

_____

Since our last visit, is [the patient] getting lost more often when walking to familiar places or home of family members?

a) Yes; b) No c) This is the first interview about this patient

If yes, describe what has changed

_____

8. Does [patient's name] behave in ways that look crazy?

Kika

a. Never or rarely (0)

If the answer is Yes, then ask if this happens:

b. Sometimes (1)

c. Consistently (2)

If the answer is b or c, then describe the problem.

_____

_____

Since our last visit, does [the patient] more often behave in ways that look crazy?

a) Yes; b) No c) This is the first interview about this patient

If yes, describe what has changed

_____

KICA-CAREGIVER TOTAL SCORE *(TOTAL NUMBER OF POINTS ON ITEMS 1–8).*: _____ / **16**

9. Would s/he be able to remember to bring you three unrelated objects? (If you asked for a machete, a bucket and a bit of rope)?

Bless

a. Yes (0)

If the answer is No, then ask if this happens:

b. Would forget some of the time (1)

c. Would forget most of the time (2)

If the answer is only sometimes or rarely, then ask for a recent example of forgetting a list of items, including what happened and when it happened.

_____

_____

10. Does s/he forget an important event completely after 1 week (e.g., trip, party, or family visit)?
    a. Never or rarely (0)
    If the answer is Yes, then ask if this happens:
    b. Sometimes (1)
    c. Consistently (2)
    If the answer is b or c, then describe the problem.

    _____
    _____

11. Does s/he completely forget important information from the past (e.g., birthplace, births of children, floods)?
    a. Never or rarely (0)
    If the answer is Yes, then ask if this happens:
    b. Sometimes (1)
    c. Consistently (2)
    If the answer is b or c, then describe the problem.

    _____
    _____

12. Does [patient name] forget where s/he put things like an identity card, knife, fan?
    a. Never or rarely (0)
    If the answer is Yes, then ask if this happens:
    b. Sometimes (1)
    c. Consistently (2)
    If the answer is b or c, then describe the problem.

    _____
    _____

13. Does [patient name] have trouble finding words?
    a. Never or rarely (0)
    If the answer is Yes, then ask if this happens:
    b. Sometimes (1)
    c. Consistently (2)

14. Does [patient name] forget debts or favors owed to others?
    a. Never or rarely (0)
    If the answer is Yes, then ask if this happens:
    b. Sometimes (1)
    c. Consistently (2)
    If the answer is b or c, then describe the problem .

    _____
    _____

N.1. Can [patient name] read?

a. Well
b. To some extent
c. Cannot read now, but could when younger
d. Never learned to read

N.2. Can [patient's name] write?

a. Well
b. To some extent
c. Cannot write now, but could when younger
d. Never learned to write

N.3. Can [patient's name] count?

a. Well
b. To some extent
c. Cannot count now, but could when younger
d. Never learned to count

Orientation:

15. Does [patient name] know what year we are in? ☐Yes ☐ No

The year exactly?

a. Very often (0)
b. Sometimes (1)
c. Rarely (2)
d. Does not know (3)
e. Knew when younger (4)

16. Does [patient's name] know what month of the year we are in? ☐Yes ☐ No

The Month exactly?

a. Very often (0)
b. Sometimes (1)
c. Rarely (2)
d. Does not know (3)
e. Knew when younger (4)

17. Does [patient's name] know what day of the week it is? ☐Yes ☐ No

The day of the week exactly?

a. Very often (0)
b. Sometimes (1)
c. Rarely (2)
d. Does not know (3)
e. Knew when younger (4)

18. Does [patient's name] know what date it is? ☐Yes ☐ No
The date of the month exactly?
   a. Very often (0)
   b. Sometimes (1)
   c. Rarely (2)
   d. Does not know (3)
   e. Knew when younger (4)

19. How often does [the patient] think s/he is in the past?
   a. Very often (2)
   b. Sometimes (1)
   c. Hardly ever (0)
   d. Do not know
   Include details:

Bless ☐

_____
_____

Judgment and Problem solving

20. Rate his/her ability to handle money (e.g., make change, count)
   a. No loss (0)
   b. Some loss (1)
   c. Severe loss (2)
   d. Never could/never did (9)

Bless ☐

21. If s/he were alone, could s/he handle situations in the home (for example, how to care for a small child)
   a. As well as before (0)
   b. Worse than before due of problems thinking (1)
   c. Worse than before, another reason (2) Reason: _____

Community Activities

22. Can s/he understand what people talk about at community meetings and explain it to other people?
   a. Very often (0)
   b. Sometimes(1)
   c. Rarely (2)
   d. I do not Know (9)

Bless ☐

If s/he does not attend community meetings, does s/he understands if someone explains what was said at the meeting?
Yes (0)
No (1)

23. S/he is able to go outside the home alone to do social activities such as visiting the family, shopping, or going to church?
   a. As well as before (0)
   b. Worse than before due to problems thinking (1)
   c. Worse than before for another reason (2)
   Include details and try to explain the contribution of cognitive decline.

_____
_____

Home and hobbies

I would like to ask you questions about what tasks [Patient's name] can do for himself, that is, without help from others. *[Note to interviewer: Ask for details if any activity can no longer be performed, ask for a possible reason and from when he stopped performing the activity and if it was gradual. This is to recognize whether non-performance of activities is related to dementia or cognitive problems or not.]*

23.5 What are the regular activities that [the participant] did during the past week?

_____

_____

a. Are there changes in activities compared to 5 years ago?
No____ Little____ a lot____

b. What has changed? _____

_____

c. [If there are changes] Do you think those changes in activities are due to a cognitive/memory problem or a physical problem or both ?

Physical ____ ***Cognitive/Memory***____ ***Physical & Cognitive/Memory***____
Other_____

24. Can [patient's name] continue doing household chores as before (cooking, making fire, etc.)?
    a. Yes, as good as ever
    b. With difficulty, not as good as before
    c. Poor, not able

Bless ☐

If changes, is this because of a cognitive/memory issue, or is it a physical problem?

Physical ____ ***Cognitive/Memory***____ ***Physical & Cognitive/Memory***____
Other_____

Interviewer request examples of activities where there have been changes (making a bed, serving a meal, cleaning, preparing a meal) and the nature of those changes.

_____

25. Can [patient name] fish as before?
    a. Yes, as good as ever
    b. With difficulty, not as good as before
    c. Poor, not able
    d. It is not part of their lifestyle

If changes, is this because of a cognitive/memory issue, or is it a physical problem?
Physical ____ ***Cognitive/Memory***____ ***Physical & Cognitive/Memory***____
Other_____
Examples:

_____

26. (If he is a man) Can he hunt as before?
   a. Yes, as good as ever
   b. With difficulty, not as good as before
   c. Poor, not able
   d. It is not part of his lifestyle

   If changes, is this because of a cognitive/memory issue, or is it a physical problem?
   Physical _____ ***Cognitive/Memory***_____ ***Physical & Cognitive/Memory***_____
   Other_____
   Examples:
   _____

27. (If she is a woman) Can she still weave as before?
   a. Yes, as good as ever
   b. With difficulty, not as good as before
   c. Poor, not able
   d. It is not part of their lifestyle

   If changes, is this because of a cognitive/memory issue, or is it a physical problem?
   Physical _____ ***Cognitive/Memory***_____ ***Physical & Cognitive/Memory***_____
   Other_____
   Examples:
   _____

27a. (If she is a woman) Can she still sew as before?
   a. Yes, as good as ever
   b. With difficulty, not as good as before
   c. Poor, not able
   d. It is not part of their lifestyle

   If changes, is this because of a cognitive/memory issue, or is it a physical problem?
   Physical _____ ***Cognitive/Memory***_____ ***Physical & Cognitive/Memory***_____
   Other_____
   Examples:
   _____

28. Can [patient's name] continue to work on his farm as before?

   a. Yes, as good as ever
   b. With difficulty, not as good as before
   c. Poor, not able
   d. It is not part of their lifestyle

   If changes, is this because of a cognitive/memory issue, or is it a physical problem?
   Physical _____ ***Cognitive/Memory***_____ ***Physical & Cognitive/Memory***_____
   Other_____
   Examples:
   _____

Personal Care Questions for Informant:

Here are more questions about what [patient's name] can do for himself. *Interviewer ask for examples and rate severity from 0 to 3.*

Bless ☐

29. Does [patient] need help getting dressed?
    a. Never (0)
    b. Sometimes (1)
    c. Much of the time (2)
    d. Always (3)

Bless ☐

30. Does [patient name] forget to bathe?
    a. Never (0)
    b. Sometimes (1)
    c. Much of the time (2)
    d. Always (3)

Bless ☐

31. Does [patient name] have urinary or fecal incontinence?
    a. Hardly ever (0)
    b. Occasionally wets bed (1)
    c. Frequently wets bed (2)
    d. Doubly incontinent (3)

Summary

32. How long ago did you first notice the changes in [the patient's] memory or thinking? Interviewer use birth of patient's grandchildren or other markers.]

_____
_____
_____

33. Which of these changes happened since we last visited?

_____
_____
_____

34. Were these changes slow or fast? ? ☐ No Change ☐ Slow ☐ Fast

35. Does memory or the patient's thinking problem interfere with their ability to perform everyday activities that they would normally do? ☐Yes ☐ No

Comments

_____
_____
_____
_____

II. Report of Informant on relative's informant behavior or mood:

For all these questions, ask for details, such as what happened, when it happened. If it happened many times? Use the following list of options to answer the questions:
1) Always or most of the time; 2) Sometimes; 3) Rarely or 4) never

1. Is [name] satisfied with his life most of the time _____

2. Is [name] sad for no reason? _____
   If yes: is this different from before? _____

3. Does [name] have difficulty falling asleep or wake up at night and cannot go back to sleep (excluding physical problems)? _____
   If yes: is this different from before? _____

4. Has the patient lost his appetite? _____

5. Does the patient cry for no reason? _____
   If yes: is this different from before? _____

6. Does [the patient] see things that are not really there? _____
   If yes: is this different from before? _____

7. Does [the patient] hear things that are not really there? _____
   If yes: is this different from before? _____

8. How is the participant's way of being with family, friends and the rest of the people with whom he/she interacts now compared to how it was before?
   _____
   _____

   a) When did you begin to notice the changes? _____
   b) Were the changes were small or large? □ Small □ Medium □ Large

   c) What has changed?
   _____

   d) Is it due to a physical problem, problems with cognition/memory, or both?
   Physical _____ ***Cognitive/Memory***_____ ***Physical & Cognitive/Memory***_____
   Other_____

   If the answer was that there were changes, then ask for details such as what has changed, and examples of the change, including when it happened?

   _____

Informant Report Rating by Interviewer

36. During the survey the interviewee was:
    a. Very interested and motivated to respond to questions, required little insistence of the interviewer (1)
    b. Somewhat interested and motivated, required some insistence (2)
    c. Not very interested or motivated; seemed reluctant to answer questions or gave little thought (3)
    d. The informant understood little (4)

37. With respect to accuracy of the information provided by the informant:
    a. There is no reason to doubt accuracy, the informant understood everything, showed no inconsistency (1)
    b. The informant lacked a complete understanding, but showed no inconsistency (2)
    c. The informant lacked total comprehension and showed inconsistency (3)
    d. The informant understood little (4)
    e. Other:_____

38. Do you believe that the information provided by the informant is reliable or believeable?

_____

39. Does the interviewer think there has been a change in the patient since the last interview (personality, cognition, behavior, mood, physical function)?

_____

References

KIKA

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Morris JC. The Clinical Dementia Rating (CDR): current version and scoring rules. Neurology. 1993;43(11):2412-2414.