The Family Confusion Assessment Method (FAM-CAM) Instrument and Training Manual

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BACKGROUND

Delirium (acute confusional state) is a common, serious, and potentially preventable source of morbidity and mortality for older hospitalized patients. Delirium has assumed particular importance because patients over 65 years currently account for more than 48% of all days of hospital care. Currently, delirium occurs in 25-60% of older hospitalized patients, with associated mortality rates of 25-33%. Based on 1994 U.S. vital health statistics, each year delirium complicates hospital stays for over 2.3 million older persons, involving over 17.5 million inpatient days, and accounting for over 8 billion dollars of Medicare expenditures each year. Substantial additional costs accrue following hospital discharge because of the increased need for institutionalization, rehabilitation, and home care.

The Confusion Assessment Method (CAM) was originally developed in 1988, to improve the identification and recognition of delirium. The CAM was intended to provide a new standardized method to enable non-psychiatrically trained clinicians to identify delirium quickly and accurately in both clinical and research settings. Since its development, the CAM has become widely used because of its sensitivity and ease of use. When validated against the reference standard ratings of geriatric psychiatrists based on comprehensive psychiatric assessment, the CAM had a sensitivity of 94-100%, specificity of 90-95%, and high inter-observer reliability in the original study of 56 patients (*Inouye, 1990*). More recently this work has been extended (*Wei, 2008*), and in 7 high-quality validation studies on over 1,000 subjects, the CAM had a sensitivity of 94% (95% CI 91-97%) and specificity of 89% (95% CI 85-94%).

Most delirium assessments, including the CAM, rely on in-person, potentially time-intensive bedside assessments by clinically trained staff. The Family-CAM (FAM-CAM) was originally developed in 1988, based on the CAM, to provide a method for informant-based assessment of delirium to determine study eligibility for a largescale prospective cohort. The FAM-CAM may be administered to a caregiver either in person, on the telephone, or electronically, and allows for delirium assessment across a wide range of settings. The FAM-CAM should NOT be used as an independent diagnostic instrument; it is designed to be used in conjunction with or confirmed by expert clinicians or trained delirium assessors using the CAM. A positive result on the FAM-CAM should be followed by further assessment of the patient, which includes cognitive testing and a formal delirium rating.

In a preliminary study, when validated against the CAM, the FAM-CAM had a sensitivity of 86% and a specificity of 98% in a study of 58 caregiver/care recipient dyads (*Steis 2012*). Future work is needed to further validate these results. We encourage such work in larger samples, against reference standard ratings for delirium.

The FAM-CAM may hold many potential applications in both clinical and research settings. The instrument may be useful to facilitate and educate caregivers to pick up acute changes in mental status, and the earliest signs of cognitive changes in frail or cognitively impaired older persons. The instrument may also allow extension to settings where delirium cannot be readily assessed by healthcare providers. The instrument can be useful to assess the presence of delirium at the time of admission to a clinical setting such as hospital, ICU, pre- or post-surgery, post-hospital discharge, or extended care settings.

This manual includes the FAM-CAM instrument as well as training and scoring instructions.

Recommended Training Procedure
Research and Clinical Staff

We suggest that the staff become familiar with the Confusion Assessment Method before training themselves in the FAM-CAM. Information on the CAM can be found at the HELP website: <www.hospitalelderlifeprogram.org>. We recommend the following procedure to train clinicians and research staff on the use of the FAM-CAM.

1. Read this manual and review with either someone who is familiar with use of the FAM-CAM or with an expert delirium assessor, either a healthcare provider with expertise in delirium (e.g., geriatrics, psychiatry, neurology, neuropsychology), or trained delirium assessor.
2. With observation by the expert assessor, conduct pilot interviews with caregivers/informants for delirious and non-delirious patients. Discuss ratings and cover any elements where discrepancies in ratings occurred between expert rater and trainee.
3. For research purposes: To assure reliability of assessments if more than one interviewer will utilize the FAM-CAM, trained interviewers should interview caregivers/informants in pairs and assess their inter-rater reliability. Ratings should be compared after completion, and any discrepancies in ratings discussed and resolved. To be considered fully standardized, a minimum of 5 delirious and 5 non-delirious patients should be rated (the raters must be blinded to the true delirium status of the patient).

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Family Confusion Assessment Method (FAM-CAM)

For Research and Clinical Staff

Evaluator:

Caregiver/Informant: **Date:**

Patient: **Time:**

[Screening for an appropriate caregiver is recommended: See Instructions]

Circle the answer to each question

These questions are intended to identify changes to [family member's name] thinking, concentration, and alertness during recent days. Please stop me at any time if you do not understand the questions.

Question			
1. I'd like you to think about the past [month/week/day]*. During this [month/week/day]*, have you noticed any changes in his/her thinking or concentration, such as being less attentive, appearing confused or disoriented (not knowing where he/she was), behaving inappropriately, or being extremely sleepy all day?	Yes	No	Don't Know

* Adjust time frame as appropriate for your purposes

Question			
2. Did he/she have difficulty focusing attention, for example, being easily distracted or having trouble keeping track of what you were saying at any time?	Yes	No	Don't Know
3. Was his/her speech disorganized, incoherent, rambling, unclear, or illogical at any time?	Yes	No	Don't Know
4. Did he/she seem excessively drowsy or sleepy during the daytime at any time?	Yes	No	Don't Know
5. Was he/she disoriented, for example, thinking he/she was somewhere other than where he/she was, or misjudging the time of day at any time?	Yes	No	Don't Know
6. Did he/she seem to see or hear things which weren't actually present, or seem to mistake what he/she saw or heard for something else at any time?	Yes	No	Don't Know
7. Did he/she behave inappropriately, such as wandering, yelling out, or being combative or agitated at any time?	Yes	No	Don't Know

8. Please tell us more about the changes you noticed in any of the behaviors in #1-7 above. *Record as much detail as possible*

____

Question				
9. Were any of the changes (#1-7) present all the time, or did they come and go from day to day?	All the time	Come and go	Don't know	
10. When did these changes first begin? Would you say they began:	Within the last week Between 1 and up to 2 weeks ago Between 2 and up to 4 weeks ago More than 4 weeks ago			
11. Overall, have these changes been getting better, worse, or staying about the same?	Better	Worse	About the Same	Don't Know

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Item-by-Item Training Instructions

General Guidelines: The FAM-CAM is intended to evaluate for evidence of delirium based on observations from family members or caregivers. Throughout the interview, you may need to repeatedly clarify that you are asking about recent, new, or sudden changes ONLY—behavior that is part of a longstanding pattern should not be included as evidence of delirium. Delirium presents with an acute onset, over the course of hours to days.

Choice of Caregiver to Interview: An important aspect of this interview is to choose an appropriate caregiver who knows the patient well. A variety of screening methods are available. We recommend using the following hierarchy (in descending order): (1) lives with the patient; (2) sees the patient at least once a month (with regular phone contact in between) and knows patient well enough to report on his/her mental and physical abilities. If the proxy does not meet these criteria, then we seek another proxy-reporter. Although they are not formal components of the FAM-CAM, you may wish to collect information about the caregiver characteristics (e.g., demographics, relationship to patient, etc) and contact with patient (e.g., frequency) according to your needs.

These training instructions will provide item-by-item guidance for the FAM-CAM instrument

1. Now, I'd like you to think about the past [month/week/day]. During this [month/week/day], have you noticed any changes in her/her thinking or concentration, such as being less attentive, appearing confused or disoriented (not knowing where he/she was), behaving inappropriately, or being extremely sleepy all day?

This question is intended to identify the acute onset of symptoms. Remember to emphasize to the informant that this question asks about recent, acute changes. An acute change in mental status is defined as alteration in mental status (e.g., attention, orientation, cognition) that was new or worse, usually over hours or days. For example, if the informant reports that the patient is confused all the time but that behavior developed slowly and has been present over a long period of time, it would be coded as a 'no' for this question.

Timeframe or Look-back Period for Caregiver: The FAM-CAM can be adjusted to cover a varying time frame depending on the reasons for your assessment, or the needs of your study or clinical use. A one-month look-back is the maximum time-period recommended due to problems with recall of acute changes beyond this period. However, different timeframes can be chosen. For instance, when interviewing a caregiver in the hospital while the patient is admitted as an inpatient, it may make sense to ask about the last day or week. At a follow-up visit, you might ask about the past week or month. If you are doing serial FAM-CAM assessments, then you should record changes from the PREVIOUS assessment. Whichever time frame you inquire about should be clearly recorded.

Questions 2-7

General Instructions: Indicate only one response for each question. If informant indicates a yes to any question, let them know they will be asked for further information about that/those item(s) If the informant indicates they cannot remember, code DK (don't know), BUT first remind them "I know it may be hard to remember, I just want your best recollection" and wait a quiet moment for the respondent to offer a response.

2. Did he/she have difficulty focusing attention, for example, being easily distracted or having trouble keeping track of what you were saying at any time?

This question looks for INATTENTION—that is, reduced ability to maintain attention to external stimuli and to appropriately shift attention to new external stimuli. The patient would seem unaware or out-of-touch with the environment (dazed, fixated, or darting attention). Questions to the patient may need to be repeated, and it may be difficult to establish back-and-forth communication.

For all these questions, the behavior must reflect a change from their usual or normal (baseline) state.

3. Was his/her speech disorganized, incoherent, rambling, unclear, or illogical at any time? [Prompt: Did his/her speech relay thoughts that make sense?]

This question is intended to determine whether the patient is making sense or not. Disorganization of thought as reflected in the content of the patient's speech must be present, and can include rambling or irrelevant conversation, words that do not make sense, an illogical flow of ideas, or unpredictable switching from subject to subject (very difficult to follow the patient's train of thought). Mumbling alone should not be scored as a positive response to this question. Prompt the caregiver to verify that this is a change from their usual or normal state.

4. Did he/she seem excessively drowsy or sleepy during the daytime at any time?

Older persons may have more daytime drowsiness/sleepiness or take naps. To be scored positive on this item, the patient must demonstrate sleepiness that would be considered well outside the range of normal for this patient--the patient should be truly lethargic. Clarify that this sleepiness represents a change from their usual or normal state.

5. Was he/she disoriented, for example, thinking he/she was somewhere other than where he/she was, or misjudging the time of day at any time?

Disorientation is defined as impaired ability to locate oneself in one's environment, in reference to time, place, or person. Common manifestations of disorientation include that the patient does not know where he/she is (thinking they are at home instead of hospital), thinks it is night during the day, or thinks you are someone else. Prompt the caregiver to verify that this is a change from their usual or normal state.

6. Did he/she seem to see or hear things which weren't actually present, or seem to mistake what he/she saw or heard for something else at any time?

This question is intended to assess for the presence of perceptual disturbances such as visual or auditory hallucinations, misinterpretations, and illusions. Illusions and misinterpretations arise from a false impression of an actual stimulus (for example, seeing a pile of laundry and thinking a person is sitting there). With hallucinations, there is no stimulus (such as a patient seeing his wife in the room when no one was there). Patients can also misinterpret sounds (or hear voices). Complex perceptual disturbances, such as dream-like states or paranoid delusional interpretations should also be recorded here. Prompt the caregiver to verify that this is a change from their usual or normal state.

7. Did he/she behave inappropriately, such as wandering, yelling out, or being combative or agitated at any time?

This question is intended to assess behavior that would be considered socially inappropriate, indicating confusion or loss of inhibition. These should be behaviors that would not be considered normal or usual for this patient. Keep in mind that older persons can demonstrate odd or eccentric behavior at times, and the observed behavior should be beyond the spectrum of what would be considered normal in older adults. Some examples would include loud yelling or swearing; combative or violent behavior; wandering or getting lost; inappropriate sexual behavior; urinating in trash cans; loss of usual modesty (disrobing in public); etc.

8. Please tell me more about the changes you noticed.

Ask the informant to tell more about the change he/she notices and write the answers in the space provided. Record in a precise and detailed manner. Include direct quotes, notes about fluctuating course (if the patient had periods of lucidity before becoming confused again), and specific behaviors. This question should elaborate and expand on any 'yes' answers in questions 2-7, not simply reiterate the 'yes' answer.

If a respondent answers yes to any of the questions 2-7, go to question 9.

9. Were these problems present all the time, or did they come and go from day to day?

Probe about times when behaviors of symptoms are better or worse, or are they consistently present?

10. When did the worsening first begin? Would you say it began:

Ask the informant to identify the earliest onset of symptoms. Circle the timeframe indicated by the informant.

11. Overall, have these changes been getting better, worse, or staying about the same?

The purpose of this question is to ask the informant about the clinical course. Realizing that symptoms may fluctuate, ask informant whether the patient has been MOSTLY getting better, worse, or staying about the same. If uncertain, please write down notes verbatim.

Scoring the FAM-CAM

It is important to remember that the FAM-CAM is intended only to assist with screening and is not intended to provide a clinical diagnosis. If a positive score is suggested on the FAM-CAM, further evaluation with cognitive testing of the patient is necessary.

The FAM-CAM is considered positive if the following features are present: a) acute onset or fluctuating course **and** b) inattention **and** c) either disorganized thinking or altered consciousness. Several of the questions may help to identify whether these features are present, as outlined below.

Feature	Question #	Positive Answer
Acute Onset	Question 1,10	Yes, <4 weeks ago
-OR-		
Fluctuation	Question 9	"Come and go"
-AND-		
Inattention	Question 2	Yes
-AND EITHER-		
Disorganized Thinking	Question 3,5,6 (7 supportive)	Yes
-OR-		
Altered Consciousness	Question 4	Yes

Scoring Algorithm: Check the box if the respondent's answer is as indicated.
Delirium is suggested if there is **at least one check in each of the 3 columns.**

Question	**Column 1** Acute Onset or Fluctuation	**Column 2** Inattention	**Column 3** Disorganized Thinking or Altered Level of Consciousness
Question 1 = yes? (Any Change)	☐		
Question 2 = yes? (Inattention)		☐	
Question 3 = yes? (Disorganized Speech)			☐
Question 4 = yes? (Excess Drowsiness)			☐
Question 5 = yes? (Disorientation)			☐
Question 6 = yes? (Perceptual Disturbance)			☐
Question 9 = "come and go"? (Fluctuation)	☐		
Question 10 = <4 weeks? (Acute Onset)	☐		

Delirium is suggested if there is **at least one check in each of the 3 columns.**

Delirium Suggested? ________ yes ________ no

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Recommended Training Procedure & Instructions for Caregivers Participating in Research Studies

For some research studies, it may be necessary for family caregivers to complete the FAM-CAM on a daily or repeated basis. Instructions for training caregivers and a caregiver-friendly worksheet are provided below.

1. Provide general education on delirium and its significance.
2. Explain that family caregiver input is valuable as they know the subtle nuances of the patient better than most others.
3. Explain that although family caregiver input is valuable, diagnosis of delirium will not be determined based solely on their answers to these questions. The purpose of soliciting their input is to attempt to recognize the development of delirium as early as possible, and to bring the patient to medical attention when appropriate.
4. Review each question and answer their questions to prepare the family caregivers to answer the questions independently.
5. Encourage use of the text box to describe observed changes and/or to elaborate on observations that they are not sure are relevant to report or not.
6. After initial training, have paired observations with family caregivers and expert trainers to make sure the family caregivers understand how to score the instrument. Reinstruct the caregiver for any discrepancies observed.

Family Confusion Assessment Method

FAM-CAM

For Caregivers

Thank you for participating in this research study. Please fill out the following questionnaire regarding your friend or relative's thinking and concentration. Think about his or her behavior in the past few days and circle the answer to each question.

Caregiver's Name: **Date:**

Patient's name: **Time:**

Circle the answer to each question

Question			
1. During the past few days, have you noticed any changes in your friend or relative's thinking or concentration, such as being less attentive, appearing confused or disoriented (not knowing where he/she was), behaving inappropriately, or being extremely sleepy all day?	Yes	No	Don't Know
2. Did he/she have difficulty focusing attention, for example, being easily distracted or having trouble keeping track of what you were saying at any time?	Yes	No	Don't Know
3. Was his/her speech disorganized, incoherent, rambling, unclear, or illogical at any time?	Yes	No	Don't Know
4. Did he/she seem excessively drowsy or sleepy during the daytime at any time?	Yes	No	Don't Know
5. Was he/she disoriented, for example, thinking he/she was somewhere other than where he/she was, or misjudging the time of day at any time?	Yes	No	Don't Know

6. Did he/she seem to see or hear things which weren't actually present, or seem to mistake what he/she saw or heard for something else at any time? — Yes / No / Don't Know

7. Did he/she behave inappropriately, such as wandering, yelling out, or being combative or agitated at any time? — Yes / No / Don't Know

8. Please tell us more about the changes you noticed in any of the behaviors from questions 1-7 above:
   Please write down as much detail as possible

____
____
____
____
____
____
____
____
____
____

9. Were these changes (questions 1-7) present all the time, or did they come and go from day to day? — All the time / Come and go / Don't know

10. When did these changes first begin? Would you say they began:
    - Within the last week
    - Between 1 and 2 weeks ago
    - Between 2 and 4 weeks ago
    - More than 4 weeks ago

11. Overall, have these changes been getting better, worse, or staying about the same? — Better / Worse / About the Same / Don't Know

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Training Instructions for Caregivers

If you are not sure of how to answer the questions, please refer to this sheet for guidance.

Question 1
During the past few days, have you noticed any changes in your friend or relative's thinking or concentration, such as being less attentive, appearing confused or disoriented (not knowing where he/she was), behaving inappropriately, or being extremely sleepy all day?

- This question is asking about a new change in behavior. Is your friend or relative confused? Do they not know what time of day it is? Have they started acting out or fighting? Are they sleeping during the day when they did not do that before?
- An example would be if your friend or relative suddenly does not make sense at times when talking to you.
- Answer 'yes' if you have seen these changes mainly in the past few hours to days. These problems should be NEW (within the past few days). If they have been problems for many months, answer NO.

Question 2
2. Did he/she have difficulty focusing attention, for example, being easily distracted or having trouble keeping track of what you were saying at any time?

- The answer to this question is 'YES' if your friend or relative cannot pay attention to you. Is he or she out of touch with the environment?
- An example of this would be needing to repeat questions several times.
- Again, these problems should be NEW behavior.

Question 3
3. Was his/her speech disorganized, incoherent, rambling, unclear, or illogical at any time?

- Answer this question with a 'YES' if your friend or relative's thoughts are confused and hard to follow. This might include rambling or unrelated speech, words that do not make sense, illogical ideas, and unpredictable switching from subject to subject. It might be very difficult to follow his or her thoughts.
- For example, you ask your friend or relative if they need help with eating, and the response is: "Let's go get the sailor suits!"
- Again, this behavior must be NEW for the answer to be 'yes'.
- The answer would be NO if the unclear speech is due to mumbling or a physical problem.

Question 4
4. Did he/she seem *excessively* drowsy or sleepy during the daytime at any time?

- Many older people are sleepy in the daytime. This question should only be answered 'yes' if this sleepiness is excessive or too much for your friend or relative. This question asks if there has been a new change.
- If it is normal for your friend or relative to sleep during the daytime, then answer NO.

Question 5
5. Was he/she disoriented, for example, thinking he/she was somewhere other than where he/she was, or misjudging the time of day at any time?

- Disorientation means being confused about times, places, and people.
- An example of being confused about time is if they think it is day when it is night.
- An example of being confused about places is if they think they are in a hospital when they are really at home.
- An example of being confused about people would be seeing their sister and thinking she is their mother.

Question 6
6. Did he/she seem to see or hear things which weren't actually present, or seem to mistake what he/she saw or heard for something else at any time?

- This question asks about making mistakes about what you see and hear. You should answer yes if your friend or relative sees or hears things that are not there, or makes mistakes about what they see or hear.
- For example, if someone sees a pile of laundry and thinks it is a person. Another example could be hearing church bells ringing when there is no sound or hearing voices when no one is there.

Question 7
7. Did he/she behave inappropriately, such as wandering, yelling out, or being combative or agitated at any time?

- This question asks about behavior that breaks normal rules.
- Only answer 'YES' if there are new behaviors. Behaviors that started a long time ago do not count.

- Some examples include loud yelling, swearing, or violent behavior. Other examples include wandering and getting lost, inappropriate sexual behavior, urinating in trash cans, and taking clothes off in public.

Question 8
8. Please tell me more about the changes you noticed in Questions 1-7.

- Please describe any changes you noticed. Be specific. For example, if your friend or relative thought that spiders were crawling on the ceiling when they were not, write down "thought spiders were crawling on the ceiling", not just "saw things that were not there".
- Be sure to include changes you have noticed; many people will be better for short periods of time but get worse again. These changes are important to note.

Question 9.
9. Were these changes (from Questions 1-7) present all the time, or did they come and go from day to day?

For any behaviors reported in Questions 1-7, are they present all the time? Or are they worse at some days and times?

Question 10
10. When did these changes first begin? Would you say they began:

What is the earliest time you first noticed the new behaviors?

Question 11
11. Overall, have these changes been getting better, worse, or staying about the same?

Many of these behaviors may change over time. For this question, answer whether or not your friend or relative has been MOSTLY getting better, worse, or staying about the same.

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