



Screening for Delirium Using Family Caregivers: Convergent Validity of the Family Confusion Assessment Method and Interviewer-Rated Confusion Assessment Method

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1 **Screening for Delirium via Family Caregivers: Convergent Validity of the Family**
2 **Confusion Assessment Method (FAM-CAM) and Interviewer-Rated CAM**

3 Abbreviated title: FAM-CAM: Convergent Validity with CAM

4 Melinda R. Steis, PhD, RN*

5 Lois Evans, PhD, RN †

6 Karen B. Hirschman, PhD, MSW†

7 Alexandra Hanlon, PhD†

8 Donna M. Fick, PhD, RN‡

9 Nina Flanagan, RN, MSN§

10 Sharon K. Inouye, MD, MPH□

11 From the *Department of Veterans Affairs Medical Center, Orlando, Florida;

12 †University of Pennsylvania, School of Nursing, Philadelphia, Pennsylvania; ‡ School

13 of Nursing, The Pennsylvania State University, University Park, Pennsylvania; §

14 Decker School of Nursing, Binghamton University, Binghamton, New York;

15 □Department of Medicine, Beth Israel Deaconess Medical Center, Harvard Medical

16 School and the Aging Brain Center, Institute for Aging Research, Hebrew SeniorLife,

17 Boston, MA.

18 **Address correspondence to:** Melinda R. Steis, PhD, RN, Department of Veterans
19 Affairs, Orlando VA Medical Center, 2900 Veterans Way, Melbourne, FL 32940;
20 Phone (814) 441-3144; Fax (321) 637-3605; Email: melinda.steis@va.gov.

21 **Alternate corresponding author:** Sharon K. Inouye, M.D., MPH; Aging Brain Center;
22 Hebrew SeniorLife; 1200 Centre Street; Boston, MA 02131; Phone (617) 971-5390;
23 Fax (617) 971-5309; Email: sharoninouye@hsl.harvard.edu (not for publication).

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ABSTRACT

Background/ Objectives: As the population ages, delirium superimposed on dementia is becoming a common problem. Family caregivers may provide critical information to assist with early detection. The purpose of this study was to explore agreement between the Family Confusion Assessment Method (FAM-CAM) for delirium identification and interviewer-rated CAM delirium ratings.

Design: Exploratory analysis of agreement.

Setting: Community.

Participants: 52 family caregivers and 52 elders with pre-existing impairment on standardized cognitive testing.

Measurements: The interviewer-rating for delirium was determined by fulfillment of the Confusion Assessment Method (CAM) algorithm.

Results: The total sample included 52 paired CAM:FAM-CAM assessments completed across 52 dyads of elders with pre-existing cognitive impairment and family caregivers. The point prevalence of delirium was (7/52)13%. Characteristics did not differ significantly between the delirium and non-delirium groups. The FAM-CAM questions that mapped directly to the original four-item CAM algorithm had the best overall agreement with the interviewer-rated CAM, kappa=0.85 (95% confidence interval, CI 0.65-1.0), sensitivity 88% (CI 47-99%) and specificity 98% (CI 86-100%).

Conclusion: The FAM-CAM is a sensitive screening tool for detection of delirium in elders with cognitive impairment utilizing family caregivers, with relevance for both research and clinical practice.

Key Words: delirium, Confusion Assessment Method (CAM), dementia, caregiver

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INTRODUCTION

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Delirium superimposed on dementia (DSD) is increasingly problematic as the population ages. The prevalence of DSD ranges from 18% to 89% in hospitalized and community dwelling older adults (1, 2). Dementia is a major risk factor for the development of delirium (3, 4). Persons with dementia who develop delirium have poor functional outcomes, increased rates of re-hospitalization and mortality, and an accelerated downward trajectory of their cognitive impairment (2, 5, 6). Lowered levels of cognition and function often contribute to the decision to institutionalize (5, 7).

Although a relationship exists between delirium and dementia, there are several features of delirium that do not overlap with dementia and are potentially more easily recognized by care providers; these include an acute change in mental status, impaired attention, symptom fluctuation, and altered level of consciousness. Acute change and inattention are hallmarks of delirium. Except for persons at the end of life, level of consciousness should not be impaired in older adults with dementia and is an important indicator of a change in mental status (8-10). Early detection and treatment of DSD could slow its progression and prevent complications, both critical to remaining in the community.

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Family caregivers provide 80% of the care for the 3.57 million community-dwelling elders with dementia in America (11). Typically, family caregivers spend at least 40 hours each week caring for their family member with dementia (11). Family caregivers are present, often on a 24-hour basis, and may make critical observations about mental status changes in persons with dementia that, when shared, can result in earlier identification and treatment of delirium.

90 The Confusion Assessment Method (CAM) is widely used to screen for the
91 presence of delirium (12, 13). The only instrument available for family screening for
92 delirium, the Family Confusion Assessment Method (FAM-CAM), was developed by
93 Inouye and colleagues to screen for delirium by interviewing family caregivers (14-16).
94 Derived from the original 10-item CAM instrument (12), the FAM-CAM was adapted to
95 maximize detection of delirium (i.e., acute onset and fluctuating course, inattention,
96 disorganized thinking, altered level of consciousness, disorientation, perceptual
97 disturbances, and psychomotor agitation) from the observations of family caregivers.
98 While relatively uncommon in delirium, “inappropriate behavior” and perceptual
99 disturbances such as hallucinations were included in the FAM-CAM to maximize
100 sensitivity and specificity.

101 The specific aim of this study was to explore the convergent validity (17, 18) of
102 the FAM-CAM, completed by family caregivers, and the CAM, completed by trained
103 interviewers who directly assessed elders with pre-existing cognitive impairment. A
104 second aim was to identify the FAM-CAM items that maximize sensitivity and specificity
105 for delirium screening in older persons with cognitive impairment.

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111 METHODS

112 Study Sample

113 The sample included 88 paired CAM and FAM-CAM assessments completed across 58
114 dyads of family caregiver-elder with pre-existing cognitive impairment and their family
115 caregivers. The dyads were drawn from two separate primary studies: the “eCare for
116 Eldercare” pilot study conducted in three central Pennsylvania communities (N=13) (19)
117 and the “Hospital to Home: Cognitively Impaired Elders/Caregivers” study in
118 Philadelphia (N= 45) (20). Records were dropped from analysis if the caregiver
119 indicated he/she had not seen the elder participant in two or more days prior to FAM-
120 CAM completion (n=6 records/6 caregivers).

121 Inclusion and exclusion criteria were similar in both studies. Older adults with pre-
122 existing cognitive impairment included those who were 65 years or older, community-
123 dwelling, and English-speaking. Cognitive impairment was determined using validated
124 methods in both studies: Modified Blessed Dementia Rating Scale (21) score of >3 and
125 symptoms of dementia documented over a 6 month period (eCare for Eldercare study)
126 or, in the Hospital to Home study, either previous history of dementia or deficits in
127 orientation, recall or executive function (≤ 4 on Six Item Screen or CLOX1 ≤ 10) (22-24).
128 Exclusion criteria for both parent studies were any terminal condition (i.e., <6 months
129 prognosis). Additional exclusion criteria for the Hospital to Home study included
130 undergoing active cancer treatment, active substance abuse, and recent
131 cerebrovascular accident.

132 For family caregivers, inclusion criteria were agreement to participate, English-
133 speaking, and daily interaction with the elder. Additional inclusion criteria for caregivers
134 in the eCare for Eldercare study included daily internet access via a personal computer
135 or study-provided smart phone.

136 Measures

137 Interviewer-Rating for Delirium

138 The original CAM instrument was a 10-item instrument validated against expert
139 ratets (12). The 4-item CAM diagnostic algorithm for delirium was developed for this
140 study, and has gained widespread use for identification of delirium. By the CAM
141 diagnostic algorithm, a positive screen for delirium is indicated by an acute change in
142 mental status from the person's baseline as well as fluctuation of symptoms, the
143 presence of inattention, and either disorganized thinking or an altered level of
144 consciousness (12). Wei and colleagues (25) conducted a systematic review evaluating
145 the performance of the CAM. Based on seven high quality studies (N=1,071), the
146 combined sensitivity was 94% (95% CI = 91-97%) and specificity was 89% (95% CI =
147 85-94%). Recent studies documented the CAM maintains high sensitivity and
148 specificity when used appropriately (26, 27). Additionally, several studies documented
149 that use of the CAM can facilitate identification of delirium in the face of dementia (12,
150 28-30).

151 For the present study, the interviewer-rating for delirium was determined by
152 fulfillment of the CAM diagnostic algorithm (12), and was based on direct assessments

153 of the cognitively impaired elders made by trained research assistants (RAs). In both
154 parent studies, the CAM was completed based on results of cognitive screening tools.

155 All RAs had relevant educational preparation, training, and experience working
156 with patients and their families. The RAs received further training in administration of
157 the CAM and other instruments through self-study, didactic sessions, paired mock
158 interview sessions with inter-rater reliability assessment, and paired ratings of older
159 adults observed by an expert interviewer. During standardization, the inter-rater
160 reliability statistic for the overall delirium rating between the RAs and the expert
161 interviewer was Kappa=0.95 in 19 paired observations.

162 FAM-CAM Rating

163 The presentation of the FAM-CAM to the family caregivers was similar in both
164 parent studies. Caregivers were instructed in individualized face-to-face sessions about
165 the use of the FAM-CAM that included education about each symptom and instructions
166 in how to score each item. In addition, a one-sentence introduction on the FAM-CAM
167 form requested the family caregiver to “please answer each of the following questions
168 about the family member you are caring for at home (16).” In the eCare for Eldercare
169 study, RAs also taught the family caregivers how to access the study website, and how
170 to complete the FAM-CAM form using either their personal computer or the smart
171 phone. Participants in the Hospital to Home study were provided a paper copy of the
172 FAM-CAM and received similar didactic instructions. In both studies, the RAs were
173 available to provide additional guidance to clarify symptoms and scoring instructions on
174 an ongoing basis. Family caregivers were encouraged to provide written comments on
175 the delirium symptoms; either in a free text comment field in the eCare for Eldercare

176 study or directly to the RA in the Hospital to Home study, the caregiver was also able to
177 ask questions about completing the FAM-CAM.

178 Study Procedures

179 Demographic information was collected by the RA from interviews with the family
180 caregivers during the initial visit. RA visits with participating elders with cognitive
181 impairment were pre-scheduled according to the parent study protocols. In the eCare
182 for Eldercare study, the FAM-CAM ratings were completed and transmitted
183 electronically by family caregivers daily but paired ratings were completed by RAs
184 visiting the home to conduct the interviewer-ratings once a week (N=40). When a FAM-
185 CAM rating was positive for delirium on any daily rating, an RA was dispatched within
186 24 hours (n=8 of 40) to conduct a paired rating. RAs were blinded to the caregiver
187 responses to individual FAM-CAM questions but not to the overall conclusion
188 (delirium/no delirium). In the Hospital to Home study, the interviewer-rating (paired with
189 FAM-CAM) was done on post hospital discharge visits (N=48) scheduled at 2, 6, 12, 24
190 and 52 week intervals. The CAM was administered as part of a battery of scales
191 assessing the study participant followed by an interview using standardized instruments
192 with the caregiver for the entire study. The FAM-CAM administration was added to the
193 battery of scales administered to the caregiver for the final 28 week period. By design,
194 the RA was blinded to the caregiver FAM-CAM responses. While the caregiver was
195 completing the FAM-CAM, the RA was assessing the elder participant with pre-existing
196 cognitive impairment.

197 Statistical Analysis

198 Descriptive statistics are presented for basic demographic variables. FAM-CAM
199 sensitivity, specificity, and kappa were calculated against a interviewer-rated CAM
200 delirium rating established by carefully trained RAs, along with their 95% confidence
201 intervals. For these FAM-CAM calculations, screening “delirium positive” indicates being
202 classified as impaired by the CAM criteria which were specified a priori. True positives
203 (TP) were those who screened positive for delirium by FAM-CAM and had delirium by
204 interviewer-ratings; false positives (FP) were those who screened positive by FAM-CAM
205 but were not delirious by the interviewer-rating; true negatives (TN) were those who
206 screened negative by FAM-CAM and were not delirious by the interviewer-rating; and
207 false negatives (FN) were those who screened negative by FAM-CAM but were
208 delirious by the interviewer-rating. Sensitivity was calculated as $TP / (TP + FN)$;
209 specificity was calculated as $TN / (TN + FP)$. Sensitivity and specificity according to the
210 operational definitions were compared using the McNemar test. Cohen’s Kappa is a
211 measure of chance-corrected agreement between raters. It is based on the percent of
212 data values on the main diagonal of the table, adjusted for the amount of agreement
213 that could be expected due to chance alone.

214 Analyses using different combinations of the FAM-CAM questions were
215 performed beginning with questions which mapped to the original CAM algorithm and
216 then 11 other possible combinations of the FAM-CAM questions to assess their impact
217 on sensitivity, specificity and kappa of the FAM-CAM. Based on these preliminary
218 analyses, the focus was on 3 features which had the maximal impact on kappa (i.e.,
219 disorientation, perceptual disturbances and “inappropriate behavior”), individually and in
220 combination.

221 RESULTS

222 The final sample (Table 1) included 52 paired assessments from 52 dyads. No
223 family caregivers were dropped from the study due to inability to follow instructions
224 regarding FAM-CAM completion.

225 Table 1 shows the demographic characteristics of the participants and the
226 relationship of their caregivers. The point prevalence of positive cases of delirium was
227 13% (7/52) by the interviewer-rating. Sample characteristics did not differ significantly
228 between the delirium and non-delirium groups, or between the sub-samples from the
229 two parent studies.

230 Results were similar for the analyses completed using all records that include
231 multiple paired ratings (not shown). The numbers of paired ratings/dyad were: 1 rating
232 for 41 participants; 2 for 3 participants; 3 for 3 participants, and 4 or more for 5
233 participants for a total of 82 paired observations. The results were remarkably similar
234 comparing multiple paired ratings to those containing only the first record per patient.
235 Therefore, the findings from this study are based on the data analysis restricted to the
236 first paired rating from each of the study dyads.

237 Table 2 demonstrates the performance of the FAM-CAM items using the first
238 paired record per dyad compared with the CAM interviewer-ratings for delirium. This
239 table begins with the original CAM algorithm and then sequentially adds additional items
240 that impacted the sensitivity, specificity and kappa of the FAM-CAM in our preliminary
241 analyses. The FAM-CAM sequences are listed in descending order by their kappa
242 value. The FAM-CAM question combination that has the highest kappa (0.85) is the

243 sequence of questions that maps directly to the original CAM algorithm with no
244 additional questions.

245 FAM-CAM questions that target the delirium features disorientation, perceptual
246 disturbances and “inappropriate behavior” were included to determine their value, if any,
247 in various combinations with other FAM-CAM questions for the screening of delirium
248 symptoms. No combination including any or all of these questions improved the kappa
249 of the FAM-CAM. However, these additional questions did improve sensitivity.

250 In this exploratory study, overall agreement between the CAM and FAM-CAM
251 was 96% (50/52). There was one FAM-CAM that was false-positive where the RA rated
252 inattention and change in level of consciousness as absent while the caregiver rated the
253 same items as present. There was one FAM-CAM that was false-negative where the
254 only feature that the RA and the caregiver rated similarly was disorientation. This raises
255 the possibility of either over- or under-identification of delirium symptoms by family
256 caregivers, who sometimes weighted the significance or severity of symptoms
257 differently than the trained reviewers. The disagreement in ratings between the family
258 caregiver and the interviewer rating prompted re-training of the family caregiver on the
259 FAM-CAM; thereafter, paired ratings had complete agreement.

260 Caregivers in the eCare for Eldercare study had the opportunity to add
261 comments in a free-text field accompanying each FAM-CAM question. None of the
262 caregivers indicated problems, and uncertainties were only raised on a few questions
263 with comments, as indicated in Table 3. The question garnering the most comments
264 was the initial overall question that asks whether the caregiver has noticed any recent
265 problems with memory, concentration, attentiveness, confusion, inappropriate behavior

266 or extreme sleepiness. The other question that generated more comments was
267 regarding excessive drowsiness in the daytime, which generated four different
268 comments.

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DISCUSSION

285 This exploratory study is the first we are aware of to examine the agreement of a
286 family caregiver administered delirium instrument, the FAM-CAM, with the interviewer-
287 based CAM rating administered by a trained interviewer. Agreement between the two
288 assessments was excellent with Kappa=0.85 (95% confidence interval=0.65, 1.00).
289 Since identifying the presence of delirium as early as possible is vital to the outcomes of
290 the person experiencing delirium, the use of the FAM-CAM may have great clinical
291 relevance. The algorithm of FAM-CAM questions with the highest kappa (0.85) used in
292 this study included positive responses to the features of the original CAM algorithm.
293 These findings lend support for the proposed approach for the FAM-CAM. The level of
294 agreement found in this study should be adequate for screening purposes.

295 These findings hold important potential implications. First, substantial level of
296 agreement between the caregiver completed FAM-CAM and the interviewer CAM
297 assessment indicates that caregivers can provide accurate information to determine if
298 delirium is present. We do not propose or recommend that caregivers can “diagnose”
299 delirium with the FAM-CAM, rather, the instrument may be useful to identify symptoms
300 early which can then be brought to the attention of healthcare providers. Although this
301 study had a relatively small sample, the point prevalence of delirium was 13% in elders
302 with cognitive impairment. This finding is similar to point prevalence rates in two
303 previous study populations of community dwelling persons with dementia, which were
304 reported as 13% (31) and 18% (2).

305 Second, six of the FAM-CAM questions mapped to the items assessing acute
306 onset, fluctuating course, inattention, disorganized thinking, and altered level of
307 consciousness and had maximal agreement. Further testing of these questions is
308 recommended in larger samples including participants who are fully delirious, those with
309 and without dementia, those artificially sedated, and normal controls.

310 Strengths of this study include a high level of agreement of the FAM-CAM with
311 an interviewer CAM rating of delirium by trained RAs. The sample included community
312 dwelling older adults with pre-existing cognitive impairment as well as both white and
313 non-white races. The few comments generated by caregivers in the eCare for
314 Eldercare parent study indicate no difficulty among caregivers about answering the
315 questions independent of study personnel.

316 Major limitations of this study include the lack of a true external gold standard for
317 delirium, and the small homogenous sample, that is, participants with pre-existing
318 cognitive impairment only. In addition, different administration methods were used for
319 the FAM-CAM across the two parent studies (paper and pencil, personal computer and
320 smart phone) which may have influenced the overall results. Further, close temporal
321 proximity of assessments between the family caregiver and RA was not always
322 achieved. On two occasions, positive FAM-CAM ratings for delirium were transmitted
323 late in the evening hours; although the RA visit was made within 24 hours, it was not on
324 the same day. Additionally, only limited family caregiver demographics were collected,
325 and educational level was unknown. RAs were blinded to caregiver answers to
326 individual FAM-CAM questions in both parent studies but RAs were not blinded to the
327 overall conclusion (delirium/no delirium) to the FAM-CAM in the eCare for Eldercare

328 study. Finally, a major problem with the current version of the FAM-CAM instrument is
329 the insufficient assessment of acute onset. An adapted question was utilized, asking:
330 “in the last day or so, have you noticed [FAM-CAM symptom]...” Although that lead-in
331 specifies a recent time period, it does not explicitly ask whether the observed change
332 had an acute onset. This can be avoided by using the official FAM-CAM provided at the
333 website www.hospitalelderlifeprogram.org.

334 The FAM-CAM is a screening tool for delirium utilizing the observations of family
335 caregivers. Use of this tool may help to engage the family caregiver in alerting health
336 care professionals about a change in mental status that is worthy of further evaluation,
337 thus, heightening likelihood of earlier identification of delirium. The FAM-CAM may be
338 useful to establish the presence of delirium at hospital and emergency department
339 admission, and may facilitate longitudinal studies of delirium for homebound or
340 community-based elders. Future work may include evaluation of different modes of
341 FAM-CAM assessment, validation in larger, diverse samples against external gold
342 standards, tested against other delirium and cognitive scales (not the CAM) and
343 investigating the most effective means to communicate FAM-CAM results to health care
344 practitioners.

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Elements of Financial/Personal Conflicts	*Author 1 Steis		Author 2 Evans		Author 3 Hirschman		Author 4 Hanlon		Author 5 Fick		Author 6 Flanagan		Author 7 Inouye	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Employment or Affiliation		x		x		x		X		X		x		x
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Honoraria		X		X		X		X		X		X		X
Speaker Forum		X		X		X		X		X		X		X
Consultant		X		X		X		X		X		X		X
Stocks		X		X		X		X		X		X		X
Royalties		X		X		X		X		X		X		X
Expert Testimony		X		X		X		X		X		X		X
Board Member		X	X			X		X		X		X		X
Patents		X		X		X		X		X		X		X
Personal Relationship		X		X		X		X		X		X		X

*Authors can be listed by abbreviations of their names.

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- Steis: study concept and design, acquisition of subjects and data, analysis, interpretation of data and preparation of manuscript. No COI.
- Evans: study concept and design, analysis and interpretation of data, and preparation of manuscript. **COI:** Dr. Lois Evans is an associate editor for the Journal.
- Hirschman: acquisition of subjects and data and review of manuscript. No COI.
- Hanlon: Analysis of data and preparation of manuscript. No COI.
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Table 1

Demographic Characteristics: Elders with Pre-existing Cognitive Impairment (N=52)

Variable	Overall N=52 Mean (SD and range) or (%)	Delirium Positive n=7 Mean (SD and range) or (%)	Delirium Negative n=45 Mean (SD and range) or (%)	<i>p</i> Value Comparing Delirium Positive to Negative
Age, years	82 (8, 66-103)	83 (9, 70-103)	81 (8, 66-99)	0.503
Education, years	12 (4, 6-25)	10 (2, 6-12)	12 (4, 7-25)	0.113
Female	35 (67%)	5 (71%)	30 (67%)	1.000
Male	17 (33%)	2 (29%)	15 (33%)	
Race:				
• Caucasian	26 (50%)	3 (43%)	23 (51%)	0.743
• African-American	25 (48%)	4 (57%)	21 (47%)	
Caregiver relationship:				
• Son/Daughter	30 (58%)	3 (28%)	27 (61%)	0.461

• Spouse	12 (23%)	3 (38%)	9 (20%)
• Other relative	8 (15%)	2 (25%)	6 (14%)
• Friend	2 (4%)	0 (0%)	2 (5%)

NOTE: Delirium – positive and negative based on interviewer-rating.

For Review Only

Table 2

Sensitivity, Specificity and Kappa for FAM-CAM Questions (first record/dyad, N=52)

FAM-CAM Questions	Sensitivity % (95% CI)*	Specificity % (95% CI)**	Kappa (95% CI)
Original CAM Algorithm:	88 (7/8)	98 (43/44)	0.85
Acute Onset + Fluctuation + Inattention + Disorganized thinking or Altered consciousness	(47, 99)	(86, 100)	(0.65, 1.00)
Added: Disorientation	75 (6/8) (42, 100)	98 (43/44) (85, 100)	0.77 (0.51, 1.00)
Added: Perceptual Disturbances (Hallucinations)	50 (4/8) (40, 100)	100 (44/44) (80, 98)	0.63 (0.30, 0.95)
Added: "Inappropriate behavior"	38 (3/8) (10, 74)	100 (44/44) (90, 100)	0.50 (0.14, 0.86)
Added: Disorientation + Perceptual Disturbances (Hallucinations) + "Inappropriate behavior"	13 (1/8) (<1, 53)	100 (44/44) (90, 100)	0.19 (-0.13, 0.52)

NOTE: CAM=Confusion Assessment Method; FAM-CAM=Family Confusion Assessment Method;
 *Sensitivity=proportion screened as delirious using the FAM-CAM among those screened as delirious
 using the CAM; **Specificity=proportion screened as not delirious using the FAM-CAM among those not
 screened as delirious using the CAM.

Table 3

FAM-CAM Free Text Comment Field Entries

FAM-CAM Question Topics	Caregiver Comments
1. Overall question:	"slightly"
memory, concentration,	"forgot day of the week"
attentive, confusion,	"concentration"
inappropriate behavior,	"confused"
extreme sleepiness	"behaving inappropriately, bad day"
	"last night when out to dinner"
2. Inattention	"normal"
3. Speech disturbance	"rambling"
4. Disorientation	"time"
5. Inappropriate behavior	"kept referring to wanting to go to bed"
6. Excessively drowsy in	"don't know"
daytime	"when he comes home from day care"
	"sometimes"
	"only on days he stays home because he's bored or just
	watching TV"