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The impact of delirium and recall on the level of distress in patients with advanced cancer and their family caregivers

E Bruera, MD[*], **SH Bush, MBBS**[*], **J Willey, MSN**, **T Paraskevopoulos, RN**, **Z Li, MS**, **JL Palmer, PhD**, **MZ Cohen, PhD**, **D Sivesind, MSN**, and **A Elsayem, MD**
The University of Texas M. D. Anderson Cancer Center

Abstract

Background—Delirium is the most frequent neuro-psychiatric complication in patients with advanced cancer. In this exploratory study, we aimed to determine the proportion of patients who were able to recall their experience of delirium and the level of distress experienced by patients, family caregivers and health care professionals.

Methods—Patients with advanced cancer who had completely recovered from an acute delirium episode, had Memorial Delirium Assessment Scale <13, and had a family caregiver present during the delirium. Patients were given the Delirium Experience Questionnaire. Patients' and family caregivers' demographics, and the frequency and distress associated with different delirium symptoms, were also collected. Bedside nurses and palliative care specialists reported the frequency of recalled delirium symptoms and their distress score.

Results—A total of 99 patient/family caregiver dyads participated in the study. The main identified causes for delirium were opioids, infection, brain metastases, hypercalcemia, and dehydration. Seventy-three patients (74%) remembered the episode of being delirious, with 59/73 patients (81%) reporting the experience as distressing (median distress level of 3). The median overall delirium distress score was higher in family caregivers (median 3, 25–75% quartile, 2–4) than in patients (median 2, 25–75% quartile, 0–3), p=0.0004. Bedside nurses and palliative care specialists expressed low median overall delirium distress scores (median 0, 25–75% quartile 0–1).

Conclusion—The majority of patients with advanced cancer recall their experience of delirium, causing moderate to severe distress in both patients and family caregivers. Appropriate interventions to reduce this are needed.

Keywords

Delirium; Confusion; Neoplasisms; Palliative Care

INTRODUCTION

Delirium is one of the most frequent and serious complications in advanced cancer patients [1,2,3]. It is a complex syndrome with multiple causes described as a disturbance of consciousness with reduced ability to focus, sustain or shift attention, changes in cognition or perceptual disturbances that occur over a short period of time and fluctuate over the

Correspondence regarding this manuscript should be addressed to: Eduardo Bruera, MD, M. D. Anderson Cancer Center – Unit 008, Palliative Care & Rehabilitation Medicine, 1515 Holcombe Blvd., Houston, TX 77030, Tel: 713-792-6084, Fax: 713-792-6092, E-mail: ebruera@mdanderson.org.
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course of the day [4]. The essential components of delirium have been recognized as disordered attention and cognition with acute onset and organic etiology [5].

The frequency of delirium in patients with advanced cancer upon admission to acute care hospital or hospice is between 28–48% [6,7,8,9]. The frequency increases to 85 to 90% in the hours and days before death [3,5,6,10].

Delirium is usually multifactorial. The overall burden of terminal illness increases the person's vulnerability for delirium. The most common contributors in patients with advanced cancer include medication (opioids, anticholinergics, steroids, antidepressants), infection (pneumonia, urinary tract infection), fluid imbalance (dehydration, overload), and electrolyte imbalances (hypercalcemia) [1].

Delirium reversibility in advanced cancer has been the subject of much debate [11] but relatively limited research, mainly as retrospective studies [9,12,13,14], case reports [15,16], and a few prospective studies [3,6,17]. Some investigators have reported that 30–50% of acute delirium episodes in patients with advanced cancer are completely reversible within 48–96 hours [3,6,9,]. This complete resolution is usually associated with discontinuation of drugs, appropriate management of infections and metabolic abnormalities [9,18]

There has been limited data on the distress level associated with delirium among cancer patients and their families. Our group previously observed that agitated delirium in patients was associated with increased frequency of conflict between the palliative care team and the patient's family [19]. We also observed that patients with delirium had no recall of the episode of delirium or distress associated with it [19]. However, Breitbart et al reported on 154 cancer patients with delirium, in which 101 patients had complete resolution [20]. Fifty-four (53.5%) patients recalled their delirium experience. The mean delirium-related distress levels (on a 0–4 numerical rating scale of the Delirium Experience Questionnaire [DEQ]) were 3.2 for patients who recalled delirium, 3.75 for spouse/caregivers, and 3.09 for nurses.

The purpose of this study was to determine the frequency of recall of the delirium experience and the associated level of distress for patients with complete recovery from an episode of acute delirium and for their primary caregivers, and also to determine the frequency of symptom recall.

METHODS

Subjects and Procedures

The study was reviewed and approved by the Institutional Review Board (IRB) at M. D. Anderson Cancer Center before initiation. All participating research nurses underwent eight hours of training directed by the principal investigator, psychiatric advanced practice nurse, and a nursing research expert, and included protocol review, overview of the delirium process including etiologies, diagnoses, symptoms and treatment, and conduct of patient and caregiver interviews.

This study included patients with advanced cancer who met DSM-IV-TR criteria for delirium during the current inpatient admission, were 18 years of age or older, had complete resolution of all delirium symptoms (according to DSM-IV-TR criteria) within 3 days of study entry, had Memorial Delirium Assessment Scale (MDAS) <13, and were able to communicate in English. In all cases the diagnosis of delirium was made by a board certified palliative medicine specialist with expertise in the daily assessment and management of delirium. In all cases patients had recent onset of neuro-psychiatric symptoms with a background of previously apparent normal cognition, they had a score of >13 in the MDAS

and were followed up by the palliative care team on a daily basis until complete resolution of the episode. Family caregivers, defined as patient's spouse, adult child, sibling, parent, other relative, or significant other (any other person defined by the patient as a partner), 18 years of age or older, at patient's bedside at least 4 hours each day during patient delirium episode, and able to communicate in English were also included in the study. Clinical nurses, defined as the inpatient bedside nurses who provided care while the patient was experiencing delirium during day shift, and the palliative care specialists (PCSs), defined as mid-level advanced nurse practitioners and palliative care physicians delivering care for the patient during the episode of delirium, were also interviewed for the purpose of this study. Written informed consent was obtained from patients and their caregivers.

All patients underwent thorough clinical, laboratory and imaging investigations in order to establish all possible reversible causes of delirium. In addition, all patients received the standard neuroleptic treatment used by the palliative care team. For patients with hyperactive or mixed delirium, this consists of regular haloperidol 2mg every 6 hours with rescue doses of haloperidol 2mg every hour as needed for psychomotor agitation, hallucinations or delusions, up to 30mg/day. Patients with hypoactive delirium are treated with haloperidol 2mg every hour as needed for the management of hyperactive elements. All patients were followed up on a daily basis by a PCS.

Outcome Measures

Participants' sociodemographic and medical variables were collected at the initial assessment, and included age, gender, ethnic background, cancer diagnoses, etiologies of delirium and duration of the acute episode of delirium. In addition, the following study measures were used.

Memorial Delirium Assessment Scale (MDAS) is a 10-item, four-point clinician-rated scale (possible range, 0–30) designed to quantify delirium severity in patients with cancer and other medically ill patients [21]. This is a validated instrument [22]. Scores of 13 or above likely reflect the presence of delirium [21]. This instrument was used at baseline. Patients who scored 13 or above were excluded from our study.

Mini-Mental State Examination (MMSE) is one of the most widely used tools to evaluate cognitive status. It is easy to administer and requires less time than longer mental status tests or neuropsychological batteries [23]. This tool was used at baseline to ensure patient's cognitive status.

The Delirium Experience Questionnaire (DEQ) assesses recall of the delirium experience and the level of distress related to the delirium episode in patients [20]. The DEQ asks six questions of patients who have recovered from a delirium episode including: 1) Do you remember being confused? Yes or No; 2) If no, are you distressed that you can't remember? Yes or No; 3) How distressed? 0–4 numerical rating scale with 0=not at all, and 4=extremely; 4) If you do remember being confused, was the experience distressing? Yes or No; 5) How distressing? 0–4 numerical rating scale; and 6) Can you describe the experience? This question was tape recorded and transcribed verbatim but it is not reported in this paper.

The research nurse interviewed individually the patient, family caregiver, bedside nurse and PCS regarding the patient's recent episode of delirium. For each symptom of delirium, [1) not aware of where they were; 2) not aware of time, date, year; 3) visual hallucinations; 4) tactile hallucinations; 5) auditory hallucinations; 6) delusional thoughts; 7) psycho-motor agitation], the research nurse explained the meaning. All respondents were asked to recall the frequency of these symptoms scoring from 0=not present, 1= a little of the time, 2= some

of the time, 3= good part of the time, and 4=most or all of the time. In addition, the patient, family caregiver, bedside nurse and PCS were asked to score the emotional distress for themselves associated with each delirium symptom on a scale from 0–4 [0=no distress, 1= a little, 2=a fair amount, 3=very much and 4=extremely distressed] and also to give an overall delirium distress score [0–4 numerical rating scale].

The study assessments were conducted ≤3 days after delirium resolution to ensure the highest possible level of recall by the patient, family caregiver, nurse and PCS.

We summarized patient and family characteristics using descriptive statistics including means, standard deviations, medians, quartiles and percentages. Recall of delirium and other symptoms were compared between groups using chi-square tests or Fisher's exact tests. Patient distress levels were summarized using means and medians and differences were tested using Wilcoxon rank sum tests. We report means to better allow our results to be compared to other studies and nonparametric medians and tests because much of the data were distributed non-normally. Differences between patient and family caregiver recalled symptom frequency and distress scores and other combinations of patients, family caregivers, nurses and PCSs were compared using Wilcoxon rank-sum tests. We used regression analyses and stepwise regression to determine associations between ranked average distress scores and clinical and delirium variables. Analyses were conducted using SAS, version 9.1 (Cary, North Carolina).

RESULTS

Between July 2005 and September 2007, we approached a total of 175 patients for study participation. Twenty-seven patients were ineligible for the study mainly due to incomplete resolution of delirium according to DSM-IV-TR, or having passed the 3-day window of recovery. Forty-eight patients refused to participate in the study (either the patient or the family refused). One patient gave written informed consent and later withdrew from the study. Ninety-nine patient/family caregiver dyads were included in the study. Patients' and family caregivers' demographic information and patients' baseline assessment information are listed in Table 1. All patients had experienced complete resolution of their delirium as documented by a normal MDAS and MMSE score at the moment of assessment. (Table 1).

The subtype of delirium was categorized as hypoactive in 20 patients (20%), hyperactive in 13 (13%), and mixed in 66 (67%). The causes of delirium episode varied among patients. The majority of patients (92%, n=92) had more than one cause. We identified 250 contributing factors, the most common ones including opioids in 69 (28%), infection in 38 (15%), other medications in 18 (7%), brain metastases in 15 (6%), hypercalcemia in 11 (4%), and dehydration in 10 (4%).

Seventy-three patients (74%) remembered being confused. Recall was not significantly different according to delirium subtype (hyperactive vs. hypoactive vs. mixed). 59/73 patients with delirium recall (81%) stated that the experience was distressing versus 11/26 patients with no recall (42%) (p=0.01).

Among the 73 patients who remembered being confused on answering the DEQ, 48 reported abnormal space orientation (66%), 51 reported time disorientation (70 %), 41 visual hallucinations (56 %), 11 tactile hallucinations (15 %), 14 auditory hallucinations (19 %), 28 delusional thoughts (38 %), and 45 psychomotor agitation (62%).

The median distress level reported, according to the DEQ, among patients with recall was 3 (25–75% quartile, 1–4). This was significantly higher than for patients with no recall, who reported a median distress level of 2 (25–75% quartile, 0–4), p=0.03. [Table 2]. There were

no significant differences according to delirium subtype, gender, or race. For the family caregiver, the median overall delirium distress score expressed was 3 (25–75% quartile, 2–4).

Table 3 demonstrates the symptoms recalled by patients, family caregivers, clinical nurses, and PCSs. Table 4 shows the median recalled symptom frequency score (0= not present – 4= most or all of the time) and distress score associated with different symptoms as rated by the patients and family caregivers who reported symptom recalls. Family caregivers reported symptom recall more frequently than patients (Table 3). However, among those patients and family caregivers who reported recall, the median frequency of different symptoms was not significantly different (Table 4).

For most symptoms, patients and family caregivers expressed a high level of distress (a median of 3/4 for most symptoms), Table 4.

Table 5a and 5b show highly significant agreement with regard to both recalled symptom frequency and symptom related distress between patients and family caregivers. However, there was low and generally non-significant agreement with the nurse and PCS with regard to symptom frequency. Nurses and PCSs were not asked to estimate patient/family caregiver distress, but to express their own distress in delivering patient care. Therefore, in Table 5b, the nurse and PCS have not been analyzed. The median overall delirium distress score associated with delivering care to delirious patients reported by the nurse and PCS was low, (0.00 (25–75% quartile, 0–1) for the nurse and 0.00 (25–75% quartile, 0–1) for the PCS) and significantly lower than those reported by the patient and family caregiver, with median overall delirium distress scores of 2.00 (25–75% quartile, 0–3) $p<0.0001$ and 3.00 (25–75% quartile, 2–4), $p<0.0001$, respectively. The difference between these median distress scores reported by the patient and family caregiver was also significant, $p=0.0004$.

We conducted univariate and multivariate analyses to determine the associations between the ranked average distress scores and different clinical and delirium variables. There were no significant univariate associations between patients' delirium distress and gender, age, race, duration of the delirium episode, MDAS score, MMSE score, or delirium subtype [hyperactive vs. hypoactive vs. mixed]. There were significant associations (all $p \leq 0.05$) between delirium distress and recall of psychomotor agitation, delusions, and time and space orientation. In multivariate analyses, the only significant predictor of patient distress was psychomotor agitation ($F=5.73$, $p<0.0001$).

DISCUSSION

In this prospective study, we have observed that 74% of patients who recovered from a delirium episode had clear recall of the episode. Patients with delirium recall had significantly higher levels of distress, primarily associated with psychomotor agitation, delusions, and temporal and spatial disorientation. The frequency of delirium recall observed by our group is significantly higher than by other authors. Duppils, et al [24] reported 9 out of 28 (32%) patients with a median age of 80 years, who had recovered from delirium after hip-related surgery, were able to recall their experience of delirium, often describing dramatic scenes triggering feelings of fear, panic and anger. Schofield [25] interviewed 19 patients (>65 years old) post delirium recovery, and about 50% admitted to experiencing perceptual disturbances. Breitbart et al. [20] conducted a prospective survey in a convenience sample of 101 hospitalized patients with cancer who had completely recovered from delirium. In their study, a MDAS score of ≤10 was used to indicate delirium resolution. Fifty-four (53.5%) patients recalled their experience of delirium with 80% reporting severe distress. The strongest predictor for patient distress was the presence of

delusions. In their patient population, only 46.5% patients were classified as having hyperactive or mixed delirium, compared with 80% in our study. This difference might explain the higher frequency of recall among our patients. Breitbart et al observed that lower performance status was a strong predictor of poor prognosis [20]. Since delirium in palliative care often corresponds to a patient dying, research in this area needs to be thoughtful about how to determine the extent to which caregiver distress is due to patient delirium versus other sources such as the patient's overall proximity to death.

More research is necessary to better determine the factors associated with delirium recall.

In our study, family caregivers recalled more delirium related symptoms than patients, clinical nurses or PCSs, [Table 3]. In a previous study conducted in 60 unresponsive inpatient hospice patients, caregivers also reported behaviors such as grimacing, groaning, shouting, purposeless movement, or touching/rubbing an area significantly more frequently than the nurses [26]. The agreement between caregivers and nurses was poor. The findings of these two studies suggest that bedside caregivers could potentially monitor patient behavior and/or response to neuroleptic treatment with higher sensitivity than health care providers. An alternative explanation might be that family members over-interpret what they are witnessing. Their personal anxiety might affect their recall. Future studies should attempt to obtain objective visual and audio evidence of the different symptoms to provide a better "gold standard" for comparison of the recall by patients, caregivers, and healthcare professionals.

The analysis of recall showed statistically significant agreement between the patient and caregiver for all symptoms. On the other hand, most of the agreement was not statistically significant between patient and nurse and between patient and palliative care specialist [Table 5]. There was also lack of statistical agreement between the family caregiver and the nurse or palliative care specialist. These findings strongly suggest that the family caregiver provides the most accurate proxy interpretation of frequency of symptoms for delirium. This information might be useful for recall studies regarding delirium at the end of life since more than 80% of patients who die of cancer develop delirium [5].

There was also considerable lack of agreement between the nurse and palliative care specialist regarding symptom frequency [Table 5]. These findings raised concerns that delirium may continue to be overlooked and it also raises questions about the accuracy of the clinical assessment of delirium conducted at the bedside. Future research should focus on the regular administration of delirium screening tools in all inpatient cancer settings where delirium is likely to occur very frequently.

Our results suggest that family caregivers experience severe distress when patients develop delirium [Table 4]. This may impact on the psychological wellbeing of the caregiver. Buss et al. [27] recently reported that primary informal caregivers of patients with cancer with caregiver-perceived delirium were 12 times more likely to have generalized anxiety. We have also observed that delirium is a frequent cause of conflict between relatives and healthcare professionals [19]. Our study suggests that healthcare professionals should be aware that family members observe patient behaviors more frequently than themselves and this may result in different perceptions of suffering and need for pharmacological interventions. Our findings suggest that it is important to regularly assess the behaviors observed by family members and to provide ongoing counseling in order to minimize distress and the potential for conflict. An interdisciplinary approach focused on attempts to reverse the delirium episode, optimal use of neuroleptics, non-pharmacological measures to minimize patient stimulation and to provide orientation clues, and caregiver education and counseling are required to reduce family caregiver distress.

In our study, PCSs and nurses were less distressed by their patient's delirium than the family caregiver. This may be a reflection of their training and experience to enable competence with management of patients with delirium. One possible explanation for the lower level of distress among the nurses might be the intensive seven days a week presence of the palliative care specialist and other members of the team providing extra support to the bedside nurses. More research needs to be conducted to better clarify this finding. The level of health care professional distress may have been higher if they had observed more patient symptoms, leading them to perceive their patient to be distressed.

Better bedside assessment tools are required for screening, early diagnosis, characterization of different behaviors and monitoring of delirium. Structured and frequent monitoring of the delirium episode, not forgetting the often overlooked hypoactive delirium subgroup, will also be useful in determining predictors for symptom recall and guide earlier management. It could be hypothesized that patients experiencing less severe delirium symptoms are more likely to experience a higher level of recollection. Family caregivers at the bedside could be asked to regularly report observed patient behaviors utilizing simple observation forms. In the hospital setting, professional sitters are often used if no family is available and they too could complete simple bedside assessment tools in order to assist nurses and physicians with patient management. Future research should attempt to carefully characterize delirium episodes in an effort to determine recall and distress predictors.

Our findings raise concern regarding the level of distress experienced by patients during and after an episode of delirium. Current pharmacological and non-pharmacological interventions used to minimize delirium symptoms in acute care settings appear to be insufficient for the majority of patients. Future research needs to address the potential advantages of early application of non-pharmacological interventions, such as providing re-orientation or familiarity clues, avoiding excessive stimulation with light, noise, or questioning, providing familiar objects, and counseling carers on the best management approach for delusions and psychomotor agitation.

This study has a number of limitations. The study inception point was the presence of complete recovery from a delirium episode. Patients did not undergo close observation and/or video monitoring during their delirium so we are unable to report the frequency of symptoms during the actual delirium episode or categorize the severity for individual patients, as in Breitbart's study [20]. Further information on the descriptor characteristics of a delirium episode would be useful to characterize the likelihood of recall associated with different symptoms and different delirium subtypes, as well as to better define the characteristics associated with recall and distress among caregivers. However, our study provides greater information on distress and recall associated with specific symptoms of the delirium syndrome. We observed significant differences in frequency of recalled symptoms and overall distress elicited for the patient and their family caregiver vs. healthcare professional. These findings should assist researchers planning clinical studies in this area. Our study is limited to an assessment performed within three days after the resolution of a delirium episode. We are therefore unable to determine how long the distress will last. If this distress is very transient, distress overall might be less important. Future research should attempt to provide longer term follow up in these patients. For logistic reasons only daytime nurses were queried. Delirium symptoms may become worse at night and this might explain some of the differences in nurses reporting versus others reporting. It is possible that the information shared during nursing reporting at the end of shifts might not be sufficient with regard to symptoms of delirium. Future research should address potential reasons for these differences.

We conclude that symptom recall and distress occur in the vast majority of patients who recover from an episode of delirium and they are also a source of considerable distress to their family caregivers.

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Table 1

Patient and Family Caregiver Characteristics

	Patient	Family caregiver
Age, mean (Standard deviation)	60 (12)	55 (12)
Female (%)	46 (46)	72 (73)
Ethnicity (%)		
Caucasian	76 (77)	76 (77)
African-American	15 (15)	15 (15)
Hispanic	7 (7)	6 (7)
Asian	1 (1)	2 (2)
Total	99 (100)	99 (100)
Primary Cancer Diagnosis (%)		NA
Lung	30 (30)	
GI	20 (20)	
GU	13 (13)	
Breast	8 (8)	
GYN	8 (8)	
Leukemia	5 (5)	
Melanoma	5 (5)	
Other	10 (10)	
Total	99 (100)	
Median duration of acute episode of delirium in days (25 to 75 quartile)	3 (2–5)	NA
Median MDAS* Score (25 to 75 quartile)	3 (2–5)	NA
Median MMSE** Score (25 to 75 quartile)	28 (26–29)	NA
Educational Level (%)		
<6 years	1 (1)	0
6–9 years	4 (4)	1 (1)
9–12 years	37 (37)	28 (28)
College	41 (41)	54 (54)
Graduate school	15 (15)	13 (13)
Total	98 (99)	96 (97)
Relationship to patient (%)		
Spouse/significant others	----	61 (62)
Adult Child	----	21 (21)
Sibling	----	8 (8)
Friend	----	4 (4)
Parent	----	5 (5)
Total		99 (100)

MDAS* = Memorial Delirium Assessment Scale: MMSE** = Mini-Mental State Examination Both scores were obtained at the time of patient enrollment.

Table 2

Patient distress level according to the delirium experience question (DEQ) and delirium subtype

		N (%)	Number of Evaluable Reports (%)	Median Distress Level (Q1-Q3)	P value*
Remember	No	26 (26)	25 (96)	2 (0–4)	0.03
	Yes	73 (74)	69 (94)	3 (1–4)	
Delirium Subtype	Hypoactive	20 (20)	19 (95)	2 (0–3)	0.32
	Hyperactive	13 (13)	13 (100)	2 (2–4)	
	Mixed Delirium	66 (67)	62 (94)	3 (1–4)	
Gender	Male	53 (54)	49 (92)	3 (1–4)	0.67
	Female	46 (46)	45 (98)	3 (1–4)	
Race	White	76 (77)	74 (97)	2.5 (1–4)	0.40
	Non-White	23 (23)	20 (86)	3 (2–4)	

* P value reflects comparison in median distress level for each category

Table 3

Patients', family caregivers, clinical nurses and PCS' recall of different symptoms during delirium episode

	Patient (%)	Family Caregiver (%)	Nurse (%)	PCS*** (%)	P value
Auditory hallucinations	18 (18)	30 (31)	2 (3)	12 (13)	<0.01
Delusional thoughts	33 (33)	46 (47)	15 (19)	31 (33)	<0.01
Time Orientation	57 (58)	79 (80)	54 (68)	72 (77)	0.04
Place Orientation	52 (53)	75 (76)	46 (58)	66 (70)	0.01
Psycho-motor agitation	55 (56)	82 (83)	39 (49)	63 (66)	<0.01
Tactile hallucinations	12 (12)	25 (26)	8 (10)	9 (9)	0.01
Visual hallucinations	50 (51)	55 (56)	11 (14)	49 (52)	<0.01

PCS*** = Palliative Care Specialist

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Table 4

Median recalled symptom frequency score and distress score associated with different symptoms rated by those patients and family caregivers who reported symptom recall

	Recalled Symptom Frequency					Distress Score				
	Patient		Family Caregiver		P Value	Patient		Family Caregiver		P Value
	N	Median (Q1-Q3)	N	Median (Q1-Q3)		N	Median (Q1-Q3)	N	Median (Q1-Q3)	
Auditory hallucinations	18	2(1–2)	30	2(2–3)	0.14	17	3(2–3)	29	3(1–4)	0.38
Delusional thoughts	33	2(1–3)	46	2(1–3)	0.20	31	3(1–4)	45	3(2–4)	0.31
Time Orientation	57	3(2–4)	79	3(2–4)	0.87	56	3(1–3.5)	77	3(1–4)	0.69
Place orientation	52	2(1–4)	75	2(2–4)	0.74	52	3(1–4)	73	3(1–4)	0.19
Psycho-motor agitation	55	2(2–4)	82	3(2–4)	0.43	54	3(2–4)	80	4(3–4)	0.09
Tactile hallucinations	12	2(1–2.5)	25	2(1–3)	0.79	12	3.5(2–4)	23	3(1–4)	0.68
Visual hallucinations	50	2(1–3)	55	2(1–3)	0.93	49	2(1–3)	53	3(2–4)	0.001

Table 5

Table 5-a. Agreement Analysis on Recalled Symptom Frequencies												
	Patient/Family Caregiver		Patient/Nurse		Patient/PCS***		Family Caregiver/Nurse		Family Caregiver/PCS***		Nurse/PCS***	
Symptoms	**n***	**WK** (P)**	**n***	**WK** (P)**	**n***	**WK** (P)**	**n***	**WK** (P)**	**n***	**WK** (P)**	**n***	**WK** (P)**
Auditory hallucinations	93	0.38 (<0.01)	79	0.19 (<0.01)	92	0.2 (0.02)	78	0.03 (0.52)	93	0.18 (0.01)	80	0.26 (<0.01)
Delusional thoughts	95	0.29 (<0.01)	80	0.15 (0.09)	93	0.1 (0.26)	79	0.08 (0.3)	94	0.07 (0.36)	80	0.04 (0.63)
Time Orientation	91	0.28 (<0.01)	74	-0.08 (0.4)	87	-0.02 (0.79)	79	-0.03 (0.73)	94	0.01 (0.97)	78	0.19 (0.03)
Place orientation	91	0.26 (<0.01)	74	-0.01 (0.93)	87	0.06 (0.43)	80	0.09 (0.26)	94	0.01 (0.93)	79	0.18 (0.03)
Psycho-motor agitation	94	0.25 (<0.01)	79	0.13 (0.12)	90	0.09 (0.26)	80	0.13 (0.06)	95	0.06 (0.4)	80	0.08 (0.33)
Tactile hallucinations	93	0.18 (0.02)	79	0.09 (0.37)	91	-0.003 (0.97)	79	0.13 (0.12)	94	0.07 (0.34)	80	0.13 (0.18)
Visual hallucinations	96	0.45 (<0.01)	78	0.14 (0.01)	91	0.21 (0.01)	80	0.18 (<0.01)	94	0.24 (<0.01)	79	0.05 (0.38)

Table 5-b. Agreement Analysis on Symptom Related Distress Scores		
	Patient/Family Caregiver	
Symptoms	**n***	**WK** (P)**
Auditory hallucinations	75	0.44 (<0.01)
Delusional thoughts	76	0.28 (<0.01)
Time orientation	83	0.12 (0.17)
Place orientation	81	0.31 (<0.01)
Psycho-motor agitation	80	0.29 (<0.01)
Tactile hallucinations	69	0.39 (<0.01)
Visual hallucinations	80	0.30 (<0.01)

n* = Effective Sample Size

WK** = weighted kappa

PCS*** = Palliative Care Specialist

n* = Effective Sample Size

WK** = weighted kappa