Measuring the distress related to delirium in older surgical patients and their Relatives

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Abstract

Objective

Delirium is a common postoperative complication with implications on morbidity and mortality. Less is known about the psychological impact of delirium in patients and relatives. This study aimed to;

1. Quantitatively describe distress related to postoperative delirium in older surgical patients and their relatives using the distress thermometer
2. Examine the association between degree of distress and features of delirium on the Delirium Rating Scale (DRS)
3. Examine the association between recall of delirium and features of delirium on the Delirium Rating Scale (DRS)

Methods

This prospective study recruited postoperative patients and their relatives following delirium. The distress thermometer was used to examine the degree of distress pertaining to delirium and was conducted during the hospitalisation on resolution of delirium and then at 12 month follow up. Associations between delirium related distress in patient and relative participants and severity and features of delirium (Delirium Rating Scale) were examined.

Results

102 patients and 49 relatives were recruited. Median scores on the distress thermometer in patients who recalled delirium were 8/10. Relatives also showed distress (median distress thermometer score 8/10). Associations were observed between severity of and phenotypic features of delirium (delusions, labile affect, agitation). Distress persisted at 12 months in patients and relatives.

Conclusion

Distress related to postoperative delirium can be measured using a distress thermometer. Alongside approaches to reduce delirium incidence, interventions to minimise distress from postoperative delirium should be sought. Such interventions should be developed through robust research and if effective administered to patients, relatives or carers.

Introduction

Delirium is a common postoperative complication occurring in 20% of hospital inpatients[1]. It has significant implications in terms of increased morbidity and mortality rates[2,3]. Less is understood about patients' experiences of delirium and the longer term psychological morbidity attributable to the condition. Furthermore the psychological consequences of delirium may extend to involve relatives who observe the episode. With the increasing awareness of the importance of patient related outcome measures, describing the delirium experience for both patients and relatives is advocated in the National Institute for Health and Care Excellence (NICE) guideline on delirium[4].

To date the research examining the delirium experience has been conducted in heterogenous patient populations including critical care survivors, orthogeriatric patients and those receiving end of life care and the quantitative studies have predominantly recruited patients with cancer. Overall these studies suggest that in more than half of cases patients do recall delirium, and that this recollection can be distressing. Distress can be even greater in relatives witnessing delirium and may result in longer term psychological sequelae[5-13].

Distress related to a diagnosis of cancer has been increasingly described in the oncology literature. It is thought to affect participation in treatment, quality of life and satisfaction with treatment[14,15]. Various brief tools to detect distress in busy clinical environments have been developed and evaluated[16,17]. The distress thermometer (DT) is a self completion tool which asks patients to rate how distressed they have felt in the last week on a scale ranging from 0 (not distressed) to 10 (extremely distressed). It has been incorporated by the National Comprehensive Cancer Network (NCCN)[18] with a suggested optimal cut off for detecting significant distress of 3[19]. When compared against the Hospital Anxiety and Depression Scale (HADS) for detecting anxiety and depression in a sample of patients with cancer, and using a cut point of 3, the DT showed sensitivity of 0.84 and specificity of 0.80 with AUC 0.69[16].

Whilst prevention of delirium remains paramount, interventions to minimise the distress associated with delirium should be developed in parallel. In order to assess potential interventions to reduce delirium related distress a fuller understanding of the characteristics and impact in the postoperative population is required.

Objectives

1. To quantitatively describe the distress related to an episode of postoperative delirium in older surgical patients and their relatives using the distress thermometer

2. To examine the association between degree of distress and features of delirium on the Delirium Rating Scale (DRS)[20] both on resolution of delirium and at 12 month follow up

3. To examine the association between recall of delirium and features of delirium on the Delirium Rating Scale (DRS)

Methods

This observational study was set in an inner city teaching hospital in London. Consecutive patients undergoing surgical procedures (gastrointestinal, orthopaedic, urological or vascular) between June 2013 and May 2014 who met the inclusion and exclusion criteria below were eligible for recruitment.

Inclusion criteria

[A]

1. Aged 65+
2. Surgical inpatients following operative procedure (orthopaedic, upper and lower gastrointestinal, vascular, urology)
3. Postoperative delirium, diagnosed using the Confusion Assessment Method (CAM)[21]

[B]

Attending relatives of those patients recruited (if they observed the delirium)

Exclusion criteria

1. Severe cognitive impairment limiting ability to read, comprehend or complete short questionnaire
2. Patient judged by their attending doctors to be dying and close to death
3. Patients or relatives unable to speak sufficient English to participate in the study without the use of a translator

Recruitment and consent

Patients who screened positively (≥4) on the 4AT[22] were assessed for delirium using the CAM. Those without delirium continued to receive daily screening using CAM in case delirium developed during the admission. 4AT negative patients were also flagged to the research team if the usual care team noted clinical features of delirium (e.g. drowsiness, inattention, fluctuation throughout the day). Once delirium was diagnosed, the capacity of the patient to consent to participation in the study was assessed by a research fellow or nurse in accordance with the Mental Capacity Act (2005). Patients with capacity signed a written consent form after verbal and written explanation of the study. Those who lacked capacity were managed according to sections 30-34 of the Mental Capacity Act (2005) with the use of a personal or nominated consultee.

Relatives (one or more) of patient participants were also approached for recruitment and consented, if they had observed the episode of delirium. They were identified through patient participants. Initial contact was either made by the research team on the ward or by telephone.

Tools

The Delirium Rating Scale R98 (DRS R 98) was used to examine features of the delirium. This validated tool is a 16 item scale with a maximum total scale score of 46 points (includes three diagnostic items) and a maximum severity score of 39 points. It has good internal reliability (Cronbach's alpha coefficient 0.9) and good interrater reliability[22].

The degree of delirium related distress was measured using the distress thermometer described previously. Originally designed to measure cancer related distress this tool was piloted in preliminary work showing acceptability to patients and nursing staff. No adaptions were made to the tool for this study.

Data collection

Once recruited and consented, patients were assessed daily using the Delirium Rating Scale (DRS) in order to ascertain the severity, duration and specific symptoms of delirium e.g. presence of delusional symptoms or motor agitation etc. Drugs used to treat delirium were recorded (antidopaminergics or benzodiazepines). The surgical procedure, nature of admission (i.e. elective or emergency) and baseline demographic and medical data was recorded. In patients who had undergone elective surgery it was noted whether any verbal or written information on the risk of postoperative delirium had been recorded as having been provided.
Following resolution of delirium, participating patients and relatives completed a short questionnaire about their recall and experience of delirium (appendix 3&4). Patients also underwent brief cognitive assessment using the Montreal Cognitive Assessment (MoCA)[23] and completed a Hospital Anxiety and Depression Score (HADS)[24] questionnaire. This initial questionnaire and cognitive assessment was undertaken up to a week after delirium resolution whilst the patient was still an inpatient. The questionnaire was repeated at 12 months after resolution of delirium.

Sample size calculation

Using pilot data (examining delirium related distress measured on the distress thermometer in older postoperative patients) the sample size was calculated at 68 patients (based on a standard deviation of 2.1 and a standard error of 1). Assuming (based on previous literature[5]) that between one half and two thirds of patients will recall the delirium we aimed to recruit 102 patients.

Data analysis

Patient characteristics were summarised as frequency (percentage), mean (standard deviation) or median (interquartile range). Age of patients who recalled delirium was compared to those who did not using the T-test, number of co-morbidities and disease severity compared using the Mann-Whitney test and all other characteristics compared between the two groups using Chi-square or Fisher's exact tests, as appropriate. Correlations between distress score and continuous characteristics (age, number of co-morbidities and disease severity) were assessed using Kendall's Tau-b and distress scores compared across other characteristics using the Mann-Whitney test for two groups and the Kruskall Wallis test for three or more. Associations between relative distress scores, patient characteristics and disease severity were explored in the same way. Analysis was conducted using data from all participating relatives, followed by a sensitivity analysis where one relative was randomly selected (where two or more relatives provided data relating to the same patient).

Characteristics associated with the odds of remembering delirium were identified using multivariable logistic regression, and then linear regression used models to

identify characteristics associated with degree of distress among only those who recalled delirium. For both models, factors which had a p-value of <0.1 in unvariable analysis were carried forward to multivariable models which also adjusted for age. Insignificant variables were then removed using backwards elimination.

In analysis of delirium severity the mean DRS was used. A sensitivity analysis was carried out in which highest DRS scores were used instead. Parameter estimates and p-values were very similar and choice of scoring algorithm did not alter conclusions and so only results using means are presented.

Analysis was conducted using stata 13MP.

Results

One hundred and thirteen potential patient participants were approached of whom sixty two had capacity to consent. One hundred and two patient participants were recruited into the study (fig 1). Nine potential patient participants with capacity declined with the majority of these stating they did not want to discuss the delirium. Two personal consultees declined on behalf of potential patient participants without capacity. Forty three relative participants were approached and all consented to study participation (figure 1).

The relationships between patient characteristics and recall of delirium are summarised in Table 1. The likelihood of recalling delirium did not differ significantly across any of the patient characteristics.

Table 1 – Patient recall of delirium by patient characteristics

The median distress score on the distress thermometer was 6 [IQR 2-9] and differed significantly between those who did and did not recall delirium (patients who recalled: median = 8 [4-9] versus 2 [0-5] in those who did not, p<0.001). There was also a weak negative correlation between distress score and age in all patients (tau=-0.16, p<0.033) and a slightly weaker, but non-significant correlation in only patients who recalled delirium (tau=-0.14, p=0.118). No association was seen between level of distress and other baseline patient characteristics across the whole group or if those who recalled delirium were analysed separately (table S1). As per our hypothesis, the level of distress was higher in those who recalled delirium. There was no difference in delirium related distress between those patients who received preoperative verbal or written information on the risk of postoperative delirium and those who did not.

The relationships between severity of delirium, recall of delirium and distress are summarised in table 2. The first columns compare distress scores in those who did and did not recall delirium while the last two summarise the correlation between mean DRS and distress. Perceptual disturbance, delusions and lability of affect were all significantly associated with degree of distress.

Table 2: Associations between patient recall of delirium/degree of distress and the DRS

Data were collected from 43 relatives of 38 patients. The median level of distress recorded on the distress thermometer in relatives who witnessed delirium was 8/10 [7-9]. Carer distress increased significantly with duration of delirium (tau=0.307, p=0.009). DRS severity score (t=0.363, p=0.002) and total score (0.318, p=0.006) were also positively associated with carer distress. The individual features associated with carer distress were lability of affect (tau=0.744, p=0.021), language (tau=0.253, p=0.034), thought process (tau=0.386, p=0.001), motor agitation (tau=0.264, p=0.001) and orientation (tau=0.296, p=0.015). In a sensitivity analysis one relative was randomly selected for the five patients where two provided data. Findings were unchanged when analysis was repeated on this subsample (Table S2).

Finally models were fitted to identify factors which were independently associated with patient recall of delirium and distress. Logistic regression was used to identify factors (patient characteristics and DRS items) associated with recall of delirium after adjusting for age. In these models perceptual disturbance was the only factor identified to significantly influence recall of the delirious episode (OR=1.94, 95% CI 1.19-3.17, p=0.008). Linear models were used to examine features of delirium associated with higher distress scores. Only emergency surgery was significant after adjustment for age (beta=-2.6, 95% CI -5.2- -0.1, p=0.044).

Next the associations between features of delirium/delirium severity and distress at 6 and 12 months in patients and carers were explored (table 3). In patients, at 12 months the duration of delirium was positively correlated with degree of distress. Orientation and thought process was negatively associated with distress. Though sample sizes are very small it does appear there is a high correlation at both 6 and 12 months between the mean DRS score and distress in carers

Table 3: Associations between degree of distress and the DRS at follow up in patients who recalled delirium and their carers

Discussion

This is the first study to explore the level of distress related to postoperative delirium in patients and their relatives and describe the features of delirium most associated with delirium related distress. It shows considerable delirium related distress in those who recall postoperative delirium (median score on DT 8/10 [4-9]) with distress scores seen in relatives who observed delirium (median score on DT 8/10 [7-9.5]). Whilst no associations exist between baseline patient characteristics and delirium related distress, clear associations were observed between the severity of delirium (measured using DRS) and phenotypic features of delirium and level of delirium related distress. Clinical features associated with distress were similar in patients and relatives and include duration of delirium, presence of delusions, abnormal thought processes, labile affect, language disturbance, agitation and disorientation.

There were limitations to this study. In particular data were only available from relatives of 38 of 102 patients and follow-up data were only provided from seven and 15 patients at 6 and 12 months respectively. Although the available data can give some indication of the long term impact of delirium on distress of patients and carers in the long term, a larger sample would be need to explore this further in order to negate the impact from possible bias due to non-completion of longer term follow up. Furthermore the measurement of the emotional concept of distress is inherently problematic. Attempts to mitigate this were undertaken in this study by using the distress thermometer which has already been validated in the measurement of cancer related distress and is endorsed for use clinically by the National Comprehensive Cancer Network (NCCN). The potential for recruitment bias exists and within this study no conclusive comment can be made on whether those with a traumatic experience of delirium were more or less likely to participate. Of note though, in the co-design of the study, offering an opportunity to discuss the delirium related distress was favoured by both patients and relatives who had experienced postoperative delirium during previous hospital episodes. Finally the lack of a control group is an acknowledged limitation. Whilst this was beyond the scope of this study, previous work has reported that symptoms of anxiety and depression are more prominent in patients following haematopoetic cell transplantation if they suffered from delirium once adjusting for potential confounders including disease severity, comorbidity, steroid usage and pain [11, 12].

These findings are in keeping with similar studies in other patient populations especially those with cancer who experience delirium during hospitalisation[5]. However the longer term one year follow up in the present study adds to our understanding of this issue. Whilst numbers were small, predominantly due to death/attrition from study, the negative impact of delirium on the perception of distress appeared to persist at 12 month follow up. This is relevant in terms of both necessary translation of results into clinical services and future research in this field. Delirium related distress is already thought to result in higher rates of symptoms of depression and non-engagement in future treatments[14,15] so potential interventions to modify this negative consequence of delirium should be developed and evaluated in the clinical setting. At present no ‘delirium distress’ intervention exists but this should be a focus of future research in this field.

Conclusion

This study has shown high levels of postoperative delirium related distress in both elective and emergency surgical patients and their relatives who observed the delirium persisting at 12 month follow up. Alongside established efforts to reduce the incidence of delirium attempts should also be made to minimise the impact of this common condition. Such supportive interventions should be derived through robust research methodology and if effective administered clinically to both patients and their relatives or carers.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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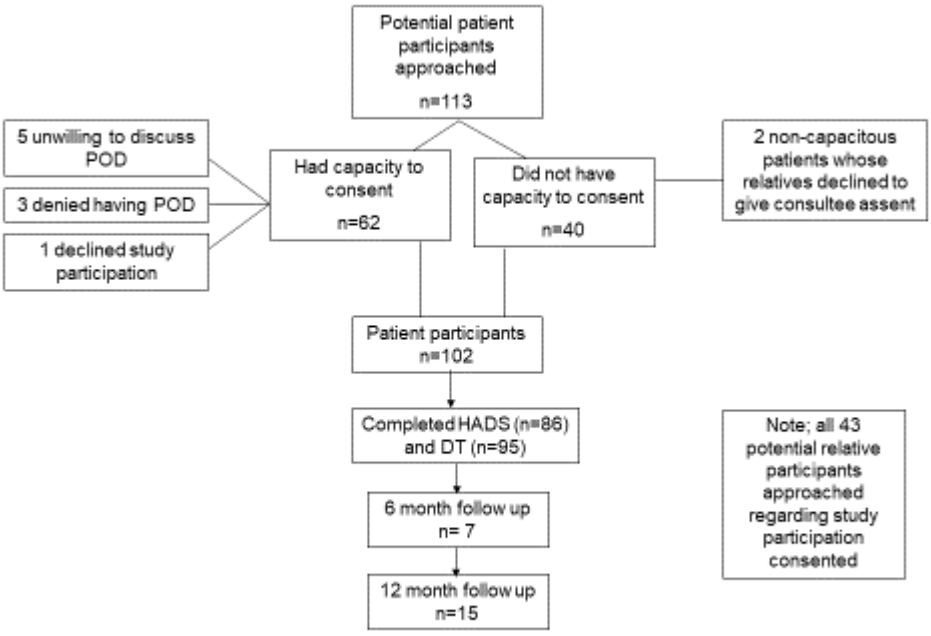


Figure 1. Recruitment into study

Table 1 – Patient recall of delirium by patient characteristics

	All, n (%)	Did not recall delirium, n (%)	Recalled delirium, n (%)	p-value
All	102	27	67	
Age, mean(sd)	78.7(7.3)	80.0(7.5)	78.5(7.3)	0.383
White Ethnicity	87(88.8)	23(85.2)	56(85.6)	0.999
12+ years in education	14(16.9)	4(14.8)	10(14.9)	0.950
Male	69(67.7)	16(59.3)	47(70.1)	0.310
Current smoker	17(17.0)	5(18.5)	10(14.9)	0.894
Alcohol consumption (per week)				
None	41(42.7)	14(51.9)	24(35.8)	0.386
<15 units (f) or <22 units (m)	35(36.5)	7(25.9)	25(37.3)	
>14 units (f) of >21 units (m)	20(20.8)	5(18.5)	13(19.4)	
Number of co-morbidities, median (IQR)	5.5(4-8)	6(4-8)	6(4-8)	0.987
Elective surgery	49(48.0)	13(48.1)	32(47.8)	0.973
Surgical subspecialty				
Urological	12(11.8)	2(7.4)	7(10.4)	0.296
GI	21(50.6)	6(22.2)	13(19.4)	
Vascular	50(49.0)	11(40.7)	36(53.7)	
Orthopaedic	17(16.7)	6(22.2)	11(16.4)	
Head and neck	1(1.0)	1(3.7)	0	
Gynaecological	1(1.0)	1(3.7)	0	
History of cognitive impairment	77(75.5)	19(70.3)	52(77.6)	0.596
Recalled delirium	67(71.3)	NA	NA	
Drugs used to treat delirium	33(32.4)	10(37.0)	18(26.8)	0.332
Patient warned of possibility of delirium	14(14.9)	5(18.5)	9(13.4)	

Table 2: Associations between patient recall of delirium/degree of distress and the DRS

	All, median (IQR) or mean (sd)	Did not recall delirium, median (IQR) or mean (sd)	Recalled delirium, median (IQR) or mean (sd)	p-value	Distress * Kendall s tau	p-value
Delirium duration	4(2-7)	5(2-7)	3(2-5)	0.484	0.14	0.142
DRS (mean) Severity score	19.8(6.6)	18.7(5.5)	20.3(6.9)	0.280	0.202	0.023
DRS (mean) severity items						
Sleep wake cycle	2(1-2)	2(1-2)	2(1-2)	0.632	0.101	0.290
Perpetual disturbance	1.2(0.7-2.3)	1(0-2)	1.6(1-3)	0.010	0.012	0.903
Delusion	1(0.5-2)	0.7(0-1.7)	1(0.5-2)	0.029	0.198	0.034
Lability of affect	2(1.3-2.2)	2(1-2)	2(1.3-2.2)	0.275	0.238	0.012
Language	1(0.3-1)	0.9(0.3-1)	1(0.3-1.4)	0.374	-0.009	0.928
Thought process	2(1.7-3)	2(1.5-2.3)	2(1.7-3)	0.076	0.152	0.110
Motor agitation	1.5(0.6-2)	1.5(0.5-2)	1.5(0.5-2)	0.751	0.126	0.174
Motor retardation	0.5(0-1.5)	1.5(0.5-2.8)	1(0-2)	0.270	-0.102	0.287
Orientation	2(1.5-2)	2(1.5-2)	2(1.5-2)	0.618	-0.015	0.877
Attention	2(1.6-2.7)	2(1.5-2.7)	2(1.5-3)	0.831	0.053	0.582
Short term memory	2(1.5-3)	2(1.5-3)	2(1.5-2.7)	0.840	0.142	0.135
Long term memory	0(0-1)	0(0-1)	0(0-0.7)	0.479	0.322	0.001
Visio-spatial	1.6(1-2)	1.8(1-2.8)	1.6(1-2)	0.464	0.131	0.164
Temporal onset of symptoms score	3(2-3)	3(2-3)	3(2-3)	0.387	0.001	1.000
Fluctuation of symptoms score	1(1-2)	1(1-2)	1(1-2)	0.089	0.174	0.099
Physical disorder score	2(2-2)	2(2-2	2(2-2)	0.033	-0.193	0.079
DRS (mean) Total Score	26.0(5.8)	24.2(6.1)	26.3(5.8)	0.122	0.170	0.063

*Patients who recalled delirium only

Table 3: Associations between DRS and degree of distress at follow up in patients who recalled delirium and their carers

	Patient Distress*				Carer distress			
	6 months, n=7		12 months, n=15		6 months, n=5		12 months, n=6	
	Kendalls tau	p-value	Kendalls tau	p-value	Kendalls tau	p-value	Kendalls tau	p-value
Baseline distress	-0.55	0.125	0.177	0.416	0.134	1.00	0.276	0.566
Delirium duration	-0.15	0.759	0.453	0.041	0.252	0.776	0.356	0.492
DRS (mean) Severity score	-0.450	0.219	-0.183	0.391	0.756	0.154	0.714	0.080
DRS (mean) severity items								
Sleep wake cycle	-0.067	1.000	-0.126	0.613	0.134	1.000	-0.214	0.697
Perpetual disturbance	-0.231	0.612	-0.011	1.000	0.429	0.533	-0.414	0.339
Delusion	-0.103	0.877	0.089	0.715	0.429	0.533	0.297	0.552
Lability of affect	0.000	1.000	0.123	0.599	0.756	0.154	0.643	0.120
Language	-0.418	0.304	-0.298	0.185	0.252	0.776	-0.309	0.545
Thought process	-0.264	0.526	-0.461	0.038	0.429	0.533	0.077	1.000
Motor agitation	-0.550	0.125	-0.262	0.233	0.252	0.776	0.661	0.159
Motor retardation	-0.109	0.873	0.057	0.831	-0.143	1.000	0.232	0.682
Orientation	-0.418	0.304	-0.475	0.034	0.714	0.213	-0.232	0.682
Attention	-0.380	0.336	-0.121	0.623	0.571	0.350	0.161	0.835
Short term memory	-0.685	0.059	-0.241	0.294	0.267	0.769	0.178	0.819
Long term memory	-0.194	0.721	-0.041	0.903	0.378	0.693	0.445	0.360
Visio-spatial	-0.513	0.162	-0.057	0.833	0.252	0.776	0.694	0.106
Temporal onset of symptoms score	0.000	1.000	0.295	0.233	0.000	1.000	0.598	0.235
Fluctuation of symptoms score	-0.194	0.721	0.233	0.351	-0.378	0.693	0.756	0.100
Physical disorder score	-0.183	0.801	0.000	1.000	0.000	1.000	0.000	1.000
DRS (mean) Total Score	-0.586	0.095	-0.140	0.540	0.756	0.154	0.857	0.032

*Patients who recalled delirium only

Appendices

Appendix 1 - Table S1 – Patient recall of delirium and degree of distress by patient characteristics

	All patients, n=102		Recalled delirium only, n=67	
	Distress, median (IQR)	p-value	Distress, median (IQR)	p-value
All				
Age*	-0.16	0.033	-0.14	0.118
Ethnicity				
White	5.5(2-9)	0.419	7.8(5-9)	0.830
Non-White	7(2-10)		7.5(1.8-9.5)	
Time in education				
Over 12 years	6(3-10)	0.352	7.5(3-10)	0.678
12 years or less	5.8(2-8)		7(3.5-8.3)	
Gender				
Male	7(2-9)	0.584	8(3-9)	0.868
Female	5.5(2-8)		7.5(5-8.8)	
Smoking status				
Never Smoked	6.5(2-10)	0.591	8(2-10)	0.989
Current smoker	7(0-8)		7.8(7-8)	
Ex-smoker	5.5(1.5-9)		7(5-9)	
Alcohol consumption (per week)				
None	5.8(2-8)	0.781	7.5(5-9)	0.875
<15 units (f) or <22 units (m)	6(2-9.5)		8(3-10)	
>14 units (f) of >21 units (m)	7(2-9)		7(5-9)	
Number of co-morbidities*	0.077	0.319	0.08	0.394
Surgery type				
Elective	7(5-9)	0.098	8(5-9)	0.436
Emergency	5(1.5-8)		7(3-9)	
Surgical subspecialty				
Urological	6(3-8)	0.986	7(3-10)	0.987
GI	5(3-9)		8(4-9)	
Vascular	7(1-9)		7.8(2.5-9)	
Orthopaedic	5.5(5-8)		8(5-9)	
History of cognitive impairment				
No	6(2-9)	0.849	8(4-9)	0.982
Yes	7(2-10)		7(4-10)	
Recalled delirium				
No	2(0-5)	<0.001		
Yes	8(4-9)			
Drugs used to treat delirium				
No	6.5(2-9)	0.983	7.5(5-9)	0.955
Yes	6(2-9)		8(3-9)	
Patient warned of possibility of delirium				
No	7(2.5-9)	0.397	7(2-9)	0.328
Yes	5.5(1-9)		8(5-9)	
Can’t remember	4(0.8-7.5)		7(2-8)	

*Kendalls tau-b.

Appendix 2 - Table S2 – Relationship between relative and patient characteristics and relative distress.

	All, n(%) or median (IQR)	Distress, median (IQR) or Kendalls tau	p-value
All	43	8(7-9.5)	
Relationship to patient			
Spouse	18(41.9)	8.5(7-10)	0.478
Son/daughter	17(39.5)	8(7.5-8)	
Other	8(18.6)	7.5(6-9)	
Relative warned about delirium			
No	34(81.0)	8(7-10)	0.425
Yes	8(19.1)	7.5(6-9)	
Delirium explained to relative			
No/can't remember	28(65.1)	8(6-10)	0.445
Yes	15(34.9)	8(7.5-9)	
Patient recall of delirium			
No	7(17.5)	8(7.5-10)	0.459
Yes	33(82.5)	8(7-9)	
Patient distress	6(1.8-9)	0.237	0.052
Delirium duration	5(3-11)	0.307	0.009
DRS (mean) Severity score*	21.5(6.9)	0.363	0.002
DRS (mean) severity items			
Sleep wake cycle	2(1-2)	0.252	0.039
Perpetual disturbance	1(1.5-2.5)	0.085	0.475
Delusion	1.3(0.5-2.5)	0.196	0.097
Lability of affect	2(1.3-2.1)	0.274	0.021
Language	1(0.3-1.5)	0.253	0.034
Thought process	2(2-3)	0.386	0.001
Motor agitation	2(0.8-2)	0.264	0.027
Motor retardation	1(0-2)	-0.125	0.304
Orientation	2(1.5-2)	0.296	0.015
Attention	2(1.6-3)	0.078	0.530
Short term memory	2(1.5-2.5)	0.182	0.132
Long term memory	0(0-0.5)	0.125	0.324
Visio-spatial	1.8(1.2-2.0)	0.131	0.276
Temporal onset of symptoms score	3(2-3)	-0.228	0.086
Fluctuation of symptoms score	2(1-2)	-0.003	0.990
Physical disorder score	2(2-2)	0.079	0.572
DRS (mean) Total Score*	26.9(5.0)	0.318	0.006

*Summarised as mean (sd)

URN:

Measuring the distress related to delirium – patient questionnaire

Thank you for taking the time to complete this questionnaire. As part of a research project we are trying to find out more about how patients and their families and carers feel about some aspects of having an operation.

We estimate that it will take about 5 minutes to complete this survey. There are no right or wrong answers. Your responses are completely **anonymous** and **confidential.** They will not be seen by your doctors and nurses. We do not need your name.

When you have completed the questionnaire please hand it back to the researcher.

Thank you very much for your help in filling out the questionnaire. If you would like any further information about this research or if you have any questions at all please email xxx or call xxx

URN:

Delirium Experience Questionnaire - patient

1. Do you remember being confused at all when you were in hospital?

   a) Yes…… ☐

   b) No…… ☐

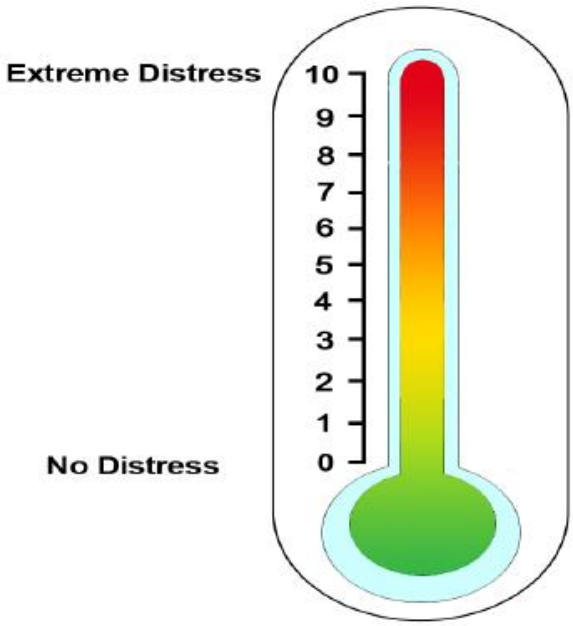
If you answered 'Yes' to Q1 please go on to answer Q3 and Q4.

If you answered 'No' to Q1 please go on to answer Q2 and then Q4.

2. Does it upset you that you can't remember this?

   Please mark how distressed you feel on the thermometer below.

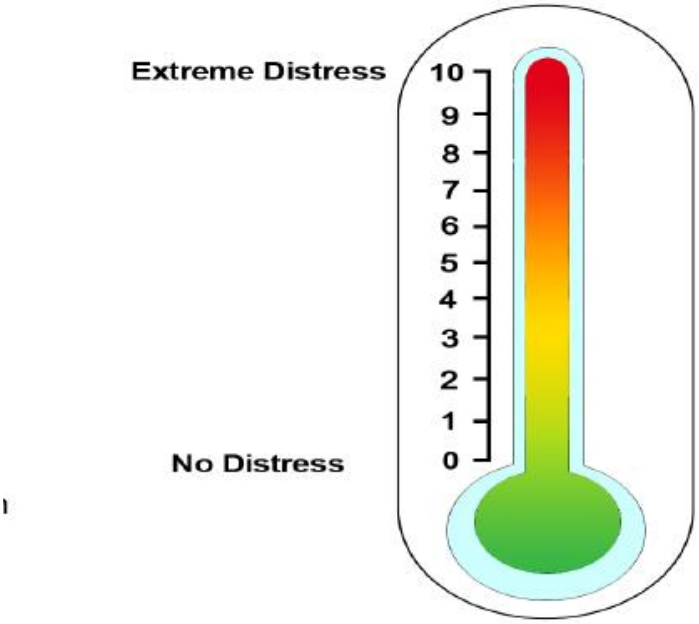
   0 is 'not at all distressed' and 10 is 'extremely distressed'.



3. How distressed were you ***by being confused*** in hospital?

Please mark how distressed you feel related to this confusion on the thermometer below

0 is 'not at all distressed' and 10 is 'extremely distressed'.



4. Were you warned that you might get confused after your operation?

a) Yes…… ☐

b) No…….. ☐

c) I don't remember……... ☐

THAT IS THE END OF THE SURVEY. THANK YOU FOR YOUR TIME IN COMPLETING IT.

Do you have anything else you would like to say about this subject? Please continue on a separate sheet if necessary.

URN:

Measuring the distress related to delirium – relative / friend / carer questionnaire

Thank you for taking the time to complete this questionnaire. As part of a research project we are trying to find out more about how patients and their families and carers feel about some aspects of having an operation.

We estimate that it will take about 5 minutes to complete this survey. There are no right or wrong answers. Your responses are completely **anonymous** and **confidential.** They will not be seen by your doctors and nurses. We do not need your name.

When you have completed the questionnaire please hand it back to the researcher.

Thank you very much for your help in filling out the questionnaire. If you would like any further information about this research or if you have any questions at all please email xxx or call xxx

URN:

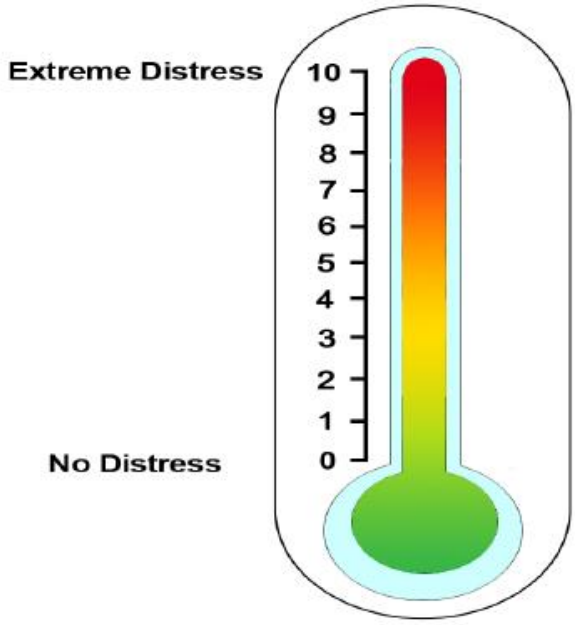
Delirium Experience Questionnaire – relative / friend / carer

1. After their operation your relative / friend became confused. We know that this can be upsetting to see.

   How distressed did it make you feel to see your relative / friend when they were confused?

   Please mark how distressed you feel on the thermometer below.

   0 is ‘not at all distressed’ and 10 is ‘extremely distressed’.



2. Were you warned that your friend/relative may get confused after their operation?

   a) Yes……☐

   b) No……☐

   c) I can’t remember……☐

3. Did anybody explain the confusion to you?

d) Yes……☐

e) No……..☐

f) I can't remember……☐

3. Please describe your relationship to the patient (e.g. daughter, son, niece, nephew, friend, neighbour etc)

…….

THAT IS THE END OF THE SURVEY. THANK YOU FOR YOUR TIME IN COMPLETING IT.

Do you have anything else you would like to say about this subject?
Please continue on a separate sheet if necessary.