

DELIRIUM RELATED DISTRESS EXPERIENCED BY PATIENTS, CAREGIVERS AND NURSING STAFF IN A MEDICAL INTENSIVE CARE UNIT (ICU)

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ABSTRACT

BACKGROUND

Delirium, a common neuropsychiatric syndrome in intensive care settings is a distressing experience for the patient, caregivers and nursing staff. Research on delirium experience has been scant and unsystematic. We set out to explore the extent of recall of delirium, differential distress it had on patients, caregivers and nursing staff and the extent to which it impacted recognition across the motoric subtypes.

MATERIALS AND METHODS

A prospective study was carried out on all consecutively admitted patients in the medical ICU of a tertiary care teaching hospital. Patients diagnosed with delirium using Confusion Assessment Method for ICU (CAM-ICU) were administered the Richmond Agitation Sedation Scale (RASS) for differentiating the motor subtypes (hypoactive, hyperactive, mixed). Distress was assessed using the Delirium Experience Questionnaire (DEQ).

RESULTS

Of the 88 patients (31.43%) who developed delirium, 60.2% recalled their experience. Recall was highest in the hyperactive subtype. 76% of patients, 94.3% of caregivers and 31.8% of nursing staff reported severe levels of distress. Motoric subtypes did not impact on the distress levels experienced by the patients or their caregivers, but influenced it significantly in the nursing staff (highest in hyperactive, least in hypoactive). Identification of delirium by nursing staff (13.4%) was significantly influenced by the motor subtypes (highest in hyperactive, least in hypoactive). Linear regression analysis revealed that distress of ICU staff ($F=1.36$, $p=0.018$) and not the motoric subtypes ($F=1.36$, $p=0.262$) significantly predicted recognition of delirium.

CONCLUSIONS

Most patients who develop delirium and their caregivers experience high levels of distress. Under-recognition is significantly influenced by the distress it causes the ICU staff than the motor subtype of delirium.

KEYWORDS

Delirium, Distress, Intensive care, Nursing staff, Caregivers.

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BACKGROUND

Delirium is an acute neuro-psychiatric syndrome common in hospitalized medical settings, especially critical care units.¹ Extensive literature already exists on the morbidity, mortality and risk factors of this condition.²⁻⁵ However, research into the psychological aspects of this syndrome has been neglected.⁶ Despite being classically described as an acute confusional state with anterograde amnesia, the experiences of those who were able to recollect it describe it as an

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extremely distressing, unpleasant, fearful and threatening experience.⁶ While a few studies have qualitatively recorded this distress they are plagued by small sample size and methodological limitations.⁷⁻⁹

The distress of relatives who care for patients in delirium has long been ignored. Feelings of loss, insecurity and mistrust have been reported when a loved one experiences an acute confusional state.¹⁰ These emotions are not only more prevalent than previously thought, but also much more severe than even the suffering experienced by the patients themselves.^{11,12} Buss et al., in a study among 200 caregivers found that stress and anxiety was twelve times more in those who witnessed delirium than those who did not.¹³

Managing patients with delirium is a stressful event for the medical team. As the nursing staff tend to be the ones who have the most contact with patients, they are generally acknowledged to have the greatest distress.¹⁴ Breitbart et al., in a survey of 101 nurses involved in the care of cancer

patients with delirium reported that 73% suffered severe distress.¹² In ICU settings, this distress is multiplied as the pressure to maintain a calm environment, workload and critical care protocols which places enormous burden on the best of nursing teams.

In consultation liaison psychiatry, delirium is one of the most under recognized, misdiagnosed and under treated conditions. This is especially true of the hypoactive subtype of delirium. One of the biggest barriers in the effective management of delirium is its non-recognition. We hypothesized that this non-recognition would be due to the lack of appreciation of distress experienced by patients and caregivers by the ICU staff. This is more often seen in hypoactive delirious states by virtue of the absence of overt behavioral problems. Since this has important therapeutic implications, clinicians might be more likely to recognize and treat delirium, if they were aware that it is in fact a distressing experience with high morbidity and mortality.

MATERIALS AND METHODS

This was a non-experimental study carried out in the medical ICU of a tertiary care teaching hospital for a period of 6 months. Patients who were comatose throughout their stay, severe aphasia that interfered with the assessment and non-consent from caregivers were excluded. All consecutive patients were assessed within 24 hours of their ICU admission. The end point was either a positive identification of delirium, discharge of patient from ICU or mortality.

Delirium was assessed using the Confusion Assessment Method- Intensive Care Unit version (CAM-ICU). This diagnostic scale for delirium was specifically developed for use even in non-verbal (i.e. mechanically ventilated) patients. With the CAM-ICU, delirium is diagnosed when patients demonstrate: an acute change in mental status or fluctuating changes in mental status, inattention measured using either an auditory or visual test and either disorganized thinking or an altered level of consciousness. CAM-ICU has a sensitivity of 95% to 100%, specificity of 93% to 98%, and inter-rater reliability of 0.79 to 0.95 (18). The scale was administered every day twice (morning and evening) to all admitted patients till discharge (or mortality) as delirium could occur anytime during the ICU stay. Those who were diagnosed with delirium were administered the following scales:

A) The Richmond agitation-sedation scale (RASS) to assess the motor subtype of delirium based on the level of arousal. It is a 10-point scale ranging from +4 to -5 with a score of 0 denoting a calm and alert patient. Hyperactive delirium was defined as having a RASS scores +1 to +4 on every CAM-ICU positive testing. Hypoactive delirium was defined when RASS scores were 0 to -3 on every CAM-ICU positive testing and mixed delirium when some RASS scores are +1 to +4 and some RASS scores are 0 to -3 (19).

B) Delirium Experience Questionnaire (DEQ) to assess delirium related distress in patients (after recovery), caregivers, and ICU staff. It is a simple face-valid tool that uses a 0-4 numerical rating scale (NRS 0 equal to "not at all" and 4 equal to "extremely") to quantify delirium related

distress in patients, caregivers, and nurses (12). This is the only scale available that quantifies delirium related distress and has been used in studies exploring this construct (20). MINITAB 17 statistical software was used for data analysis.

RESULTS

Out of 280 patients, 88 patients developed delirium (31.43%) during their ICU stay. Among this group, 51 were male (57.95%) with a mean age of 56.7 (SD 18.9) years. Their delirium lasted for 4.15 (SD 3.06) days. The number of days spent in the ICU was significantly greater for patients with delirium (T-value=4.23, 95% CI 1.778 to 4.919, p-value 0.000). Mortality (in-hospital or one-month post-discharge) of patients with delirium was significantly greater than those who did not experience delirium (Chi-square=6.867, p-value 0.009).

The distress experienced due to delirium was assessed for 83 patients (the remaining 5 were either discharged against medical advice or died before recovering from delirium preventing assessment of distress). 60.2% (n=50) recalled their delirium experience, with the highest recall in hyperactive and lowest in hypoactive subtypes (Chi-square=13.138, p-value 0.001, statistically significant). Among them, 38 patients (76%) reported their experience as severely distressing (NRS 3-4), while 12 (24%) reported no or moderate distress (NRS 0-2). Of the 88 primary caregivers of patients with delirium, 94.3% reported severe distress while the remaining 5.7% reported no to moderate distress. 31.8% of the ICU staff experienced severe distress while 68.2% experienced no to moderate distress while caring for patients with delirium.

Based on motoric subtypes (RASS), 49 (55.7%) had hypoactive, 30 (34.1%) hyperactive and 9 (10.2%) mixed type of delirium. A one-way analysis of variance (ANOVA) did not reveal any significant difference in *patient's experience* of distress across the motoric subtypes of delirium, (F=3.07, p-value 0.067). Motoric subtypes of delirium did not make any significant difference to the levels of distress experienced by *caregivers* of delirious patients (F=0.64, p-value 0.534). However, the distress levels of *ICU staff* significantly differed across the motoric subtypes of delirium (F=24.20, p-value 0.000) with the greatest distress in hyperactive, and least distress in hypoactive delirium.

Identification of delirium by the ICU staff was only 13.4% (n=12). Identification was significantly affected by motor subtypes, (Chi-square= 12.97, p-value 0.002) with the highest identification of 30% for hyperactive delirium and lowest rate of 2.04% for hypoactive delirium. Identification was also significantly determined by distress experienced by ICU staff while caring for delirium patients (F=19.14, p-value 0.001). Using recognition of delirium by ICU staff as a response variable and motoric subtype and distress level of staff as predictor variables, a binary logistic regression analysis was carried out. Results indicated that there was a collective significant association between motoric subtypes, levels of distress and recognition of delirium (Chi-square=18.93, p-value 0.000, df=3). The individual predictors were examined further, which indicate

that distress of ICU staff (Chi-square=4.78, $p=0.029$) and not the motoric subtypes (Chi-square=2.91, p -value 0.233) significantly predicted recognition of delirium in the model.

As noted earlier, this differential distress perceived by the ICU staff did not correlate with either the patient's or caregiver's distress across the motoric subtypes of delirium. To explain, while patients and caregivers did not experience significant differences in distress levels across the motoric subtypes, the ICU staff did. This distress was significantly lower for hypoactive subtype of delirium. Thus the under-recognition of hypoactive delirium, varied by virtue of it causing the least distress to the ICU staff (while causing the same levels of distress as other motoric subtypes to the patient and caregivers alike).

DISCUSSION

We set out to explore delirium related distress experienced by patients, caregivers and the nursing staff in an intensive care unit setting. Previous research in this area are scant and thus our findings should be interpreted with caution. About 60% of delirium patients in our study recalled their experience. Traditionally, delirium has been described as a state of confusion with little or no recall of the experience. However, recently there is growing evidence from qualitative and quantitative studies to disagree to this view.⁷⁻⁹ In fact, a systematic study on elderly cancer patients reported that about 54% of 101 recalled their delirium experience. An Indian study reported a recall rate of 28.3% in 53 patients. However, the study used a convenience sampling technique which could have influenced the results. We reported a significant difference in recall of delirium across the motor subtypes, with patients with hyperactive subtype recalling their experience more than hypoactive delirious patients. This makes sense as a significant number of patients with hypoactive delirium were on ventilator (Chi-square=8.723, p -value 0.013), and greater medical comorbidity (T-value=1.96, p -value 0.049).

We noted that the distress experienced by caregivers of delirious patients is greater than that of the patients themselves, a finding that has been corroborated before.^{11,12} This is probably compounded by the ICU protocols which limit the caregiver's interaction with the patient thereby increasing the insecurity and helplessness that arise when they meet their confused patient.

Majority of patients (76%) and caregivers (94.3%) reported severe distress associated with delirium while only 31.3% of the ICU staff acknowledged such distress levels. Interestingly, we observed that patients and caregivers did not significantly differ in distress experienced based on motor subtypes, a finding that has been reported before.¹² The distress levels of the nursing staff in our study differed significantly across the motor subtypes. This makes sense as hypoactive delirious patients are not agitated, restless or "disturb the peace of the ICU". This unfortunately contributes to the lack of recognition of this subtype of delirium contributing to high morbidity and mortality rates. This can be detrimental as hypoactive delirium had both the highest rate of non-recognition (98%) and mortality

(55.69%) in our sample. While earlier studies have assessed nurses distress levels while managing delirium, none of them have explored its association with non-recognition of delirium. We propose that though it is essential to train nurses to deal with this distress, it should not be forgotten that it is this distress that signals that a patient needs more attention and care.

The strengths of this study are its sample size, sampling technique, standardized assessment of delirium, and measurement of distress across all stakeholders. This study is not without its limitations. As it is carried out in the ICU, the results may not generalize to all medical settings. Distress was only measured among the nursing staff and not in doctors.

CONCLUSION

Patients with delirium recall their experiences during the period of confusion and are distressed by it. Caregivers experience greater distress while interacting with their loved ones in delirium than the patients themselves. Patients with hypoactive delirium are just as distressed as other motoric subtypes. Nurses experience lesser distress when dealing with hypoactive delirium which can hinder recognition of this condition which has high morbidity and mortality.

Prospective studies on the role of guidelines aimed at educating caregivers and nurses on dealing with distress while managing delirium needs to be studied. The impact of such a program on alleviating the distress of patients and caregivers by providing them with explanation and reassurance during an episode of delirium would go a long way in improving the quality of medical care in ICU settings. Acknowledgements: We would like to thank Dr. Bidita Khandelwal, Professor of Medicine, Sikkim Manipal Institute of Medical Sciences and the Nursing staff of the Medical ICU, Central Referral Hospital who provided insight, support and expertise that greatly assisted this research.

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