

## Quality of Life of ICU Survivors and their Loved Ones - A Pilot Asian Perspective

Sir,

Post Intensive Care syndrome is a recognized phenomenon in literature over the past several decades.<sup>1,2</sup> Even though critical care management and mortality outcomes have dramatically improved amongst this cohort of patients, several studies have shown a markedly impaired cognitive and functional trajectory post ICU discharge. Recent studies both in the UK and US have shown such patients to be physically debilitated, emotionally and cognitively at a reduced level as compared to a pre- ICU admission disposition, and often depressed and suffering from post traumatic distress syndrome.<sup>3-5</sup> However, there is a marked absence of literature coming from Asian ICUs where the population is ageing rapidly and often the average age in the ICU is 70 years plus. We aimed to investigate by means of a simple novel questionnaire the quality of life of ICU survivors in Singapore and how the ICU stay may have affected their existing function level, their needs, their dilemmas and those of their loved ones.

A simple study was conducted after IRB approval where all ICU survivors were interviewed between 2 weeks and 2 months post discharge by means of a novel questionnaire. No patient identifiers were used and confidentiality was maintained. Questions were asked about their physical, emotional, financial and social status following ICU discharge compared to their pre-ICU admission disposition by means of a score. The duration of the study was 1 month and all consecutively discharged patients were recruited. A total of 113 patients were admitted to the ICU, 7% expired and 83% were discharged. Of these, only 28 patients were enrolled in this study. In case the patient was incapable of answering, the next of kin were interviewed. Some questions were specific for the family. The average age was 59 years with a 75: 25% male preponderance. Most patients (30%) were admitted for postoperative monitoring, followed by brain hemorrhage, gastrointestinal bleeding, sepsis and trauma. Most patients (76%) stayed for less than one week with 18% staying between 1 - 2 weeks and only 5% with a greater than 2 weeks stay. Their severity of illness was judged by an APACHE II score (acute physiology and chronic health score) with a score > 20 being associated with high mortality. In our population, a score > 20 was present in 30% of the patients. Twenty seven percent of these

patients underwent ventilation mechanically during their stay and 5% experienced cardiac arrest. Eighty seven percent of the patients were interviewed in < 1 month following discharge with the rest being followed after one month. Twenty nine percent admitted to having a decreased quality of life. Of the mental health questions, 18% reported having PTSD (post traumatic stress disorder) with flashbacks and frightening nightmares, 23% deemed it an unpleasant experience; 58% felt emotionally strong, 13% said their relationships with loved ones were affected, 60% stated it was a satisfying experience, but 13% said it was a terrifying and disturbing experience. Expectations of the patients or their loved ones were met in 60% of the cases. Amongst the physical well being questions, 37% reported being debilitated and 39% were ADL dependent. Thirty four percent stated that their weakness still persisted and 34% experienced persistent and moderate to severe pain. In dealing with the financial aspect, none had gone back to work, with 42% reporting financial burden and 43% of the next-of-kin reported either mental or financial burden. Despite the high severity of illness scores only 7% had 'end of life' discussions with their doctors. Eighty four percent of the patients had some positive comments and 44% had some negative comments. Amongst the positive comments patients praised the nurses and doctors for the care, the ambience of the hospital and the prompt updates; however, amongst the negative comments made the patients admitted to 'loneliness, feeling lack of empathy, disturbances at night or during sleep, frightening nightmares, feeling bored, hungry, pain, depressed and inferior'. In males, the emotional score was higher than in females, the longer the ICU stay was the more negative trend towards an unhappy score, and people interviewed after a month post-discharge had a higher score than those interviewed after recent discharge. People who had received ventilation or experienced a cardiac arrest had an emotional score twice as negative as those who did not. The score for physical strength and social happiness was equal in males and females but showed a reducing trend with increasing length of ICU stay. Again, those interviewed after a month were physically stronger and socially more satisfied than those before a month. People who were on the ventilator or suffered a cardiac arrest in the ICU were less strong as well as had a lower social interaction score. The financial score showed that being male, being in the ICU for more than 2 weeks, being interviewed within a month of discharge and being on the ventilator or having experienced a cardiac arrest showed a trend towards a positive financial burden.

Despite the sample size being extremely small, this study showed trends in association between ICU

survival and an emotional, financial and physical burden on patients, especially the association between being ventilated and a poor score in financial burden. The rate of overall decreased quality of life (nearly 30%) was high and similar to studies carried out in the West. A PTSD rate of 18% and a total negative emotional score of 36% was higher than reported elsewhere. Almost 40% of patients had persistent weakness and pain. Forty percent of the family members also felt a financial burden as well as mental strain. Relationships were changed and the stress of critical care was high, most notably in those who had been ventilated. This study shows a marked degree of strain on the caregivers with a marked financial strain.

Pakistani ICUs differ from Western ones in the following ways: an older age group, a higher severity of illness and a larger group of caregivers involved per patient. This study may hopefully guide future research and ultimately interventional studies aimed at improving these outcomes in society.

#### REFERENCES

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