Patients’ perceptions of and emotional outcome after intensive care: results from a multicentre study

Janice Rattray, Cheryl Crocker, Martyn Jones and John Connaghan

ABSTRACT
Background: Recovery from critical illness can be prolonged and can result in a number of significant short- and long-term psychological consequences. These may be associated with the patient’s perception of the intensive care experience.

Aim: The aims of the study were to assess patients’ perceptions of their intensive care unit (ICU) experience and the effect of these on anxiety, depression and post-traumatic stress up to 6 months after discharge.

Method: One hundred and three participants were recruited from six ICUs from one Critical Care Network in the United Kingdom. A prospective, longitudinal study was designed to assess anxiety, depression, post-traumatic stress symptomatology and patients’ perceptions of their intensive care experience. Data were collected on three occasions: after intensive care discharge and before hospital discharge, and 2 months and 6 months later. Measures included the impact of events scale, hospital anxiety and depression scale and intensive care experience questionnaire.

Results: Anxiety, depression, avoidance and intrusion scores did not significantly reduce over time. At hospital discharge there was a significant association between patients’ perceptions of their intensive care experience and anxiety, depression, avoidance and intrusion scores at hospital discharge.

Conclusion: Standardised assessment of an intensive care experience is important. It provides information about the patient experience which can inform care practice within ICU, following discharge to the ward and, in the longer term, rehabilitation.

Key words: Emotional outcome • Critical care • Patient experience

INTRODUCTION
Survival from critical illness has improved greatly over the last two decades. However, it is becoming more evident that recovery from critical illness can be prolonged and can result in a number of significant short- and long-term physical and psychological consequences (Cuthbertson et al., 2004, 2005; Sukantarat et al., 2007) that can be enduring, and affect subsequent quality of life (Perrins et al., 1998; Scragg et al., 2001). Psychological problems include anxiety, depression and post-traumatic stress (Cuthbertson et al., 2004; Rattray et al., 2005).

What perhaps is less clear is the association between the patient’s intensive care experience and subsequent emotional or psychological outcome. Patients’ perceptions of intensive care are very variable, with very little or indeed nothing at all being remembered, but for some their memories are usually unpleasant or frightening in nature (Jones et al., 2003; Samuelson et al., 2007). The causes of these unpleasant or frightening memories are likely to be multifactorial. The mechanism is poorly understood, but these memories or perceptions have been associated with anxiety, depression, post-traumatic stress symptomatology (Jones et al., 2001; Rattray et al., 2005), and poorer health-related quality of life (Granja et al., 2005). Furthermore, patients with more delusional memories tend to be in
intensive care longer (Samuelson et al., 2006). To further explore patients’ memories and the relationship between these memories and subsequent emotional outcome, a study involving a collaboration between researchers based in an academic institution and nurses from a UK Critical Care Network was designed. The research questions to be addressed were:

- What are patients’ reported perceptions of their intensive care experience?
- Can these perceptions be measured?
- Is there an association between patients’ perceptions of their intensive care experience and anxiety, depression and post-traumatic stress, up to 6 months after discharge?

To address these questions a prospective, longitudinal study was designed.

**METHODS**

**Sample**

Patients were recruited from six intensive care units (ICUs) from six hospitals within one UK Critical Care Network between March 2003 and February 2005. A Nurse Consultant based in one of the network ICUs had overall responsibility for the organisation and conduct of the study. Two training events facilitated by the researchers were held prior to the study starting. This ensured that each nurse with responsibility for patient recruitment and data collection was familiar with the protocol, recruitment processes and administration of questionnaires.

Inclusion criteria were patients with an ICU stay of ≥24(221,513),(329,532) h were mechanically ventilated and aged ≥18 years. Exclusion criteria included head injured patients or those following elective neurosurgery, or unable to give informed consent.

Participants were approached after discharge from the unit and as close to discharge home as possible. The rationale for this was to ensure that patients had recovered sufficiently to be able to give informed consent. The timing of this was discussed by unit lead researchers and ward staff caring for the patient. The lead researcher from each unit approached the participant in order to describe the study, leave written information and returned 24 h later to ask for consent. As far as possible the researcher was not involved in the follow-up care of the patient. Once consent was gained, data were collected by structured interview performed by the unit lead researcher.

**Measures**

Demographic data were collected (age; gender) and clinical (illness severity using the APACHE II scoring system (Knaus et al., 1985); durations of ICU and hospital stay) from unit records.

Patients intensive care experiences were assessed by the intensive care experience questionnaire (ICEQ) (Rattray et al. 2004). Emotional outcome was operationalised as anxiety, depression and post-traumatic stress and assessed using standardised measures, i.e. the hospital anxiety and depression scale (HADS) (Zigmond and Snaith, 1983), and the impact of event scale (IES) (Horowitz et al., 1979).

The HADS and IES were assessed at time of recruitment and by postal questionnaire at 2 and 6 months following intensive care discharge. The HADS and IES, are standard, generic measures used widely in the assessment of emotional outcome and have been used within this patient population (Eddleston et al., 2000; Scragg et al. 2001; Jones et al., 2003; Kress et al., 2003; Rattray et al., 2005). The HADS contains 14 statements relating to mood, seven for anxiety and seven for depression. Each statement offers four response options and asks the participant to indicate the frequency of a feeling over the preceding seven days. Scoring results in scales of 0–21 for anxiety and depression respectively. Scores of 8–10 indicate the possibility of anxiety or depression, and 11 and above indicate that these are likely to be present. The measure has good reliability and validity (Hermann, 1997; Johnston et al., 2000), is readily accepted by patients in acute settings, and takes minutes to complete (Hermann, 1997). The IES assesses the frequency in the past 7 days of a reaction linked to a specific event (Horowitz et al., 1979). Scores for two of the core features of a post-traumatic stress reaction, i.e. intrusive thoughts (0–35) and avoidant behaviour (0–40), are obtained. There is some evidence to support ‘cut-off’ scores for the IES with scores between 0–8, 9–19 and 20+ indicating low, medium and high levels of symptoms, respectively, (Malt, 1988; Scragg, et al., 2001). The IES has demonstrated good reliability and validity (Horowitz et al., 1979; Briere and Elliott 1998; Joseph, 2000).

The ICEQ measures patients’ perceptions of their intensive care experience and its development and initial psychometric analysis is described elsewhere (Rattray et al. 2004). It includes 31 items questionnaire that assess four domains of the intensive care experience ‘awareness of surroundings’ (nine items) (e.g. I recognised my relatives); ‘frightening experiences’ (six items) (e.g. I seemed to have bad dreams); ‘recall of experience’ (five items) (e.g. most of my memories are blurred), and ‘satisfaction with care’ (four items) (my care could have been better) (Rattray et al. 2004). Items are grouped into two response formats – a Likert-type (strongly agree – strongly disagree), and
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frequency (all of the time to never). Initial factor analytic work suggested retaining 24 of this questionnaire, but because this is a developing measure, all 31 items were included in this study. Each answer is scored 1–5. Scores in each domain are summed, with high scores in the ‘awareness of surroundings’, ‘frightening experiences’ and ‘satisfaction with care’, indicating greater awareness of intensive care, more frightening experiences and greater satisfaction with care. A low score in the ‘recall of experiences’ domain indicating unclear memories and a wish to know more about the experience. This questionnaire was administered at time of hospital discharge only. The rationale for this was to capture patients’ perceptions of their intensive care experience as close to intensive care discharge as was practical. The timing of this administration also reduced the effect of repeated rehearsal of their experience.

Ethical approval
Ethics committee approval was granted. Each trust research and development department was approached and permission obtained. Confidentiality was protected, and responses coded. Patients’ names were removed from the original data and stored separately to allow contact to be made by post. General Practitioners were informed of patient consent to participate in the study prior to the 2-month contact.

It was possible that participants could suffer some level of stress or anxiety during the study as a result of the questionnaires and interviews. Some of the units provided a follow-up service; all units had a counselling service. If participants became anxious or suffered distress they were offered appointments either at the follow-up clinic or with the hospital counsellor. If participants demonstrated signs of anxiety or depression as expressed by the HADS score (a score of 11 or above) they were asked for their permission to contact their general practitioner and an appointment made for them.

Data analysis
Data was entered into an Excel file and converted into SPSS version 12. All data were cleaned and screened for normality of distribution. For normally distributed variables parametric tests were applied, i.e. Analysis of Variance and t-test. Correlational analyses were used to assess variable associations. Length of ICU stay and length of hospital stay were significantly skewed and a logarithmic transformation was successfully applied. The depression subscale on the HADS, and the avoidance, and intrusion scores on the IES were also significantly skewed at all three time points, and a square root transformation was successfully applied. Cronbach’s α statistic was used to estimate the internal consistency of scales. A reliability coefficient exceeding 0.70 is considered acceptable (Bowling and Ebrahim, 2005), although for developing measures, an acceptable level could be as low as 0.50 (Bowling, 1997).

RESULTS

Characteristics of participants
From 118 patients approached, 103 (87%) consented to participate in the study. Demographic and clinical variables of participants are reported in Table 1. No data were collected on the patients who refused consent and, therefore, comparisons to exclude sample bias were not possible.

Data screening
Patients who had missed ≥3 items from the HADS, IES and ICEQ were excluded from analysis, while those with ≤2 items missing had them replaced with subscale mean values (Tabachnik and Fidell, 1996). At time of hospital discharge this resulted in three patients excluded from the HADS analysis and two at 6 months. At 2 months three patients were excluded from the IES analysis and a further one patient at 6 months. Ninety five participants completed the ICEQ. A number of patients did not complete the postal questionnaires and this resulted in 43 patients completing the HADS at all three time points, 44 the avoidance and 42 the intrusion subscales of the IES. All subscales achieved a Cronbach’s α statistic >0.70 with two exceptions – the ICEQ recall of experiences (0.52) and satisfaction with care (0.60) subscales.

HADS
Mean anxiety and depression scores did not significantly reduce over time (see Table 2). However there was a reduction in the number of patients who had ‘cut-off’ scores of 11 and above. By 6 months this had reduced to 16%. Similarly those with depression scores of 11 and above had reduced to 18%.

Table 1 Participant characteristics

<table>
<thead>
<tr>
<th>Gender</th>
<th>65 male, 37 female (one value missing)</th>
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</thead>
<tbody>
<tr>
<td>Mean age in years (range)</td>
<td>60 (17–84)</td>
</tr>
<tr>
<td>Mean APACHE II score (range)</td>
<td>19 (6–34)</td>
</tr>
<tr>
<td>Median number of ICU days</td>
<td>7 (0–63)</td>
</tr>
<tr>
<td>Median number of hospital days</td>
<td>13 (0–368)</td>
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</tbody>
</table>
Table 2  HADS and IES subscale scores at all time points

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Hospital discharge mean (SD)</th>
<th>2/12 Mean (SD)</th>
<th>6/12 Mean (SD)</th>
<th>F value/ T value</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS subscales (n = 43)</td>
<td></td>
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<tr>
<td>Anxiety</td>
<td>6.2 (4.6)</td>
<td>7.1 (4.5)</td>
<td>7.2 (3.9)</td>
<td>0.75</td>
<td>0.47</td>
</tr>
<tr>
<td>Depression</td>
<td>6.7 (4.5)</td>
<td>7.2 (5.0)</td>
<td>6.9 (4.6)</td>
<td>0.14</td>
<td>0.87</td>
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<tr>
<td>IES subscales (n = 42)</td>
<td></td>
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<tr>
<td>Avoidance (SQRT)</td>
<td>11.2 (10.8)</td>
<td>10.7 (10.6)</td>
<td>9.7 (9.4)</td>
<td>0.25</td>
<td>0.78</td>
</tr>
<tr>
<td>Intrusion (SQRT)</td>
<td>11.0 (10.0)</td>
<td>10.4 (9.6)</td>
<td>9.9 (8.9)</td>
<td>0.14</td>
<td>0.87</td>
</tr>
</tbody>
</table>

HADS, hospital anxiety and depression scale; IES, impact of event scale.

IES

Avoidance and intrusion levels had a similar pattern, and mean scores did not reduce over time (see Table 2). By 6 months, 14% of patients met the criteria for high levels of avoidant behaviour and 16% for high levels of intrusive thoughts.

ICEQ

Descriptive analysis was performed on the responses to the ICEQ. These are presented in Figures 1 and 2. Acquiescent response bias was excluded by including the items ‘my care was as good as it could have been’, and ‘my care could have been better’ and responses demonstrate that this was not present. On the whole, memories of intensive care varied and when reporting awareness of their surroundings, approximately one-third of patients reported having no recollection of intensive care. However, patients report remembering people near to them and, in particular, relatives. Interestingly the majority of patients felt safe despite a large percentage reporting feeling helpless, seeing strange things and having bad dreams.

Association of ICEQ with clinical variables, HADS and IES

Correlational analysis was performed to explore the association of the ICEQ domains with both clinical variables and the subscale scores of the HADS and IES (see Table 3). Older patients had lower scores on the recall of experiences domain. This domain includes items that illustrated these patients had less clear memories but wanted to know more about what was happening to them. The longer a patient was in hospital then the less aware they were of their surroundings,
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Figure 2  Percentage responses to agreement items.

Table 3 Association of ICEQ domains with clinical data and HADS and IES subscale scores

<table>
<thead>
<tr>
<th>Variable</th>
<th>Awareness of surroundings</th>
<th>Frightening experiences</th>
<th>Recall of experiences</th>
<th>Satisfaction with care</th>
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</thead>
<tbody>
<tr>
<td>Clinical data</td>
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<tr>
<td>Age</td>
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<td></td>
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<tr>
<td>Length of ICU stay</td>
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<tr>
<td>Length of hospital stay HADS</td>
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<tr>
<td>Anxiety (discharge)</td>
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<tr>
<td>Depression (discharge)</td>
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<td>IES</td>
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<tr>
<td>Avoidance (discharge)</td>
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<tr>
<td>Avoidance 2 months</td>
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<tr>
<td>Intrusion (discharge)</td>
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</tbody>
</table>

HADS, hospital anxiety and depression scale; ICEQ, intensive care experience questionnaire; IES, impact of event scale.

* Correlation significant at the 0.05 level (two tailed).
** Correlation significant at the 0.01 level (two tailed).

and the longer a patient was in intensive care, the more likely they were to have higher scores on the frightening experiences component. All four domains were associated with the HADS and IES subscales, but mainly at time of hospital discharge. Patients who were less aware of their surroundings, had blurred memories and had more frightening memories and these patients also tended to have higher scores on the subscales of both the HADS and IES. However with the exception of avoidance scores at 2 months, this association was not present after hospital discharge.

**DISCUSSION**

Although there was a reduction in the number of patients who had anxiety and depression scores in the ‘probable’ category, the subscale scores did not reduce over time and this is not in keeping with previous results (Rattray et al., 2005). There are a number of explanations for this. Loss to follow up may have resulted in this study being underpowered and, therefore, a Type II error may exist. Attrition bias may have occurred and patients who were anxious or depressed may have chosen not to complete the study.

What is important is the number of patients who still demonstrated ‘probable’ anxiety and depressive disorders at 12 months. It may be that these patients...
were anxious and/or depressed prior to intensive care, but this is difficult to establish given the unplanned nature of most intensive care admissions.

Levels of avoidance and intrusion did not significantly reduce over time either, and this is more in keeping with previous results (Rattray et al., 2005). Although the incidence of post-traumatic stress is likely to be overestimated when self-report measures are used, there is also a possibility that these symptoms are under-reported as patients who exhibit avoidant behaviour are less likely to seek help or continue with a study that might trigger unpleasant memories. For those patients who have post-traumatic stress symptomatology, this can be detrimental to both physical recovery and quality of life (Rattray and Hull, 2008), and this has implications for care after hospital discharge (Crocker, 2003).

The use of a standardised measure was useful in providing information about the patient experience. This provided a quantitative assessment of such perceptions and allowed exploration of the association between these and clinical and demographic data. Another potential benefit of using such a measure would be as a means of identifying patients at risk of emotional problems after discharge. Earlier work using this questionnaire, demonstrated a significant relationship between two of the ICEQ domains and subsequent anxiety, depression and post-traumatic stress (Rattray et al., 2005), however, this is still a developing measure. Two of the four domains had a low Cronbach’s alpha statistic and this means that further psychometric analysis is need to support its use. The questionnaire was administered on once occasion only, and perhaps it would be beneficial to repeat its administration to test stability of memories over time.

Approximately one-third of patients recruited to this study reported no recollection of being in intensive care. This is higher than that presented by (Ringdal et al., 2006; Samuelson et al., 2006) who reported 15% and 18% of patients had no recollection of intensive care. Case mix and variations in may explain these differences. For example Ringdal et al. (2006) recruited trauma patients who were younger with a shorter ICU than our sample, and those recruited by Samuelson and colleagues were older, had higher mean APACHE II scores and a shorter intensive care stay. Patient reports of ‘bad dreams’ or ‘nightmares’ are also variable and in this study, 59% reported having bad dreams at least some of the time. Reports of nightmares or odd perceptual experiences vary from 9% (Rundshagen et al., 2002) to 73% (Green, 1996), and although a number of patients report pleasant dreams (Roberts and Chaboyer, 2004), these experiences tend to be very unpleasant in nature. Patients often use words such as ‘frightening’, ‘terrifying’ or ‘horrible’ to describe these nightmares or delusions (Lof et al., 2006) and they may recur some time after ICU discharge (Granja et al., 2002). Patients’ recall of these dreams or nightmares tends to be vivid and can be recalled in detail some months later (Lof et al., 2006). This may be a reflection on how upsetting such dreams or nightmares were or that these memories had been retold by the patient on a number of occasions and therefore, rehearsed during this time. There are a number of factors associated with such experiences, for example, length of time in intensive care, and type of admission (Roberts and Chaboyer, 2004). Importantly there is an association between the occurrence of such memories and subsequent emotional outcome (Jones et al. 2001; Rattray et al., 2005), and this was observed in this study, although not maintained after hospital discharge. Whilst our understanding of patients’ perceptions of their intensive care experience is increasing, there is no definitive intervention to ameliorate or prevent such experiences. There has been increasing interest in the incidence and consequences of delirium within intensive care. Predictors of delirium have been identified and a number of proposed interventions, but as yet there is no empirical evidence to support treatment in this area (Girard et al., 2008). Future research might explore the association between delirium and patients reported memories.

Patients’ awareness of intensive care varied. Approximately half the patients reported remember relatives being with and disappointingly 48% remembered being in pain. What is difficult when ascertaining patients’ memories of intensive care is to be precise about where those memories occurred. It is not easy for some patients to separate out whether their memories are from intensive care, a step down unit such as high dependency or a ward area.

One of the main limitations of this study was the number of patients lost to follow up. The sample size in this study was insufficient to perform regression analyses to identify predictors of emotional outcome after intensive care or perform further psychometric analysis of the ICEQ, and this is work for future studies. This reflects the challenges of such studies and was disappointing given the number of units involved in recruitment. Recruitment was staggered between units and this was influenced by a number of factors including staff changes and resource constraints. Funding for this study was minimal, and one of the secondary aims of this study was to test whether it could be performed through this formal nursing network. To some extent this was achieved, and importantly highlighted issues such as participant retention which might be improved with additional funding for a research
assistant or project manager. Another limitation of the study was the lack of data on those who chose not to consent. This meant that we could not establish whether sample bias was present. This was a pragmatic decision given the limited resources that were available and one that could be resolved with sufficient funding. However the sample was representative of UK ICU patients in terms of gender split, age and APACHE II scores (Cuthbertson et al., 2004; Rattray et al., 2004). Median length of ICU stay was perhaps slightly longer than other units and this reflects local practice. The heterogenous nature of intensive care patients and the relatively small sample size in this study meant that any subgroup analysis of patients with similar diagnosis or admission history was not possible. This would require much larger sample sizes. Administering questionnaires by post has a number of advantages including reducing interviewer bias and social desirability responses. However responses rates using this approach are lower (Bowling and Ebrahim, 2005), and this is what was seen in this study.

Implications for practice
There are a number of implications for practice. This is not just related to the ICU environment but also following discharge to the ward and longer term rehabilitation. Understanding and assessing the patient experience is vital if we are to shape practice and to make this a truly patient-centred service. There is a growing body of evidence that links the patients' intensive care experience with longer term outcomes and having a standardised questionnaire that measures this can help identify at risk patients. This information can inform follow-up services after intensive care discharge. Such services are best delivered by a multidisciplinary team, comprising of physiotherapists, psychologists or psychiatrists, ICU clinicians and importantly this team should be able to referral patients to specialist support (Rattray and Crocker, 2007).

CONCLUSION
This small study has added to our understanding of patients’ intensive care experience. It has confirmed the presence of unpleasant memories and the association between this and emotional outcome. This is important for care after intensive care discharge and should help inform such services. However, there were a number of limitations of this study that should be addressed in subsequent research.

ACKNOWLEDGEMENTS
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WHAT IS KNOWN ABOUT THE TOPIC
- Patients can have psychological or emotional problems after intensive care.
- These problems are associated with perceptions of the intensive care experience.
- Patients’ reports of intensive care usually include descriptions of nightmares and/or hallucinations.
- Research into patients’ perceptions of intensive care is predominantly qualitative.

WHAT THIS PAPER ADDS
- A standardised approach to assessing patients’ experiences of intensive care is possible and useful.
- Patients’ perceptions of their intensive care experience is associated with subsequent recovery.
- Confirms the presence of psychological problems for some patients in the short to medium term after intensive care discharge.

REFERENCES


